

Building Patient-Centeredness in the Real World:

The Engaged Patient and the Accountable Care Organization

By Michael L. Millenson
President, Health Quality Advisors LLC



In collaboration with



Executive Summary

The accountable care organization began life as a catchphrase signifying a shift in the relationship between a hospital and its doctors. By forming an ACO, a hospital and medical staff shared clinical and financial responsibility for coordinating care to improve quality and lower costs. The patient's role was essentially passive, like a car door that ends up with fewer dents and nicks thanks to better management of the auto assembly line.

By contrast, the ACO model that emerged as a signature initiative of the Affordable Care Act (ACA) may not quite put patients in the driver's seat, but at least they're holding the road map. The law recognizes that rethinking the relationship between the patient and professional caregivers is a cornerstone of successful health system redesign and that ACOs cannot ultimately succeed in their mission without it. Consumer engagement, whether in the exam room or in a health care organization's boardroom, is a central element.

This paper examines the separate but intertwined ethical, economic and clinical concepts of patient-centeredness and how ACOs provide a structure for turning those concepts into a functioning reality. It reviews the evidence that patient-centeredness can significantly improve care and costs, and it looks ahead at challenges related to making patient-centeredness an essential part of care.

For patient-centeredness to achieve its potential, the patient must become an integral part of three core functions of health care organizations: 1) governance and policies; 2) quality improvement activities; and 3) individual patient-clinician interactions. Medicare's ACO requirements, when simplified from their original Federal Register format, provide actionable guidance for implementing patient-centeredness at all three of these levels.

The *governance-level requirements* require the ACO's governing body to promote patient-centered care; the patient's voice in the boardroom can shape how care is delivered in the exam room. *Quality improvement activities* address the actual care provided. This includes ensuring that evidence-based medicine has a patient-centric focus, producing internal quality and cost reports related to patient-centered care and using data to manage population health. Requirements related to *individual level patient-clinician interactions* include promoting the active participation of patients and their families in medical decision-making, taking into account factors such as race, gender, sexual orientation, disability and income status.

Because patient-centeredness is a relatively new concept, many policymakers and providers are unaware that engaging patients in these different ways can produce significant clinical, economic and social gains. Health information technology, used appropriately, can catalyze the needed changes. The same is true of appropriate financial incentives. Finding a way to harness these forces in a systematic manner was one motivation behind the creation of the ACO in both its Medicare and private sector incarnations.

This white paper examines five organizations that have engaged patients in the hospital and outside of it in ways that have improved the patient experience of care, clinical metrics and cost-effectiveness. Two of those organizations – Mercy Clinics, Inc., in Des Moines, and the University of Pittsburgh Medical Center's Patient- and Family-Centered Care program – have won national recognition for innovative use of technology and innovative team concepts involving both clinicians and patients.

While cultural changes inside and outside medicine are making patient-centeredness more important, many clinicians remain reluctant to involve patients in decisions. Similarly, although Medicare ACO regulations suggest a framework for patient involvement in everything from governance to clinical decisions, their resonance with providers in general remains to be seen. However, the wide availability of Internet-based medical information and tools, including a panoply of mobile apps, provides constant pressure for transparency of information and accountability for results.

At the same time, patients face their own adjustment to new roles. Medical practices could find themselves distributing formal "rules of engagement" with explicit expectations about the respective responsibilities of patients and providers to share information candidly and listen to each other's concerns.

It has taken a full century for the patient's perspective to go from being routinely ignored to being hailed as a pillar of an ideal health care system. Although that ideal has yet to be realized, the path to building a patient-centered health system in the real world is clearly marked. There are practical ways to integrate the patient's perspective into governance, clinical quality improvement and enhancing the individual's experience of care. Deep and lasting change is possible, and ACOs are well-positioned to spearhead that change.

The declaration of empowerment that began with the disability rights movement – “Nothing about us without us” – is inexorably becoming health care's cultural norm. Ethically, economically and clinically it is the right course. The organizations that embrace it may be ahead of the pack, but there is no doubt that others will soon follow after.

About the Author

Michael L. Millenson, president of Health Quality Advisors LLC, is a nationally recognized expert on quality of care improvement, patient-centered care and web-based health. He is the author of the critically acclaimed book, *Demanding Medical Excellence: Doctors and Accountability in the Information Age*, and holds an adjunct appointment as the Mervin Shalowitz, M.D. Visiting Scholar at Northwestern University's Kellogg School of Management. National Public Radio called him "in the vanguard of the movement" to measure and improve American medicine.

In addition to work in health policy and strategy, Millenson has designed and implemented an Accountability AuditSM for hospitals, websites to help in consumer quality-of-care decisions and a joint doctor-patient program to improve communication during office visits. His clients have included health plans, hospitals, pharmaceutical companies, entrepreneurs and non-profits. As a senior adviser to the Markle Foundation, he helped launch the Connecting for Health interoperability initiative. Prior to starting his own firm, Millenson was a principal in the health-care practice of a major human resources consulting firm. Before that, he was a health-care reporter for the *Chicago Tribune*, where he was nominated three times for a Pulitzer Prize.

Millenson has testified before Congress and the Federal Trade Commission, lectured at the National Institutes of Health and served as a faculty member for the Institute for Healthcare Improvement. He co-authored a case study for the Harvard Business School and policy papers on behalf of the Urban Institute, and he has written for publications ranging from the *British Medical Journal* and *Health Affairs* to *The Washington Post*, Kaiser Health News and Forbes.com. He also serves on the board of directors of the American Medical Group Foundation, the AHIMA Foundation and the Society for Participatory Medicine and is on the editorial board of the *American Journal of Medical Quality*.

About The National Partnership

The National Partnership is a non-profit, non-partisan organization dedicated to promoting access to quality health care, fairness in the workplace, and policies that help women and men meet the dual demands of work and family. More information is available at www.NationalPartnership.org.

Acknowledgements

The author would like to thank Christine Bechtel, Debra Ness and their colleagues at the National Partnership for Women & Families for their critical contributions to this white paper and for their commitment to ensuring that the patient's voice is heard at every level and in every aspect of the health care system. Thanks, also, to Beverly Johnson of the Institute for Patient- and Family-Centered Care for her thoughtful input. Lygeia Ricciardi and Robert Heyl (under different affiliations than their current ones) helped turn idea into implementation, and Phil Dunn and Juliana Macri improved the final writing with fresh and critical eyes.

A final thanks to Dr. Lonny Reisman and his colleagues at Aetna for their sponsorship of this collaboration between Health Quality Advisors and the National Partnership.

Building Patient-Centeredness in the Real World: The Engaged Patient and the Accountable Care Organization

By Michael L. Millenson
President, Health Quality Advisors LLC

A Brief Guide to ACOs

Accountable care organizations (ACOs) went from a concept for health system reform to codified in federal law without any sort of demonstration project along the way. That led one prominent skeptic to deride ACOs as “unicorns;” that is, mythical creatures no one had ever seen. But ACOs have become real, and variants are proliferating for both Medicare and private payers.

The most prominent version comes from Section 3022 of the Affordable Care Act (ACA), which established ACOs under the Medicare Shared Savings Program (MSSP). A Medicare ACO agrees to be responsible for all the care needs of a group of patients inside and outside the hospital and to be paid based on its success in achieving specific targets related to those patients’ health outcomes, satisfaction and costs. Unlike in fee-for-service medicine, clinicians and the hospital have a financial incentive to work as a team to keep patients healthy and to better coordinate care.

The specific quality targets set ACOs apart from health maintenance organizations and other managed care arrangements. There are 33 publically disclosed quality measures related to care coordination and patient safety, preventive health services, at-risk populations and the patient experience of care. In addition, Medicare ACOs

The accountable care organization (ACO) began life as a catchphrase signifying a shift in the relationship between a hospital and its doctors.¹ By forming an ACO, a hospital and medical staff shared clinical and financial responsibility for coordinating all care in order to improve quality and lower costs. The patient’s role was essentially passive, like a car door that ends up with fewer dents and nicks thanks to better management of the auto assembly line.

By contrast, the ACO model that emerged as a signature initiative of the Affordable Care Act (ACA) may not quite put patients in the driver’s seat, but at least they’re holding the road map. Consumer engagement, whether in the exam room or in a health care organization’s boardroom, is a central element. That message is reinforced by a long list of “patient-centeredness criteria” in the final federal regulations.² (See Sidebar: A Brief Guide to ACOs)

Turning a flawed and disorganized fee-for-service system into an efficient and organized system of care is often characterized as a kind of engineering challenge. That is only partly true. While carefully calibrated clinical process controls, fine-tuned financial management and innovative information technology are integral to the task, equally essential is a deliberate and sustained focus on human interactions. Rethinking the relationship between the patient and professional caregivers is a cornerstone of successful system redesign, and ACOs cannot ultimately succeed in their mission without it.

This paper examines the separate but intertwined ethical, economic and clinical concepts of patient-centeredness and how ACOs provide a structure for turning those concepts into a functioning reality. It reviews the evidence that patient-centeredness in governance, quality improvement and at the individual clinical level can significantly improve care and costs, and it looks ahead at the challenges related to making patient-centeredness an integral part of care.

Because patient-centeredness is a relatively new concept, many policymakers and providers are unaware that engaging patients in these different ways can produce significant clinical, economic and social gains. Health information technology, used appropriately, can catalyze the needed changes. The same is true of appropriate financial incentives. Finding a way to harness these forces in a systematic manner was one motivation behind the creation of the ACO in both its Medicare and private sector incarnations.

¹ Elliott S. Fisher, Douglas O. Staiger, Julie P.W. Bynum and Daniel J. Gottlieb, “Creating Accountable Care Organizations: The Extended Medical Staff,” *Health Affairs* 26, no. 1 (2007): w44-w57.

² Douglas Hastings, “Value-based Payment, Accountable Care, and the ACO Final Rule: Are We Making Progress?” *Health Affairs Blog*, October 22, 2011. <http://healthaffairs.org/blog/2011/10/22/value-based-payment-accountable-care-and-the-aco-final-rule-are-we-making-progress/>

are controlled by providers, not insurers, and they commit to a long-term relationship with a patient population. ACOs must accept responsibility for at least 5,000 Medicare beneficiaries for no less than three years.

Providers voluntarily decide to form an ACO. The MSSP launched in April 2012 with 27 ACOs in 18 states. Earlier, CMS chose 32 more organizationally advanced groups to be part of the Pioneer ACO demonstration project run by its Innovation Center. Those ACOs have a somewhat different payment scheme, but the same kind of quality and patient-centeredness goals.

Together, these ACOs and another six ACO-like organizations in a different Medicare demonstration program serve more than 1.1 million Medicare beneficiaries. Another 150 groups have applied for a July 1 launch date. CMS expects up to two million Medicare beneficiaries to receive services from up to 270 ACOs over the next three years.

Regardless of the fate of the ACA, virtually every major insurer is experimenting with ACOs. Leavitt Partners identified 164 ACOs, mostly in the private sector, in a late 2011 report. Their count included 99 that are primarily sponsored by hospital systems, 38 by physician groups and 27 by insurers.

Effective patient engagement is widely seen as critical to reaching the ACO's quality and cost goals. The Premier health alliance, for example, encourages its members to design all ACO components from a "people-centric" perspective to foster patient engagement, activation, satisfaction and accountability for their health. Said Stacey Brown, vice president of alliance operations, "We talk about people, not patients. We don't want them to be patients. It's a philosophy."

The high expectations for ACOs of all kinds is why they are the focus of this paper. It begins with a brief history of the patient's changing roles, examines the patient engagement requirements of Medicare ACOs and reviews the medical evidence linking patient engagement to improved outcomes. It then provides case studies of two innovative organizations that have won national recognition for integrating the patient's perspective into care. Finally, the paper reviews cultural changes inside and outside of medicine and the challenges both providers and patients must confront if patient-centeredness is to achieve its full potential to improve quality and control costs.

The Meaning of Patient-Centeredness

A landmark 2001 report by the Institute of Medicine (IOM) that pronounced patient-centeredness one of six core goals of U.S. health care first brought the concept to prominence as a central element of health policy.³ (The other five goals were safe, effective, timely, efficient and equitable care.) Patient-centeredness requirements are now integral to the National Strategy to Improve Health Care Quality, laid out in the ACA and updated yearly; to innovative delivery system restructuring that affects both the public and private sectors, such as the Patient-Centered Medical Home; and to many private-sector initiatives by payers and providers alike.

Yet the meaning of "patient-centered" is an evolving one. The basic concept was traditionally defined as part of professional beneficence; that is, a doctor's duty to act for the benefit of the patient seeking care. The originators of the term "patient-centered" built on that definition, asserting that doctors should treat patients as unique human beings with physical and psychological needs, rather than as a bundle of symptoms.⁴

Although these professional obligations remain important, patient-centeredness as a health system goal is defined "through the patient's eyes"⁵ and in a broader societal context. Those definitions incorporate three distinct, though intertwined, threads.

- The **ethical** concept of patient-centeredness sees patient autonomy and self-determination as basic human rights. While today that might seem self-evident, deference to physician beneficence was once so strong that it took a Supreme Court ruling at the start of the 20th century to compel doctors to simply inform patients in advance what surgery they had decided to perform.⁶ The case involved a surgeon who removed a woman's ovaries

³ Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century* (Washington, DC: National Academy Press, 2001). <http://www.jopm.org/evidence/reviews/2011/06/21/spock-feminists-and-the-fight-for-participatory-medicine-a-history/>

⁴ Enid Balint, "The Possibilities of Patient-Centered Medicine," *The Journal of the Royal College of General Practitioners* 17, no. 82 (1969): 269-276.

⁵ Margaret Gerteis, Susan Edgman-Levitan, Jennifer Daley, and Thomas L. Delbanco, eds., *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care* (San Francisco: Jossey-Bass, 1993).

⁶ Michael L. Millenson, "Spock, Feminists and the Fight for Participatory Medicine: A History," *Journal of Participatory Medicine* 3 (2011).

to treat her epilepsy without telling her of his plans; he argued he acted properly because she might have resisted the care she needed had he been more candid. The Court disagreed, with one justice famously writing that invading a citizen's body without that person's consent amounted to assault.

Yet it was not until the 1950s that doctors were legally required to disclose potential harms as well as benefits of a procedure, and it was not until the 1960s and 1970s, as the civil rights and feminist movements swept the country, that a nascent "patient rights" movement also took hold. During that era, courts ruled that the disclosure of harms and benefits must be in plain English, with the extent of disclosure "measured by the patient's need."⁷ And hospitals agreed that patients had the right to know the names of all the doctors treating them.

By the 1990s, disability rights activists popularized a slogan that made clear they were not simply the objects of clinical good intentions: "Nothing about us without us." Transferred to the context of the individual clinical encounter, that became, "Nothing about me without me."⁸ Over time, the language of patient rights has changed to include terms such as "patient- and family-centered care" and "person-centered care."

Medicare ACO regulations, citing work by the IOM and the National Partnership for Women & Families, refer to patient-centeredness as "care that incorporates the values of transparency, individualization, recognition, respect, dignity and choice in all matters, without exception, related to one's person, circumstances and relationships in health care."

- The *economic* concept of patient centeredness, revolving around service providers and consumers in a health care marketplace, is a more recent idea that has grown steadily in importance. Doctors and patients have wrangled over fees since Hippocrates made his first house call, but consumerism today connotes a concern about both costs and benefits. As early as 1974, an IOM report endorsed the publication of outcomes measures "so consumers can be informed of the relative effectiveness of various health providers and make their choices accordingly."⁹

⁷ Cobbs v. Grant, 8 Cal. 3d 229 (1972), <http://www.lawandbioethics.com/demo/Main/LegalResources/C5/Cobbs.htm>

⁸ Tom Delbanco, Donald M. Berwick, Jo Ivey Boufford, Susan Edgman-Levitan, et al., "Healthcare in a Land Called PeoplePower: Nothing About Me Without Me," *Health Expectations* 4, no. 3 (2001): 144-150.

⁹ Institute of Medicine, *Advancing the Quality of Health Care* (Washington, DC: National Academy Press, 1974), 1-4.

Transparency of quality and cost information is intended to encourage patients-as-consumers to go to doctors and hospitals that provide the greatest value. (Value-based purchasing is one of the goals of the ACA as a whole.) And, of course, the ACO itself is an innovation anchored in marketplace principles, since a core ACO characteristic is the assumption by providers of financial risk for meeting quality and cost benchmarks.

- The *clinical* concept of patient-centeredness as an independently important measure of and significant contributor to successful treatment represents perhaps the greatest break with the past. Avedis Donabedian, the originator of the measurement triad of structure, process and outcome for evaluating clinical quality, proposed a patient-centric definition in 1966. He wrote: “[T]he effectiveness of care...in achieving or producing health and satisfaction, as defined for its individual members by a particular society or subculture, is the ultimate validator of the quality of care.”¹⁰

Patients’ experience of care and patient-reported functional outcomes began to be measured in validated clinical formats only in the 1980s. As time went on, research has shown that patients’ and physicians’ perceptions of outcomes differed and taking into account patients’ self-perceptions of health status could lead to more effective interventions.¹¹ Meanwhile, other studies that showed treatment decisions were frequently shaped more by doctor preferences than by the evidence gave rise to an emphasis on patient preferences and values being part of a shared decision-making structure.

It is not intuitively obvious how to weave together these disparate ideas in order to create a patient-centered delivery system. For that reason, detailed infrastructure set out in the federal requirements for Medicare ACOs can serve as a guide to all stakeholders, whether or not they are participating in the federal program.

Rules to Turn Patient-Centeredness into Reality

Historically, patients have not been engaged in the design of new health care delivery models. But when the National Partnership for Women & Families asked consumers what they consider “patient-centered” health care, their answers fell into four categories:¹²

¹⁰ Avedis Donabedian, “Evaluating the Quality of Medical Care,” *Milbank Memorial Fund Quarterly* 44, no. 3 (1966): 166-203.

¹¹ Alvin R. Tarlov, John E. Ware, Sheldon Greenfield, Eugene C. Nelson, et al., “The Medical Outcomes Study: An Application of Methods for Monitoring the Results of Medical Care,” *JAMA* 262, no. 7 (1989): 925-30.

¹² Christine Bechtel and Debra L. Ness, “If You Build It, Will They Come? Designing Truly Patient-Centered Health Care,” *Health Affairs* 29, no. 5 (2010): 914-920.

- **Whole-person care** (clinicians understand the full range of factors affecting a patient's ability to get and stay well and treatment recommendations align with patients' values, life circumstances and preferences)
- **Coordination and communication** (providers organized in teams, effective communication among care providers and smooth transitions between settings)
- **Patient support and empowerment** (e.g., expanding patients' and caregivers' capacity to get and stay well and support for self-management tools and services)
- **Ready access** (e.g., getting appointments promptly and accommodating barriers such as language or physical or cognitive problems)

For health care organizations to fulfill these consumer expectations about patient-centeredness within an ethical, economic and clinical context, the patient's voice must become an integral part of three core functions: 1) governance and policies; 2) quality improvement activities; and 3) individual patient-clinician interactions. The patient-centered/person-centered requirements for ACOs that are part of Medicare begin to enable that kind of commitment by providing detailed and actionable guidance in all three areas:

- 1) *Governance-level requirements* focus on the ACO as an organization. One requirement reads:

Patient-centered care must be promoted by the ACO's governing body and integrated into practice by leadership and management working with the organization's health care team.¹³

The Centers for Medicare & Medicaid Services (CMS) insists the patient's voice be heard in the boardroom in order to influence how care is delivered in the exam and hospital rooms. Each ACO in the Medicare Shared Savings Program must include one fee-for-service Medicare beneficiary who receives care from the ACO. (Retired hospital execs and former medical staff are excluded.) In CMS's Pioneer ACO program, the ACO must also include a consumer advocate, although the beneficiary and advocate could be the same individual. (There are exemptions in certain cases where state laws on medical practice governance might conflict.)

- 2) *Quality improvement activities* address the actual care provided. That care should "incorporate the values of transparency, individualization, recognition, respect, dignity and choice in all matters, without exception, related to one's person, circumstances and relationships in health care."

ACOs must promote *evidence-based medicine* with a patient-centric focus, using guidelines that "cover diagnoses with significant potential

¹³ Centers for Medicare & Medicaid Services, "Medicare Shared Savings Program: Accountable Care Organizations." 42 C.F.R. Part 425, 76 Fed. Reg. 212 (Nov. 2, 2011).

The Patient Will See You Now: A Doctor Reflects on His Training and Practice

Dr. John Krueger is a practicing family physician who is employed as the Medical Director of Quality Management for the Cherokee Nation Health Service in Oklahoma and was a George W. Merck Fellow at the Institute for Healthcare Improvement. A longer version of this essay appeared in the Dec. 28, 2011 issue of the *Journal of Participatory Medicine* and is excerpted with permission.

“Health care,” as I would come to experience it as a medical student and physician, was very different than I had imagined it. When I heard patients complain about their medical care, it was hardly ever about the lack of technical care or competence. Instead, it followed a common theme: “He just didn’t seem like he cared.”

During medical school education, the patient’s story was relegated to the category of “poetry” or “essay.” Health care valued technical competence more than these stories. As I listened and learned, becoming increasingly proficient in medicine, I kept looking for what had inspired me to become a physician in the first place. And I was having trouble finding it!

As I entered practice, the more the pressures of a busy medical office competed for my ability to participate in the patient’s story, the less effective I found myself as a healer and the less joy I found in medicine. Practicing rural family medicine helped me discover that patients often come to physicians with much more than just medical problems. They brought legal, marital, spiritual, financial, educational issues, and more. I discovered that I could solve as many

for the ACO to achieve quality improvements, taking into account the circumstances of individual beneficiaries.” ACOs also must communicate clinical knowledge about evidence-based medicine to patients.

As noted earlier, patient-centeredness must also be “integrated into practice by leadership and management, working with the organization’s health care teams.” It’s a requirement with real teeth: prospective ACOs must tell CMS how they’ll comply and ensure compliance by participating providers and suppliers.

ACOs must also be able to report internally on quality and cost metrics related to patient-centered care, and CMS suggests they invest in population health data management systems or clinical reminder systems to help meet this goal.

3) *Individual level patient-clinician interactions* relate to the “active participation of patients and their families in the process of making medical decisions.” (See Sidebar: “*The Patient Will See You Now*”) Specific “patient engagement” requirements include:

- *Evaluating the health needs* of the ACO’s population, taking into account factors such as race, gender, sexual orientation, disability and income status. There’s also a push to foster health literacy. One in three patients struggles with tasks such as understanding a short set of instructions.¹⁴ The more serious or numerous the medical issues, the more difficult it can be even for well-educated individuals to decipher complex health information.
- *Patient engagement in shared decision-making*, including support and tools allowing patients to assess the merits of various treatment options in the context of their own “values and convictions.”
- *Written standards for clear communication* to beneficiaries and for providing them access to their medical records.

Coordinating care requires ACOs to identify high-risk individuals and develop individualized care plans tailored to health and psychosocial needs and respectful of patient preferences and values. Use of surveys that track patients’ self-reported physical and mental health before and after treatment are not required, but the regulations implicitly encourage them. ACOs must also identify “community and other resources to support the beneficiary” in following the plan.

Health information technology (HIT) can be a critical enabler of patient engagement. Even a partial list of interventions includes patient portals linked to the electronic medical record, secure messaging capabilities between doctors and patients, shared decision-making

¹⁴ Kevin B. O’Reilly, “The ABCs of Health Literacy,” *American Medical News*, March 19, 2012, accessed April 19, 2012, <http://www.ama-assn.org/amednews/2012/03/19/prsa0319.htm>.

health problems with a car ride, phone call, letter, or chain-saw as I could with penicillin.

My eyes were opened to the story of the patient, and what care they expect and need at this moment in their story. My fascination grew with the idea that the patient's life is a story in which health care only intermittently plays a role. Care meant something more.

Though medicine is necessarily standards driven, we often thrust these on patients without their full understanding or engagement. And this approach tends to set up a dependent relationship. If it occurs without kindness, caring, and respect, patients may even perceive it as a form of harm, and either avoid care or disengage completely. And when it is unwelcome, it creates antagonism, yet another form of harm.

But, with my hand on the doorknob, the simple "Oh by the way..." offered up by the patient at the conclusion of an office visit invites me to delay my agenda and just listen. I am offered a chance to become a part of the patient's story, where the patient is at the center and I am being asked to care. It is in the "oh by the way" moment when I discover that a "normal appearing" woman is abused by a model citizen husband; a spouse's alcoholism is driving a family apart; a teenager has been taking her mother's pain medications; and I learn how depressed and close to suicide the seemingly carefree successful father of three is as his business descends into bankruptcy and his marriage into divorce....

Pauses such as the hand on the doorknob can be transitional points to discovery and relationship.... Health care providers must embrace the goals of improved safety, efficiency, effectiveness, and timeliness, but must also realize that health care does not own health and care. If it is owned by anyone, it is owned by patients. We need to include patients as we listen, learn, and redesign our current systems of care with them and for them.

tools, devices enabling remote monitoring of patient health and a plethora of mobile "apps."

Because focusing on patient-centeredness is a relatively new development, these requirements may strike some as arbitrary. In fact, they are backed by a great deal of evidence showing they can help improve individual and population care and control costs. A brief review of that evidence follows.

The Evidence for Engagement

Clinicians have historically pursued patients' welfare via a predominantly provider-centered model of care.¹⁵ But there is good evidence that involving patients and families in redesigning care can produce a wide range of quality, safety and financial improvements. Some examples include:

- **Dana-Farber Cancer Institute (DFCI)**, Boston, has more than 400 active patient and family advisors. Spurred by a highly publicized patient death from an avoidable error in the mid-1990s, the organization became a national leader in involving patients and families in making care safer. Patient and family advisors help shape virtually every aspect of the organization, including safety and quality improvement, facility design and the hospital's management priorities. Their work has led to a profound culture shift, as staff moved from skepticism to "wonder[ing] how they ever ran Dana-Farber without having patients and families deeply involved." The collaborative culture has contributed to more than a decade free of fatal medication errors.¹⁶
- **Contra Costa Regional Medical and Health Centers**, Martinez, California, worked with patient and family advisors, staff, and community agencies to redesign emergency behavioral health services. The facility trimmed hundreds of staff hours from administrative processes (leaving more time for patients), cut care delays and reduced by half the number of psychiatric patients leaving the emergency department prior to receiving care. Meanwhile, 90 percent of those emergency patients were sent back to the community with a full discharge plan, up from 50 percent previously.¹⁷
- **University Health Systems of Eastern Carolina**, Greenville, North Carolina, has embedded a culture of patient-family partnerships across the organization. Since integrating

¹⁵ Christine Laine and Frank Davidoff, "Patient-Centered Medicine: A Professional Evolution," *JAMA* 275 (1996):152-156.

¹⁶ James L. Reinertsen, Maureen Bisognano and Michael D. Pugh, *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care, 2nd Edition* (Cambridge, MA: Institute for Healthcare Improvement, 2008).

¹⁷ Ibid.

Table 1: Contextual factors affecting clinician-patient/family communications

Disease related factors

- Type of cancer
- Stage of disease
- Comorbid conditions
- Overall health status

Social factors

- Social support
- Prejudice and bias based on race, ethnicity, social class, or other factors

Cultural factors

- Cultural beliefs, values, and expectations
- Adaptation and assimilation

Communication media

- Use of electronic communication
- Access to and use of the Internet
- Media coverage of health topics

Health care delivery factors

- Environment (noise, privacy)
- Organization (scheduling, etc.)
- Access to multidisciplinary teams, hospice, navigation programs, and clinical trial protocols

Societal factors

- Access to care, transportation, insurance
- Legal and regulatory factors (informed consent, disclosure of private information, assisted suicide)
- Eligibility for specific health services (palliative care)

Source: Epstein and Street²⁴

patient-family advisors into improvement programs patient, staff and physician satisfaction increased; nurse turnover decreased from 15 percent in 2008 to 5 percent in 2011; hospital-acquired infections have decreased by half in the past two years; serious safety events have decreased 73 percent since 2007; and the eight-hospital system achieved 94 percent optimal care in publicly reported measures.¹⁸

Implementing patient engagement at the individual clinical level poses its own set of challenges. New habits of information sharing, relationship building and shared decision-making inevitably feel strange at first, involving changes that are “stressful and challenging for both patient and physician.”¹⁹ Yet a recent *JAMA* commentary illustrated why engaging patients as partners can be so powerful:

Excellent medical care combines sophistication in scientific knowledge with equally sophisticated communication skills to understand the needs of the individual patient, to address his/her feelings and concerns with sensitivity and compassion, and to educate patients about their choices in care....The benefit of good communication on patient care and outcomes is unequivocal.²⁰

One benefit is better self-management of chronic disease.²¹ Chronic illness accounts for more than eight of every ten dollars spent by Medicare;²² as the number of chronic conditions per beneficiary increases, so, too, do total Medicare expenditures. In 2005, they went from an average of \$7,000 for patients with one chronic condition to \$15,000 for two conditions to \$32,500 for three.

Better communication can improve clinical outcomes in ills such as diabetes, hypertension and cancer.²³ Diabetes affects about one-quarter of Medicare beneficiaries, costing about \$13,000 per beneficiary in 2005, and about half of diabetics also have hypertension. Cancer affected six percent of beneficiaries and cost about \$16,000 per beneficiary in 2005. (For factors affecting communication related to cancer care, see Table 1.)

More broadly, studies show “unequivocal and significant relationships” between doctor-patient communication and patient outcomes such as

¹⁸ Ibid.

¹⁹ Stephanie J. Lee, Anthony L. Back, Susan D. Block and Susan K. Stewart, “Enhancing Physician-Patient Communication,” *Hematology* (2002): 464-83.

²⁰ Wendy Levinson and Philip A. Pizzo, “It’s About Time: Patient-Physician Communication,” *JAMA* 305, no. 17 (2011): 1802-1803.

²¹ Wendy Levinson, Cara S. Lesser and Ronald M. Epstein, “Developing Physician Communication Skills for Patient-Centered Care,” *Health Affairs* 29, no. 7 (2010): 1310-1318.

²² Kathleen M Schneider, Brian E O’Donnell, and Debbie Dean, “Prevalence of Multiple Chronic Conditions in the United States Medicare Population,” *Health and Quality of Life Outcomes* 7, no. 82 (2009).

²³ Ibid.

²⁴ Ronald M. Epstein and Richard L. Street, *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*, NIH Publication No. 07-6225 (Bethesda, MD: National Cancer Institute, 2007).

Table 2:
Health Outcomes

Survival and disease-free survival

- Prevention and early detection of cancer
- Accurate diagnosis and completion of evidence-based treatment
- Maintenance of remission

Health-related quality of life

- Functioning: cognitive, physical, mental, social and role
- Well-being: physical, emotional
- Health perceptions

Societal outcomes

Cost-effective utilization of health services
Reduction in disparities in health and health care
Ethical practice (e.g., informed consent)

Source: Epstein and Street²⁴

psychological and functional status and symptom recovery.^{25 26} Effective patient-centered communication is associated with fewer diagnostic tests, fewer referrals and fewer subsequent office visits.²⁷ It helps physicians use time more efficiently, avoid professional burnout and increase professional fulfillment.²⁸ (For a longer list of outcomes, see Table 2)

ACOs must also consider how gender, ethnic and other differences can affect communication. For example:

- Women are more likely than men to respond to emotional messages with social consequences for themselves or those close to them, whereas men are more influenced by unemotional messages emphasizing personal physical health consequences.²⁹ A collaborative relationship with the physician also seems to have a greater impact on adherence for women than for men.³⁰
- Korean-Americans and Mexican-Americans are more likely to favor a family-centered model of medical decision-making rather than the individual patient model favored by most African-Americans and European-Americans.³¹ Those of Pacific, East Asian and Indian Asian ethnicity are more likely to want the doctor to make the decisions.³²
- Elderly patients may be less likely to express a desire to be “involved” with care decisions, but may become much more confident about the care they receive after clinicians take the time to make them partners in those decisions.³³

To be sure, better communication does not by itself produce a patient-centered health care system. As mentioned earlier, that requires involving patients and families in governance, clinical systems and

²⁵ Moira A. Stewart, “Effective Physician-Patient Communication and Health Outcomes: A Review,” *CMAJ* 152, no. 9 (1995): 1423–1433.

²⁶ Rainer S. Beck, Rebecca Daughtridge and Philip D. Sloane, “Physician-Patient Communication in the Primary Care Office: A Systematic Review,” *Journal of the American Board of Family Practice* 15, no. 1 (2002): 25–38.

²⁷ Moira Stewart, Judith B. Brown, Allan Donner, Ian R. McWhinney, et al., “The Impact of Patient-Centered Care on Outcomes,” *Journal of Family Practice* 49, no. 9 (2000): 796–804.

²⁸ Anthony L. Back, Robert M. Arnold, Walter F. Baile, James A. Tulsky, et al., “Approaching Difficult Communications Tasks in Oncology,” *CA: A Cancer Journal for Clinicians* 55, no. 3 (2005): 164–177.

²⁹ Punam A. Keller and Donald R. Lehmann, “Designing Effective Health Communications: A Meta-Analysis,” *Journal of Public Policy & Marketing* 27, no. 2 (2008): 117–130.

³⁰ Alexis Arbuthnot and Donald Sharpe, “The effect of physician-patient collaboration on patient adherence in non-psychiatric medicine,” *Patient Education and Counseling* 77, no. 1 (2009): 60–67.

³¹ Leslie J. Blackhall, Sheila T. Murphy, Gelya Frank, Vicki Michel, et al., “Ethnicity and Attitudes Toward Patient Autonomy,” *JAMA* 274, no. 10 (1995): 820–825.

³² Timothy Kenealy, Felicity Goodyear-Smith, Susan Wells, Bruce Arroll, et al., “Patient Preference for Autonomy: Does it Change as Risk Rises?” *Family Practice* 28, no. 5 (2011): 541–544.

³³ David Burton, Nicholas Blundell, Mari Jones, Alan Fraser, et al., “Shared Decision-Making in Cardiology: Do Patients Want It and Do Doctors Provide It?” *Patient Education and Counseling* 80, no. 2 (2010): 173–179.

individual care. But better communication builds trust, “the essential foundation” of patient-centeredness.³⁴ Because ACOs take on financial and clinical responsibility for an enrolled population, trust is critical to assuring patients they can stay within the ACO and still get the best care.

However compelling the evidence for all the aspects of patient-centeredness may be, making them part of an organization’s governance and of its patient care processes remains a formidable challenge. Yet turning these sometimes complex concepts into an everyday clinical reality can and is being done.

Intent Becomes Implementation: *Two Case Studies*

Mercy Clinics, Inc., Des Moines, and the Patient- and Family-Centered Care program at the University of Pittsburgh Medical Center’s Magee-Womens Hospital have each been recognized nationally as successful innovators. Whether it is Mercy’s unique chronic disease outreach or Magee-Womens’ path-breaking orthopedic program, both institutions have enhanced quality, patient satisfaction and cost-effectiveness through comprehensive efforts that put the patient at the center.

Mercy Clinics Inc., Des Moines, Iowa

Employing a care manager to work with chronic disease patients is not uncommon. What has made the health coach program at Des Moines-based Mercy Clinics, Inc. a national model is a sophisticated, high-tech and high-touch approach that uses patient-centeredness to improve quality and lower costs.³⁵

The multispecialty group employs more than 150 physicians to handle some 900,000 patient visits annually at more than 50 clinics in urban and rural areas of Iowa. Owned by Mercy Medical Center, part of the Catholic Health Initiatives system, the medical group began a sweeping practice redesign in 2004 with seven goals: a whole person orientation; systems to ensure patients receive proper care; registries to track patients; team-based care; self-management support; safety ensured by processes; and improved access.

³⁴ Bechtel and Ness, “Designing Truly Patient-Centered Health Care,” 914-920.

³⁵ The description of the Mercy Clinics program and quotes from Mercy employees are taken from the following sources: David Swieskowski, “Office-Based Health Coaches: Creating Healthier Communities,” *Group Practice Journal* (2008): 41-45.; “Mercy Clinics: The Medical Home,” *Group Practice Journal* (2008), adapted from the 2007 Mercy Clinics, Inc. Acclaim Award Application.; David Swieskowski and Kelly Taylor, “A Care Setting Experience with Shared Decision Making,” (presented at the Foundation for Informed Medical Decision Making Research & Policy Forum, Washington, DC, January 26, 2011).; Tracy G. Wetzel, “Health Coaching,” *Hospitals & Health Networks*, May 2011, 20-24; Kent Darr, “Coaching Better Health at Mercy Clinics,” *Business Record*, Des Moines, Iowa, August 26, 2011, accessed at, <http://www.businessrecord.com/print.asp?SectionID=38&SubsectionID=101&ArticleID=14823>; Del Konopka, education coordinator, Mercy Clinics, personal communication with author, March 6, 2012.

“Physician office-based health coaches” (their formal title) are registered nurses who complete a 28-hour certification course that includes training in motivational interviewing and other behavior change techniques. “One of the important things about the program is that it’s based on patient needs and wants,” said Kelly Taylor, Mercy Clinics’ director of quality.

This focus on effective “high touch” interactions with chronically ill patients is matched by a similar approach to health information technology. An electronic registry is critical. It creates patient summary reports; actionable lists for patients who may be overdue for care or who are not meeting outcome goals; physician-level performance reports linked to evidence-based medicine criteria; and documentation of compliance with pay-for-performance programs.

The health coaches oversee this registry, conduct pre-visit chart reviews, work with patients and families on self-management support, coordinate care across the continuum and are involved in quality improvement. Since the coaches’ expertise is behavior change, not a specific condition, they can work with any disease. The group’s patients are consistently in the 90th percentile of national measures, such as HEDIS, of chronic care goals such as blood sugar or blood pressure control.

“Any clinical goal we set, we can hit pretty easily,” said David Swieskowski, a family practitioner who was vice president for quality when the program began. “Cholesterol, cancer screening – it’s all the same process. Any type of follow up that needs to be done, we think we can get 95 to 97 percent of patients to do so.”

Swieskowski became the clinic’s chief executive officer in 2008 and in early 2012 was promoted to senior vice president, accountable care organization, as Mercy Clinics and Mercy Medical Center became clinically integrated to pursue private and Medicare ACO contracts.

Patient participation in the health coach program is voluntary. However, when a patient with a chronic condition does join, coaches use a structured process known as the “5As.” The process is based on principles of mutual discovery and respect

for patient values that result in collaboratively picking goals that are patient-directed. Coaches then develop a behavior-change plan with one- to two-week follow-up periods.

“We might tell somebody that they need to start exercising,” said Taylor. “But does anybody ask a patient if that’s important to them? What are they motivated to do? Let’s break it down to what they can achieve.”

Patients can contact the coaches easily, and the coaches, in turn, try to reduce incoming phone calls to the office by anticipating patient needs; e.g., calling patients the day after hospital discharge or when there are lab results. Patient advisory councils augment patient satisfaction surveys in determining each site’s performance on patient-centered topics and identifying areas for improvement.

Self-Management Support – 5A's

Patient Name: _____ Date: _____

Agree To an agenda - what does the patient want to work on?
*Patient Goal: _____

Assess READINESS to change Not ready Unsure Ready
 IMPORTANCE in relation to other values Low Medium High
 CONFIDENCE of success Low Medium High

Advise What would the patient like to talk about? _____
 Information exchanged (elicit-provide-elicited): _____

Assist Patient to develop a personal action plan (if patient is ready).

Dealing with resistance

- Emphasize personal choice and control
- Reassess importance, confidence, readiness
- Do not confront resistance with force – use reflective listening

- Options for behavior change (usually there are many possible courses of action)
- Patient’s preferred option: _____
- Are there barriers the patient needs help with (depression)?
- Follow up plan - When : _____ How: Phone _____ Other _____
 Educator Signature: _____

Arrange: to contact the patient between visits.
 *Follow-up Contact: _____ Completed on - Date: _____

- Results of behavior changes
- Barriers encountered (if any)
- Preferred option for new plan
- Follow up plan - When : _____ How: Phone _____ Other _____
 Follow-up Signature: _____

© 2007 Mercy Medical Center, Mercy Clinics, Inc. All rights reserved.
 4/5/10

Used with permission.

In addition to clinical improvements, the program has increased the efficiency of physicians' offices and freed up Mercy doctors to provide other medically necessary services. As a result, Mercy estimates it brings in at least four dollars in revenue for every dollar spent on health coach salaries and benefits. That's important since each site is responsible for its own bottom line, and each health coach must provide services local physicians value.

The health coach program is expanding to other parts of the care continuum, such as the transition from hospital to home, where problems can result in unanticipated readmissions. The program has also begun using shared decision-making tools for conditions such as acute and chronic low-back pain and knee and hip osteoarthritis.

Mercy Clinics was named the 2007 Acclaim Award Honoree by the American Medical Group Association for demonstrating "dramatic, measurable progress" towards health system goals set by the IOM, and it has been featured by the Institute for Healthcare Improvement (IHI). Its success has led Mercy Clinic to train other Catholic Health Initiatives organizations and to partnering with The Advisory Board Company to spread the program nationally.

Health coaches, said Swieskowski, have improved patient outcomes and moved physician practices from reactive to proactive. The biggest payoff, he added, "is the creation of healthier communities."

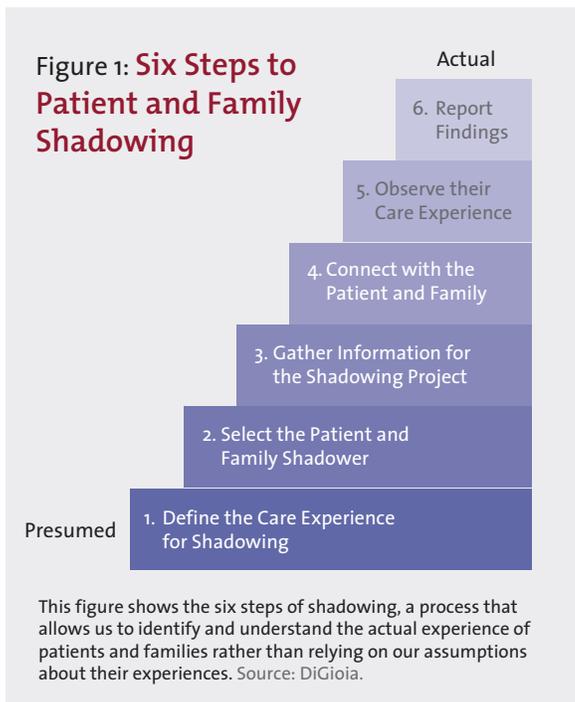
Magee-Womens Hospital, University of Pittsburgh Medical Center, Pittsburgh, PA

The \$9 billion University of Pittsburgh Medical Center (UPMC) health system is a dominant presence in western Pennsylvania, with more than 20 hospitals, 400 ambulatory sites and a 1.6 million-member health plan. From his base at UPMC Magee-Womens Hospital, Anthony M. DiGioia III oversees a Patient- and Family-Centered Care (PFCC) program that began in 2006 and has spread to other system hospitals as a formal performance improvement process.

"We developed a true methodology to establish PFCC, and to our knowledge no one has done that," said DiGioia, an orthopedic surgeon who trained as a civil and biomedical engineer.³⁶

The PFCC process starts with staff members selecting a patient care experience they want to change, then forming a guiding council that includes a clinical champion. Staff members, interns or volunteers "shadow" patients and families in a structured way, creating a flow map

³⁶ The description of the Patient and Family Centered Care program at the University of Pittsburgh Medical Center and quotes from officials there are taken from the following sources: Dale Shaller and Charles Darby, *Profiles of High-Performing Patient- and Family-Centered Academic Medical Centers: University of Pittsburgh Medical Center, Pittsburgh, Pennsylvania*, March 2009. Prepared for Picker Institute, accessed April 19, 2012, <http://pickerinstitute.org/profiles-of-medical-centers/>; Pohla Smith, "UPMC Matches a Method to Patient-Centered Care Model," *Pittsburgh Post-Gazette*, January 6, 2010, accessed April 19, 2012, <http://www.post-gazette.com/pg/10006/1025997-114.stm>; Maureen Leahy, "Viewing Care Through the Eyes of Patients and Their Families," *AAOS Now*, October 2010, accessed April 19, 2012, <http://www.aaos.org/news/aaosnow/oct10/clinical5.asp>; Harris Meyer, "Innovation profile: At UPMC, Improving Care Processes to Serve Patients Better and Cut Costs," *Health Affairs* 30, no. 3 (2011): 400-403.; Anthony M. DiGioia III and Pamela K. Greenhouse, "Care Experience-based Methodologies: Performance Improvement Roadmap to Value-driven Health Care," *Clinical Orthopaedics and Related Research* 470, no. 4 (2012): 1038-45.; Anthony M. DiGioia III, personal communication with author, March 14, 2012.



and pinpointing improvement opportunities. Representatives from every part of the system touched by the flow map are then invited to form working groups.

It is those working groups which tackle the hard work of creating a shared vision for change, in part by writing a story that details the ideal patient and family experience and serves as a guide for closing the gap between the actual and that ideal. A patient and family advisory council helps ensure that every care experience is viewed through the eyes of the patient and family. Finally, groups meet to test solutions, revise them and look for new improvement possibilities.

DiGioia defines caregivers as “anyone in the organization who touches a patient’s or family’s care experience.” PFCC “includes the entire experience...parking, food delivery...things like home health experiences, the lobby and the ways of finding things [in the hospital].” Among PFCC’s principles are “seek low-tech solutions, simplify and streamline processes;” “minimize handoffs inside and outside the hospital;” and “don’t be afraid to fail – you will learn from the experience.” What emerges, says DiGioia, is “co-design of care” with patients.

The Orthopaedic Program at Magee-Womens is the “home” for patients needing hip or knee or arthritis care. After an initial office visit, patients come to the hospital for pre-operative testing and a two-hour educational session. In the program’s version of self-management support, each patient brings a family member or close friend to be trained as a coach who will accompany them through the care experience.

The structured pre-op preparation has produced economic and clinical efficiencies. In spine surgery, 272 of 743 patients admitted in 2010 were discharged ahead of schedule and 312 on schedule, saving 336 hospital days and \$117,600 versus what would have been spent before the improvements. Length of stay decreased by 0.87 days, while Press Ganey satisfaction scores for spine surgery patients rose from an average of 65 percent to 88 percent. (See Table 3) The hospital also seeks detailed patient feedback post-surgery.

The public rooms in the orthopedic wing are filled with rocking chairs and attractive art. Patient rooms have mini-desks and small refrigerators. The rehabilitation center looks like a gym. There are interactive games because, said DiGioia, “competition works.”

The average length of stay (ALOS) for total knee arthroplasty patients was 2.9 days in 2009, compared to the national ALOS of 3.8 days, with an infection rate of zero. The ALOS for total hip arthroplasty patients was 2.5 days, compared to the national ALOS of 4.9 days, with an infection rate of 0.3 percent.

And in a patient-centered statistic few institutions likely track, the incidence of patients’ belongings getting lost between the emergency department and other hospital services dropped from 12 to 25 losses per week to zero.

The UPMC program was one of six academic medical centers programs profiled by the Picker Institute. The IHI has called the PFCC methodology

Table 3: The impact of the Patient- and Family-Centered Care Methodology and Practice (PFCC M/P) on patient satisfaction* in the total joint arthroplasty program, trauma services, and orthopaedic spine services (2010 data)

Clinical program or department	Patient satisfaction compared with national rates	Patient satisfaction “Top Box” percentile ranking <i>preimplementation</i>	Patient satisfaction “Top Box” percentile ranking <i>postimplementation</i>	Percentile point increase
Total joint arthroplasty (hips and knees)	99th percentile			
Emergency department**		77%	87.4%	11.4
General trauma inpatient**		70.3%	79.7%	9.4
Trauma stepdown unit**		68.3%	72.5%	4.2
Orthopaedic spine program***	<p>89% of patients checked the top box (“satisfaction with discharge”) compared with 83% of patients from the other 600 + -bed participating hospitals</p> <p>91% of patients checked the top box for “staff talked with patient about help after discharge” compared with 80% of patients from the other 600 + -bed participating hospitals</p>			

Source: DiGioia. * Patient satisfaction is based on Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey data; **part of UPMC Adult Trauma Services—preimplementation measurement from July 2008; ***part of the larger Surgical Services PFCC M/P initiative.

“groundbreaking work.” It has been implemented at various UPMC hospitals in 40 processes ranging from women’s cancer care to bariatric surgery.

While DiGioia is passionate about organizational changes, he still sees individual patients: “The bottom line is that no matter ...how far you go in the journey toward delivering patient- and family-centered care, if you improve the care experience for one patient and for one family you’ve succeeded.”

Patient-Centeredness in the Real World: Looking Ahead

It has taken a full century for the patient’s perspective to go from being routinely ignored to being hailed as a pillar of an ideal health care system. Although that ideal has not yet been realized, new laws, new economic incentives and new mores are bringing it closer.

The Medicare ACO rules exemplify the power of the first two factors, mandates and money. The 27 ACOs announced in April, 2012 as initial participants in the Medicare Shared Savings Program must measure and manage four specific domains of patient-centeredness: patient care/ caregiver experience; care coordination/patient safety; preventative health; and at-risk populations. If they score at least 70 percent on each

domain's measures and meet other requirements, they share any money they save on care with the government. If they fail to meet the threshold, they risk being expelled from the program. More than 1.1 million Medicare beneficiaries are now participating in this and the Pioneer ACO program, which has similar patient-centeredness rules.

However, it is new mores, reflecting cultural change inside and outside medicine, that are most powerfully reshaping care. The American Board of Internal Medicine has declared "patient autonomy" to be a core professional principle, while the American Academy of Orthopaedic Surgeons describes its members as "strong advocates" of patient-

centered care. More recently, an American Heart Association scientific statement described shared decision-making in treating advanced heart failure as a clinical necessity.³⁷

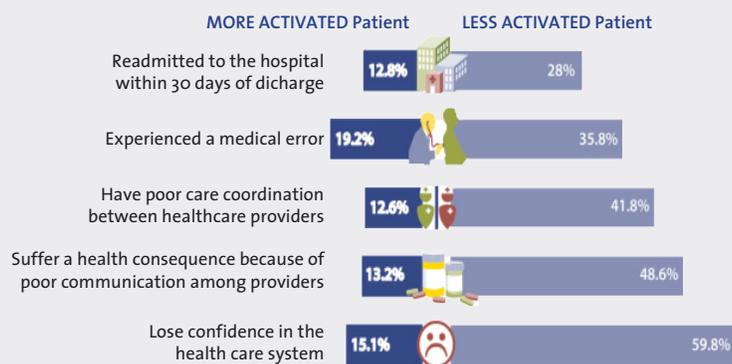
The professional evolution reflects a change in patients' expectations. The wide availability of Internet-based medical information and tools, including a panoply of mobile apps, provides constant pressure for transparency of information and accountability for results. At the same time, the spread of health insurance plans that encourage shopping for cost-effective care is feeding a fast-growing medical consumerism. Even the research literature that links patient activation to better care is being translated into terms the public can understand.

Patient advocacy groups are also pressing for a new relationship; e.g., "partnerships among providers, patients and families"³⁸ or a "cooperative model of health care that encourages and expects active involvement by all."³⁹ This emerging emphasis could

have profound consequences. An effective physician-patient alliance "can literally make the difference between life and death, can improve quality of life and diminish human suffering, and can limit the costly social and economic effects of chronic medical illnesses."⁴⁰

While the gap between ideal and real in patient-centeredness is shrinking, many clinicians remain reluctant to involve patients in decisions or to share reasons not to go ahead with a procedure.⁴¹ Similarly, although Medicare ACO regulations suggest a detailed

Figure 2: **The MORE ACTIVATED you are in your own health care, the BETTER HEALTH CARE you get.**



Source: Adapted from AARP & YOU, "Beyond 50.09" Patient Survey. Published in AARP Magazine. Study population age 50+ with at least one chronic condition. More Involved = Levels 3 & 4, Less Involved = Levels 1 & 2

³⁷ Larry A. Allen, Lynne W. Stevenson, Kathleen L. Grady, Nathan E. Goldstein, et al., "Decision Making in Advanced Heart Failure: A Scientific Statement From the American Heart Association," *Circulation* 125 (2012): 1928-52.

³⁸ Susan B. Frampton, Sara Guastello, Carrie Brady et al., *Patient-Centered Care Improvement Guide* (Derby, CT and Camden, ME: Planetree and Picker Institute, 2009). Accessed April 19, 2012, <http://www.patientcenteredcare.org>.

³⁹ "Welcome!" Society for Participatory Medicine, accessed April 19, 2012, www.participatorymedicine.org.

⁴⁰ Jairo N. Fuertes, Alexa Mislawack, Jennifer Bennett, Laury Paul, et al., "The Physician-Patient Working Alliance," *Patient Education and Counseling* 66, no. 1 (2007): 29-36.

⁴¹ Floyd J. Fowler, Patricia M. Gallagher, Julie P. W. Bynum, Michael J. Barry, et al., "Decision-Making Process Reported by Medicare patients Who Had Coronary Artery Stenting or Surgery for Prostate Cancer," *Journal of General Internal Medicine* (2012). doi: 10.1007/s11606-012-2009-5.

framework for patient involvement in everything from governance to individual clinical decisions, their resonance with providers in general remains to be seen.

Moreover, just as individual clinicians will have to adjust to new kinds of patient centeredness, so, too, will patients. Whether in regard to ACOs or any of the other new care delivery models, “clear definitions of the roles and responsibilities of consumers in management of their health will be needed, defined in ways that consumers believe is feasible and appropriate for them to carry out,” one analyst says.⁴²

For instance, some health advocacy organizations have said that outcomes data should serve only as a guide to medical decisions, not the basis for them.⁴³ Will shared decision-making be used to demand treatments of dubious clinical value, or is it more likely, as research shows, that patients engaged in shared decisions tend to choose more conservative treatment options?⁴⁴ Medical practices could find themselves distributing formal “rules of engagement” with explicit expectations about the respective responsibilities of patients and providers to share information candidly and listen to each other’s concerns.⁴⁵

While there will be disagreements, detours and delays along the way, the path to building a patient-centered health system in the real world is clearly marked. There are practical ways to integrate the patient’s perspective into governance, clinical quality improvement and enhancing the individual’s experience of care.⁴⁶ Deep and lasting change is possible, and ACOs are well-positioned to spearhead that change.

The declaration of empowerment that began with the disability rights movement – “Nothing about us without us” – is becoming health care’s cultural norm. Ethically, economically and clinically it is the right course. The organizations that embrace it may be ahead of the pack, but there is no doubt that others will soon follow after.

⁴² Harold D. Miller, *How to Create Accountable Care Organizations* (Pittsburgh, PA: Center for Healthcare Quality & Payment Reform, 2009).

⁴³ Sheila M. Rothmann, “Health Advocacy Organizations and Evidence-Based Medicine,” *JAMA* 305, no. 24 (2011): 2569-2570.

⁴⁴ Annette M. O’Connor, Carol L Bennett, Dawn Stacey, Michael Barry, et al., “Decision Aids for People Facing Health Treatment or Screening Decisions,” *Cochrane Database Systematic Review* 3 (2009). doi: 10.1002/14651858.CD001431.pub2.

⁴⁵ Jessie Gruman, Dorothy Jeffress, Susan Edgman-Levitan, Leigh H. Simmons, et al., *Supporting Patients Engagement in their Health and Health Care* (Washington, DC: Center for Advancing Health, 2011), accessed April 19, 2012, http://www.cfah.org/pdfs/CFAH_PACT_Special_2010.pdf.

⁴⁶ Adapted from Institute for Patient- and Family-Centered Care, accessed April 19, 2012, <http://www.ipfcc.org/faq.html>.