



RESEARCH REPORT

The Road to Making Patient-Centered Care Real

Policy Vehicles and Potholes

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The Road to Making Patient-Centered Care Real: Policy Vehicles and Potholes

Introduction

In a landmark 2001 report on improving American health care, the Institute of Medicine (IOM) called patient-centeredness one of six aims of a 21st-century health care system.¹ That designation in the *Crossing the Quality Chasm* report was oft-quoted, but its impact for many years remained mostly symbolic.

More recently, the focus on patient-centeredness has shifted from rhetorical to real-world implementation. In part that's due to growing acceptance of measures such as patient experience and patient-reported outcomes as valuable in themselves, whatever their impact on cost and quality.² However, it's also because patient-centered measures are playing an increasingly important role in the health system's historic transition "from volume to value;" that is, from long-established payment methods based on activity to alternative payment models that feature some amount of provider financial risk and quality measurement. There is a broad consensus that, as a 2013 IOM workshop concluded, "Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs and better health."³ (In mid-2015, the IOM was renamed the National Academy of Medicine.)

Much of the change is being driven by delivery system reforms emanating from Washington, including the "meaningful use" provisions of the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act; numerous sections of the 2010 Patient Protection and Affordable Care Act (ACA); and key portions of the Medicare Access and CHIP Reauthorization Act (MACRA), signed into law in April 2015.

In 2014, a diverse group of knowledgeable stakeholders laid out a robust "roadmap" leading to broader patient and family engagement, the centerpiece of patient-centered care. It set forth a menu of actions to be taken by payers, providers, policymakers and patients.⁴ That goal-setting, while a major contribution, left largely unanswered the first question asked by map users: "Where are we now?"

This paper answers that question in several ways. First, after examining the origins of the term “patient-centered care” and its current meaning, the paper reviews laws that have been important vehicles for moving patient-centeredness from ideal to real. The focus here is the clinical component of the provider-patient interaction. Initiatives to stimulate “consumerism” through insurance design and pricing innovations fall outside this paper’s purview, as do efforts to incorporate patient input into research or into regulatory review. Even within those limits, this appears to one of the first policy surveys of its kind.

Next, a successful journey requires reliable guidance. This paper’s second contribution is to review some of the measurement tools and research involved in enabling patient-centeredness to become operational as well as aspirational.

Finally, even when everyone agrees on a trip’s destination and route, obstacles can obstruct the way. The third part of this paper examines several. In particular, three separate concepts of patient-centeredness—the ethical, economic and clinical—can reinforce each other, but they can also conflict.

In sum, the journey making patient-centered care goals requires accurate knowledge of the starting point and the destination, as well as confidence in the vehicle and guidance system to get there. This paper aims to inform a more detailed discussion of federal policies affecting all those important elements.

What Patient-Centered Care Means

In 1987 the Picker/Commonwealth Program on Patient-Centered Care invented that term and eventually proposed six dimensions. These included

- respect for patients’ values, preferences and expressed needs,
- coordination and integration of care,
- Information, communication and education,
- physical comfort,
- emotional support, and
- involvement of family and friends.⁵

The IOM's *Chasm* report adopted those categories and summarized the concept this way: "Patient-centeredness encompasses qualities of compassion, empathy and responsiveness to the needs, values and expressed preferences of the individual patient."

Unfortunately, these categories are broad enough to include everything from convenient appointments and clean hospital rooms to electronically sharing the doctor's notes and customizing therapy based on patient genotype. Moreover, the plain English meaning of "patient-centered" seems to include traditional professional beneficence on the patient's behalf, as well. Unsurprisingly, then, an examination of more than 60 articles on patient-centered care from the health policy, medical and nursing literature found "few common definitions."⁶

"Patient-centered" is also being employed by some as political shorthand for warding off "government micromanagement of personal medical decision making," as a conservative think tank put it.⁷ Similarly, Speaker of the House of Representatives John Boehner vowed after the Supreme Court's *King v. Burwell* decision to continue efforts to replace "Obamacare" with "patient-centered solutions."⁸

Finally, some observers object to the term's linguistic assumptions and prefer "person-centered" or another label. While those arguments have merit, "patient-centered care" remains the term with the widest policy and professional acceptance. In the context of this paper, it will be used to refer directly to care delivery processes and measures, including patient experience of care, patient and family engagement, patient activation, shared decision-making and patient-reported outcomes.

Advancing Patient-Centeredness Legislatively

Mandates to put specific patient-centered practices into place are already fueling change. Three of the most prominent laws giving rise to new mandates are discussed below.

The Health Information Technology for Economic and Clinical Health Act (HITECH)

As of December 2014, hospitals and physicians had received \$28.1 billion in incentive payments for adopting electronic health records meeting Stage 1 and 2 "meaningful use" (MU) regulatory standards.⁹ Those standards have consistently included measures meant to advance electronic engagement of patients throughout the health care system. By the end of 2013, almost 3 in 10 individuals were offered

access to an online medical record, according to the Office of the National Coordinator for Health Information Technology (ONC).¹⁰

Stage 3 MU regulations include patient engagement as a formal objective and set goals for the percentages of patients who must actually view their data and receive a clinically relevant electronic message after hospital discharge. For the first time there's a provision related to patients contributing their own data, with providers required to incorporate so called "patient-generated health data" into the EHR clinical information from "non-clinical" settings such as physical therapy or a wearable device.¹¹ Providers could report on these criteria in 2017 and must meet them in 2018 or suffer a payment penalty.

The draft rule prompted substantial pushback from some in the provider community and in Congress, particularly in regard to the timetable for specific goals; e.g., 25 percent of patients viewing, downloading or transmitting their health information by 2018. The final rule, issued Oct. 6, included an additional 60-day comment period, signaling possible further changes to mollify critics. Whatever the specific modifications, however, incenting providers to fully use the EHR as a vehicle to engage patients in their care remains an important policy focus.

The Affordable Care Act (ACA)

The term "patient-centered" appears some 40 times in the ACA, and there are additional references within specific initiatives to "patient satisfaction," "patient experience of care," "patient and family engagement" and "shared decision-making."¹² Perhaps the law's most prominent effort to reshape care delivery, the accountable care organization (ACO), has resulted in the most detailed patient-centered care parameters. As of mid-2015, those regulatory requirements affected 404 Medicare Shared Savings Program (MSSP) ACOs with 7.3 million assigned beneficiaries. (The 19 Pioneer ACOs serving 600,000 beneficiaries are governed by an agreement with the Center for Medicare and Medicaid Innovation that has similar but less detailed requirements.)

Organizations applying to become an MSSP ACO must explain how they will promote evidence-based medicine and patient engagement, report on quality and cost measures and coordinate care.¹³ The Centers for Medicare & Medicaid Services (CMS) evaluates all ACOs on 33 quality measures across four domains. Seven measures, and 25 percent of quality-related compensation, relate to the patient and caregiver experience.

The breadth, depth and specificity of the regulatory guidance set this rule apart as it presses for patient-centered care at three levels, summarized here:¹⁴

- *Governance-level requirements* call for patient-centered care to “be promoted by the ACO’s governing body and integrated into practice by leadership and management.” That governing body must include one fee-for-service Medicare beneficiary receiving care from the ACO.
- *Clinical-level requirements* prescribe clinical policies, such as communicating about evidence-based medicine with patients and tracking care systematically through population health data management or clinical reminder systems.
- *Individual level patient-clinician interactions* call for promoting “active participation of patients and their families in the process of making medical decisions,” including support and tools allowing patients to assess treatment options in the context of their own “values and convictions.” A requirement to develop individualized care plans also mentions factors such as race, gender, sexual orientation, disability and income status.

The extent to which individual ACOs are actually traveling where these detailed instructions have pointed them is unclear. At present, there’s no evidence CMS has assessed whether ACO implementation has followed proposed action plans to promote patient engagement.¹⁵ The overall burden of ACO measures also remains controversial.

The Medicare Access and CHIP Reauthorization Act (MACRA)

MACRA eliminated the sustainable growth rate (SGR) formula, which was supposed to constrain spending under Medicare’s physician fee schedule, and replaced it with pay-for-performance and incentives to adopt “alternative payment methods.” Beginning in 2019, the Physician Quality Reporting System, MU and the Physician Value-Based Purchasing Program will be replaced by the Merit-Based Incentive Payment System (MIPS). A publicly reported MIPS score will determine provider bonuses or penalties based on four domains: quality measures, efficiency measures, meaningful use of electronic health records and clinical practice improvement activities.

The quality domain must incorporate at least these areas: clinical care; safety; care coordination; patient and caregiver experience; and population health and prevention. The law assigns priority to outcomes measures, including patient-reported outcome and functional status measures; patient

experience measures; care coordination measures; and measures of appropriate use of services, including measures of overuse.¹⁶

Providers who have already traveled a substantial way along the “pay for value” road won’t be burdened by being given a new set of directions. Those already receiving a significant portion of their income via alternative payment mechanisms that use similar cost and quality metrics, such as an ACO or advanced patient-centered medical home (PCMH), can opt out of MIPS. However, they may be subject to comparable performance metrics applied at the organizational level.

Other Patient-Centered Policy Initiatives

Title III of the ACA requires the Secretary of Health and Human Services (HHS) to develop a National Strategy to Improve Healthcare Quality and report annually on it to Congress. First published in 2011, what is now called the *National Strategy for Quality Improvement in Health Care* has three overarching aims (better care, healthy people/healthy communities and affordable care) and six priorities.¹⁷ The second of those, “ensuring that each person and family is engaged as partners in their care,” contains three parts:

- Improve patient, family and caregiver experience of care related to quality, safety and access across settings.
- In partnership with patients, families and caregivers—and using a shared decision-making process—develop culturally sensitive and understandable care plans.
- Enable patients and their families and caregivers to navigate, coordinate and manage their care appropriately and effectively.¹⁸

The strategy document is separate from the *National Healthcare Quality & Disparities Report* from the Agency for Healthcare Research and Quality (AHRQ). This researcher version of a GPS-like locator includes national information on shared decision-making and on the experience of care by adults and children in the doctor’s office and hospital.¹⁹

In addition, measures linked to the patient experience of care or similar metrics are part of HHS’s “Better, Healthier, Smarter” initiative that aims to tie 50 percent of Medicare payments to value-based models by the end of 2018.²⁰

The department has launched lesser-known efforts ranging from a framework for health risk assessments for Medicare beneficiaries to the establishment of PCMHs by community health centers and the Indian Health Service. CMS has also provided more than \$1.25 billion in Health Care Innovation Awards to about 150 organizations to improve care and lower costs for those in Medicare, Medicaid and the Children's Health Insurance Program (CHIP). Some of those grants target patient-centered care interventions, such as shared decision-making.²¹

Patient-centered care components are also routinely cited in regulatory actions. For instance, a 2015 rule authorizing Medicare payment for annual lung cancer screening using low-dose computed tomography for some current and former smokers specifically covers a “counseling and shared decision-making visit.”

HHS continues to push for patient-centered measures across the continuum of care, including in long-term care, rehabilitation and other venues. CMS has its own quality strategy that aligns with the national one, and a Person and Family Engagement affinity group created to implement it is developing a national framework to enable patients and families to become engaged and informed partners in improving safety and reducing inappropriate care.²²

The Department of Veterans Affairs also backs a number of care delivery initiatives related to patient-centeredness, including support of the PCMH, within its Office of Patient-Centered Care and Cultural Transformation.

Though this paper focuses on care delivery, the most prominent effort to promote the patient perspective in research on drugs and devices and in care delivery merits brief mention. As of mid-2015 the Patient-Centered Outcomes Research Institute (PCORI) had awarded \$869 million to 400 projects ranging from understanding patient priorities for research into Crohn's disease to developing a video empowering patients facing major surgery.²³

Measuring Patient-Centered Care

The Spread of CAHPS

While “patient-centered care” itself is imprecisely defined, discrete components can be measured and tracked to provide guidance as to whether milestones are being achieved. The best-known and most-

tested instrument is the family of patient experience of care surveys known as the Consumer Assessment of Healthcare Providers and Systems (CAHPS). The CAHPS tool, now overseen by AHRQ, was first deployed in the 1990s to assess health plans.

Patients are the best and often only source of reliable information on the clarity of clinician communication, respect and similar aspects of care. In addition to CAHPS for hospitals (HCAHPS), there's a survey for clinicians and medical groups (CG-CAHPS) and, as a subset, one for the PCMH. There are CAHPS for ACOs, health plans, home health, nursing homes, behavioral health, surgical care, dental care, the Medicare drug benefit and children with chronic conditions. A CAHPS to assess care delivered by the Choctaw tribe evolved into the American Indian Survey standardized questionnaire. CAHPS results are often publically available on the web, a further spur to action.

As the financial impact of CAHPS has grown, both in direct payment (as with ACOs, hospital value-based purchasing and other programs) and through the indirect impact of transparency of scores, so have concerns about possible negative effects. For example, CAHPS may be better at assessing provider responsiveness to the vast majority of patients who are healthy or effectively managing a chronic condition, while missing a subpar response to a smaller group with acute problems that needs urgent attention and support.

Separately, an ethics journal broached another common concern this way: "The pursuit of high patient-satisfaction scores may actually lead health professionals and institutions to practice bad medicine by honoring patient requests for unnecessary and even harmful treatments."²⁴ However, despite anecdotal reports of this occurring, a literature review found no evidence CAHPS scores lead to care that is "inappropriate, ineffective and/or inefficient."²⁵

Other studies support CAHPS as a reliable proxy for various quality objectives. One literature review found that higher patient experience scores are associated with higher levels of adherence to recommended prevention and treatment processes, lowered utilization and improved patient safety and are linked to better clinical outcomes.²⁶ And a study of U.S. hospitals found that those with high patient satisfaction provided more efficient surgical care and were associated with higher surgical quality."²⁷

Beyond "Experience"

The impact of patient communication and patient engagement, concepts also promoted in legislative and regulatory language, has been studied using methodology that goes far beyond reliance on CAHPS.

A literature review found “compelling evidence” that better communication can lead to improved clinical outcomes in the management of diabetes, hypertension, and cancer.²⁸ In the patient engagement realm, the extensively tested Patient Activation Measure (PAM) assesses an individual’s skills, knowledge and confidence in managing their health and engaging in shared decision-making.²⁹

Improving PAM scores at one large health system helped improve 12 of 13 outcomes linked to prevention, unhealthy behaviors, clinical indicators, and utilization.³⁰ Patients with lower activation scores also had higher costs.³¹

Another extensively tested tool is the Health Confidence Measure, a single-question inquiry (“How confident are you that you can control and manage most of your health problems”) that can be used by primary care physicians in their practices. The measure has been shown to be directly associated with physician performance and patient outcomes.³²

Patient-reported outcomes measures (PROs or PROMs) began to be collected and reported in a validated format in the 1980s.³³ Examples include health-related quality of life, symptoms (such as pain), functioning, and adherence to therapy. Interest is growing in integrating PROs into additional contexts, including adverse event reporting;³⁴ a recent issue brief by the Consumer-Purchaser Alliance urged their wider adoption.³⁵ Since 2004, the National Institutes of Health has funded the Patient-Reported Outcomes Measurement Information System (PROMIS) for research into patients’ physical, mental and social well-being.³⁶ These measures may help in comparing different treatments and providers, as well as changes in performance over time.³⁷

Separately, a torrent of patient-generated health data is beginning to arrive from outside the traditional care system via clothing and other wearables that can monitor heart rate, pulse and a growing list of other indicators. A Microsoft fitness band that provides constant heart rate monitoring, for example, was said to be part of a “platform” employing algorithms to deliver “actionable information” and contextual analysis.³⁸ Whether or not policymakers confront this issue through MU regulations, traditional providers will inevitably be challenged to integrate this data into their EHRs while simultaneously protecting privacy and confidentiality.

Obstacles

For all the progress in measurement and the agreement on goals, much more work is needed on the actual impact of implementation. It is here that potholes invisible in the satellite view of the patient-centered care journey start to rattle the axles of policy vehicles.

To begin with, “patient-centered” will vary by the individual. Patients are not homogenous. For example, a collaborative relationship with the physician may have a greater impact on women’s adherence to medication than men’s.³⁹ The goal of collaboration trumpeted at policy conferences may not resonate with underserved minorities harboring underlying deep mistrust of “the system.”⁴⁰ (And, distressingly, one recent study found that doctors talked less often with patients of “other” races and ethnicities about the reasons for treatment recommendations.⁴¹) “Autonomy” can mean different things to the young and to the old and to different ethnic groups.⁴²

In addition, the guidance system for the implementation journey remains in a nascent state. A recent IOM report emphasized the need for better collaborative tools and more training for physicians.⁴³ And an analysis of 234 performance measures being considered in more than 20 federal programs found that “a relatively small number of measures under consideration addressed person- and family-experience/population health.”⁴⁴ Condition-specific measures remain largely in a research stage.

Measures other than traditional surveys are also drawing attention, including an analysis of hospital Yelp ratings that found a statistically significant correlation between high Yelp ratings and high HCAHPS scores. There was also a statistically significant correlation between high marks in Yelp and in HCAHPS with lower mortality for heart attack and pneumonia.⁴⁵ The burst of measurement activity has unsurprisingly spurred concerns about measure proliferation and usefulness.

Converging and Diverging Goals

Meanwhile, while the umbrella term “patient-centered care” attracts near-universal acclaim, it encompasses three separate concepts that can overlap, be synergistic or even conflict with each other.⁴⁶

The *ethical* aspect of patient autonomy relies heavily on notions of individual rights and free choice founded on more than a century of legal decisions establishing every person’s right to be fully informed about a proposed treatment.⁴⁷ The *economic* aspect of patient-centeredness, on the other hand, puts

the patient in the position of a customer. As early as 1974, an IOM report endorsed publishing outcomes measures “so consumers can be informed” in their choices.⁴⁸ Meanwhile, the *clinical partnership* domain focuses on communication and collaboration as a means of achieving the goal of better outcomes.⁴⁹

The three aspects can reinforce each other: high CAHPS scores that signal respect for autonomy and a clinical partnership are also useful for marketing purposes. Each aspect of patient-centeredness also has independent value; for example, whether or not shared decision-making saves money⁵⁰ or improves outcomes,⁵¹ helping patients who want to become clinical partners do so is the morally right course.

Finally, conflicts lurk. Patients may choose a provider in part based on price, but the successful shopper expects a clinical partnership rather than the *caveat emptor* relationship of seller-buyer once inside the exam room. On the other side of the stethoscope, physicians worry what happens to their ethical obligations if a “patient” becomes the “customer.”⁵²

In this period of flux, past assumptions about relationships may no longer hold. Consider the individual who seeks care from her family physician one week, a nurse practitioner at a drugstore clinic the next, a previously unknown doctor via a telehealth connection the week after that and advice from the doctors and patients on CrowdMed, based on readings from her glucometer and smartphone apps, to finish off the month.

While this behavior could be characterized as the “prepared, engaged patient” of the IOM’s policy ideal, it is far from certain that when writ large in all of American health care it will turn out to be “a fundamental precursor to high-quality care, lower costs and better health.”⁵³ As patient-centeredness goes from ideal to implementation, the assumption that all possible aspects work in harmony will surely be tested. Despite a consensus roadmap on goals, paths may diverge, and it will be up to policymakers to decide which is the road not taken.

Conclusion

The implementation of multiple patient-centered care interventions is beginning to turn an aim for the 21st-century US health care system into a measurable aspect of care. Details of what this means will become clearer as the aspirational language in HITECH, the ACA, MACRA and future legislation is articulated as rules and regulations further guiding practice.

The goals and guidance of a roadmap are a major contribution to the patient-centeredness journey. Others have laid out the rationale for a “policy push.”⁵⁴ For those accelerated efforts to be successful however, policymakers and those in the front lines of care also need a clearer picture of where current policies have already taken us and where they are heading. Multiple agencies and departments are involved in patient-centered initiatives; only a few have been touched upon here.

These efforts in HHS and elsewhere in the federal government should be comprehensively catalogued and subjected to the same strategic scrutiny as other care improvement activities. That hasn’t yet happened, yet is particularly important at a time of rapid innovation in patient-generated health data.

The pace of change also underlines the need for better measures and more information on effective implementation. Specific measures must not only be technically valid, but trusted by everyone, a challenge as the economic stakes rise with changes in public and private payment rules.

Though some may propound “patient-centered” for partisan purposes, that usage nonetheless reflects an instinctive understanding of the value Americans attach to personal autonomy and to the clinical relationship. The new practices of patient-centered care are an unsettling product of powerful cultural, economic and technical forces; that’s the essence of a paradigm shift. This uncertainty makes it all the more important to emphasize that patient-centered care is a disruptive innovation that will ultimately enhance rather than detract from the doctor-patient bond.

Doctors are fond of quoting Dr. William Mayo’s pronouncement, “The best interest of the patient is the only interest to be considered.” Patient activists prefer, “Nothing about me without me.” Policymakers should encourage the evolution of a health care system where all sides see these two visions of patient-centered care not as an “either/or” choice but a possibility for “both.”

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