

Will the Affordable Care Act Move Patient-Centeredness to Center Stage?

Timely Analysis of Immediate Health Policy Issues

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Listening to the Patient's Voice

Nearly a decade after the Institute of Medicine (IOM) designated “patient-centeredness” as one of six goals for a 21st century health care system, the Patient Protection and Affordable Care Act (ACA) has mandated the use of measures of the quality of care, public reporting, and performance payments that reflect this ambitious aim.¹ The law repeatedly refers to patient-centeredness, patient satisfaction, patient experience of care, patient engagement, and shared decision-making in its provisions. Even when the law only uses the more general term “quality measures,” patient-centered assessments are being required when these provisions are turned into regulations for specific programs such as with Medicare’s Value-Based Purchasing Program. (See Table: “Key ACA Provisions Related to Quality Measurement and Reporting.”)

The ACA requirements and similar efforts taking hold in the private sector represent an unsung transformation. Questionnaires asking patients about emotional support, communication, and “maintenance of [a hospital] patient’s self-esteem” go back at least to the late 1950s,² but the context has changed radically. In 1957, the American Medical Association’s (AMA’s) Code of Ethics said of patient opinions, “Reasonable indulgence should be

granted to the caprices of the sick.”³ The current code sounds a very different tone: “A physician shall respect the rights of patients, colleagues, and other health professionals.”

Similarly, it took the American Hospital Association (AHA) until 1973 to institute a Patient’s Bill of Rights (and then only under threat of federal legislation).⁴ The Bill of Rights guaranteed patients such basic information as their diagnosis and the names of all treating doctors.⁵ Today, the AHA proffers *The Patient Care Partnership: Understanding Expectations, Rights and Responsibilities*, a document intended to be “a straightforward, plain language statement that clearly outlines what patients should expect during their hospital visit.”⁶

Growing research reflects the new emphasis on accurately measuring patient feedback. From 1968 to 1977 there were fewer than 100 mentions of patient satisfaction in Medline,⁷ although hundreds of satisfaction measures had been catalogued.⁸ From 1998 to 2007 there were nearly 4,000 mentions of satisfaction in Medline.⁹

A panoply of patient-oriented measures is moving toward center stage, but they still face challenges before they can play the starring role expected of them.

The Patient’s Changing Role

In the 1960s and 1970s, three separate ideas took hold with regard to the patient’s role. The first was *ethical*, building on the idea of patient autonomy as a human right that supersedes physician beneficence. Courts during this period expanded the requirements for informed consent, ruling for the first time that doctors must disclose potential harms and benefits in advance in plain English, with the scope of disclosure measured by the patient’s need.¹⁰

The 2001 IOM report adapted a definition of patient-centeredness that was anchored in this realm.¹¹ To the IOM, patient-centeredness meant “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”¹²

The second idea was the *economic* concept of health care as a marketplace filled with consumers and providers weighing costs and benefits. As early as 1974, an IOM report endorsed publishing outcomes measures “so consumers can be informed of the relative effectiveness of various health providers and make their choices accordingly.”¹³ Ethics and economics together brought new attention to consumer choice and patients’ rights.¹⁴



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By the early 1980s, the patient's voice also acquired an explicit *clinical* role beyond the patient-as-an-informed-shopper. For instance, patient-reported outcomes, such as physical functioning, began to be collected and reported in standardized, validated formats that could provide feedback about ongoing treatment decisions.¹⁵

The history of patient-reported measures shows that one purpose is protective. Responses are meant to provide an early-warning system about possibly substandard care; for example, a failure by health plans to appropriately refer members to specialists.¹⁶ At the same time, a more typical role is prescriptive, where patient experience data provide specific information about areas for improvement.

The separate threads of ethical, economic and clinical concerns are intertwined in the ACA. Translating these ideas into implementable change is the critical challenge providers face in meeting the ACA mandates.

Developing a Measurement Infrastructure

When objective measurement of the quality of medical care began winning widespread acceptance in the late 1980s, Congress requested a report that included a comprehensive review of measures involving patient feedback about inpatient and ambulatory care.¹⁷ At the time there was neither agreement on the role to be played by patient feedback nor consensus on measurement instruments.¹⁸ By the early 1990s, when health plans assumed a more prominent health system role under the Clinton administration's "managed competition" reform proposal, the measurement focus shifted there.

Because of fears that health plans serving Medicare beneficiaries might cut corners to control costs, the government funded development of a survey of health plan members about access, provider communication, and other measures of quality.¹⁹ This was known as the Consumer Assessment of Health Plans Study (CAHPS). Launched in 1995, CAHPS was a standardized and validated questionnaire that could be used to compare results among different plan sponsors and over time.

In the wake of the failed Clinton administration reform initiative and a managed care backlash, the importance of health plans waned and attention turned back to providers. The language of "consumers" still lingers in the CAHPS acronym;²⁰ however, it has evolved into a family of surveys. (See Table: "CAHPS Surveys Endorsed by the National Quality Forum.") Hospital CAHPS (HCAHPS), which built on existing surveys and additional research, was launched in 2006.²¹

The CAHPS surveys seek to assess the *patient experience of care* by addressing behaviors the patient directly observes. By contrast, in *patient satisfaction* questionnaires, patients rate care instead of reporting on objective experiences, and those ratings can be more easily influenced by prior expectations that are a function of age, socioeconomic status or other factors.²² So, for instance, an HCAHPS question asks, "During this hospital stay, how often did doctors explain things in a way you could understand?" instead of asking, "How satisfied were you with your doctors?" (For additional examples, see Box: "Taxonomy of Measures: Examples.")

In addition to using both those terms, the ACA refers to *patient engagement*, which was defined in

later federal rulemaking as "the active participation of patients and their families in the process of making medical decisions," and *shared decision-making*, defined as involving "decision support tools and... methods with which the patient can assess the merits of various treatment options in the context of his or her values and convictions."²³

Distinctions among different terms, however, are sometimes honored only in the breach. For example, some of the CAHPS questions (e.g., "During this hospital stay, after you pressed the call button, how often did you get help as soon as you wanted it?") are identical to those in classic satisfaction surveys, even if worded in a manner designed to remove expectation bias. As a result, CAHPS questions are often referred to as satisfaction surveys, both in the peer-reviewed literature²⁴ and in normal discourse, such as a medical society referring to HCAHPS results being available on a "patient satisfaction portal."²⁵ Some CAHPS questions (e.g., "Were you involved as much as you wanted to be in decisions about the best medicine for you?") clearly break the patient satisfaction question mold and are measuring a patient experience that overlaps with shared decision-making, which is an outgrowth of informed consent.

The hierarchical relationship among terms is even less clear. Patient experience measures either fall under "patient-centeredness" or vice versa, depending on who is defining them.

Table 1. CAHPS Surveys Endorsed by the National Quality Forum

Endorsed Measure	Respondent
<i>Ambulatory Care Surveys</i>	
CAHPS Health Plan Survey	
Adult Health Plan Survey 4.0	Adult health plan members
NCQA Supplemental items (CAHPS 4.0H)	Members of health plans seeking NCQA accreditation or providing quality measures (HEDIS) for public reporting (<i>see Table Note</i>)
Child Health Plan Survey 4.0	Parents or guardians of children (under 18 years of age)
Children with Chronic Conditions Item Set	Parents or guardians of children with special health care needs
CAHPS Clinician & Group Survey (CG-CAHPS)	
Adult Primary Care Survey 1.0	Adult outpatient primary care patients
Pediatric Primary Care Survey 1.0	Parents or guardians of pediatric outpatient care patients
Adult Specialist Care Survey 1.0	Adult outpatient specialist care patients
CAHPS Experience of Care and Health Outcomes (ECHO) Survey	
CAHPS Home Health Care Survey	Adults receiving skilled home health care services
<i>Facility Care Surveys</i>	
CAHPS Hospital Survey (HCAHPS)	Adults with recent inpatient experiences
CAHPS In-Center Hemodialysis Survey	Adults with end-stage renal disease (ESRD)
CAHPS Nursing Home Surveys	
Long-Stay Resident Instrument	Long stay (greater than 100 days) residents
Discharged Resident Instrument	Discharged short stay (5 to 100 days) residents
Family Member Instrument	Residents' family members

Table Note: The National Committee for Quality Assurance (NCQA) is a private, not-for-profit organization whose accreditation programs are intended to drive improvement in health care quality. NCQA has developed the Healthcare Effectiveness Data and Information Set, a tool to measure performance across multiple dimensions.

Meanwhile, there are new concepts that further confound clear distinctions. Shared decision-making is now seen as an attribute of “participatory medicine,”²⁶ leading to an “activated patient”²⁷ who makes informed health decisions, along with family and caregivers, as part of a “person-focused” system.²⁸

Choosing Measures for the ACA

The ACA requires a “consensus-based entity” to provide input to the Department of Health and Human

Services (HHS) on the measures to be used for public reporting, value-based payment and other programs.²⁹ To do this, HHS selected the National Quality Forum (NQF), which was established in 1999.³⁰ The status of the NQF as a “voluntary consensus standards-setting body”³¹ enables the measures it endorses to be adopted by the government without a formal rulemaking process. NQF in turn has created a special Measure Applications Partnership (MAP) to provide input related to ACA requirements.³² In cases where measures have already been proposed,

the MAP will consider revision of those measures in subsequent years.

The first MAP reports were released in early October 2011 under the direction of a Coordinating Committee co-chaired by a health plan medical director and a prominent health services researcher.³³ About a third of the committee members represent consumer organizations. Various work groups contain voting representatives from more than 60 stakeholder organizations and ex officio representatives from nine federal agencies. There are also 40

voting individuals with expertise in fields ranging from vulnerable populations to health information technology.³⁴

Although the MAP's structure is complex, there will be strong pressure to reach consensus in order to influence ACA implementation over time. However, initial ACA implementation is proceeding, with the MAP recently posting to its website 366 possible quality members for HHS consideration. The Medicare Shared Savings Program, in assessing the care provided by Accountable Care Organizations (ACOs) included measures that were deemed "high impact" even though not all of them are endorsed by NQF.³⁵ Of the 33 individual measures chosen, seven are related to the patient's or caregiver's experience of care,³⁶ and that set of measures was given equal weight with three others related to care coordination and patient safety, preventive health, and at-risk populations.³⁷

The Role of CAHPS

The CAHPS program is funded and administered by the Agency for Healthcare Research and Quality, which works with a consortium of private and public organizations that includes federal agencies such as the Centers for Medicare & Medicaid Services (CMS). Together, these organizations are responsible for conceiving, developing, testing, and refining the various CAHPS surveys. The CAHPS family of surveys has emerged as a common thread connecting disparate parts of the health care system. CAHPS instruments are divided into ambulatory surveys (including health plans) and facilities surveys (for institutions such as hospitals). There are supplemental items that can be integrated into the "core" CAHPS instruments, and CAHPS questions are under development for specific areas of policy interest, such as patients' experiences with non-physician providers at medical groups.

To encourage use of CAHPS data for selecting providers—and to encourage those being measured to make improvements—CMS posts performance results for hospitals, nursing homes, home health agencies, and dialysis facilities. Participants in the clinician and group survey (CG-CAHPS) can compare themselves against unnamed others using the national CAHPS Benchmarking Database. (CG-CAHPS has been endorsed by NQF.) There are also financial incentives (e.g., in an example of pay-for-performance, hospitals that fail to report HCAHPS face a reduction in Medicare reimbursement).³⁸

Fears that government-led standardization would put private survey companies out of business³⁹ have proved baseless. Private firms continue to offer surveys that go beyond CAHPS (or help providers implement it) and provide consulting assistance. Two of the most prominent firms are NRC Picker, adapting the patient-centered care survey

Taxonomy of Measures: Examples

Patient Experience

In the last 12 months, when you phoned this doctor's office to get an appointment for care you needed right away, how often did you get an appointment as soon as you thought you needed?

In the last 12 months, when this doctor ordered a blood test, x-ray or other test for you, how often did someone from this doctor's office follow up to give you those results?

Source: CAHPS® Clinician & Group Survey –Adult Primary Care Questionnaire, Version 1.0.

Patient Satisfaction

How satisfied are you with the ease of making appointments for checkups (physical exams, well visits, routine follow-up appointments)?

How satisfied are you with our office's appearance?

How caring is your doctor?

Source: Patient Satisfaction Survey, American Academy of Family Physicians, 1996.

Patient Activation

I am confident I can tell my health care provider concerns I have even when he or she does not ask.

I know the different medical treatment options available for my health condition.

Source: The Patient Activation Measure (PAM) Questionnaire, authors/creators Judith H. Hibbard, Jean Stockard, and Eldon R. Mahoney, 2005.

developed by the Picker Institute, and Press Ganey, a leading hospital survey company which the AMA has also chosen as a vendor that doctors can use to assess satisfaction among their patients.⁴⁰

At the same time, web-based entrepreneurs are bypassing traditional methods of collecting patient experience data. Websites range from popular, general feedback sites with a health care component, such as Yelp or Angie's List to lesser-known sites focusing on particular medical conditions, such as PatientsLikeMe or MyAutismTeam. The latter websites allow consumers to compare their experiences to those of individuals with similar illnesses and perhaps of similar ages, genders or other characteristics.⁴¹ This type of information specificity could one day prove more powerful in influencing a consumer's choice of provider than CAHPS-type surveys that include a broad range of conditions and patients at a particular institution.

Costs and Benefits

To reduce the proliferation of different measures, the ACA explicitly seeks measure integration (e.g., for the Physician Quality Reporting Program and for regulations governing "meaningful use" of health information technology) and measurement alignment (e.g., for incentives under value-based purchasing programs). Nonetheless, providers can feel overwhelmed, which is one reason for the reduction in the number of quality measures and different domains of quality (which would require separate surveys) in the final ACO regulations.⁴² CMS also decided to fund the CAHPS survey in calendar years 2012 and 2013 during the start-up period for ACOs, addressing the concerns of those worried about an

unfunded mandate for this new care delivery arrangement.

Balancing worries about the growth of patient-centered measurement and its costs is mounting evidence about the benefits. Involving patients can lead to positive effects that include greater patient adherence to medical advice, fewer patient complaints and grievances, fewer and less serious malpractice claims, and improvement in patient health and functional status outcomes.⁴³ While some research on patient experience measures in particular has found that the link to better clinical outcomes is modest,⁴⁴ more recent research has found a "high correlation between frontline clinicians' assessments of patient care quality and the HCAHPS patient satisfaction measure."⁴⁵ A recent study also found a correlation between high patient satisfaction scores and lower risk-adjusted rates of readmission for acute myocardial infarction, heart failure, and pneumonia.⁴⁶

Just as important, having satisfied patients is an outcome of care with value in and of itself. Avedis Donabedian, father of the quality movement's triad of structure, process and outcome, proposed a patient-centric definition of clinical success back 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."⁴⁷

More broadly, chronic disease simply cannot be treated effectively without patient participation and cooperation, and health care institutions cannot form long-term partnerships without listening to patient needs more closely. Some hospitals are already using the requirement to collect

HCAHPS data on the Hospital Compare website as a way to prompt a wholesale culture change in regard to the patient's role in the institution.⁴⁸ In a 2011 survey of nearly 800 hospitals, improving patient experience and patient satisfaction was picked as the second-highest priority (behind quality and safety) for the next year and the highest priority in the two years after that.⁴⁹

Conclusion

The increased emphasis on a patient-centered care system now resonates on many levels. For example, a new definition of physician professionalism proposed by the American Board of Internal Medicine included patient autonomy as one of three fundamental principles.⁵⁰ There is also increasing acceptance within health care of such previously foreign business concepts as value-based competition based on customer needs,⁵¹ "disruptive innovation,"⁵² and attracting repeat customers in an "experience economy."⁵³ In addition, technological advances are opening up the way to "patient as provider," allowing patients to assume responsibilities that once demanded "interaction with the professionals of the health care system."⁵⁴ In response to these types of changes, some hospitals have turned for guidance to outside role models such as Disney,⁵⁵ while others have looked to health care organizations such as Planetree⁵⁶ or the Institute for Patient and Family-Centered Care.

A serious and sustained effort to build a patient-centered health care system is starting to gain momentum, in part because of the ACA and in part because of a growing evidence base showing the importance and usefulness of engaging patients as a way to improve clinical and financial outcomes. Measures endorsed by the

MAP could emerge as a national standard. The establishment of a clear taxonomy differentiating the various aspects of patient-centered (or “person-focused”) care could enable a nascent movement to jell and accelerate the use of better and more useful measures.

While the ACA may signal a turning point in the transparency and accountability revolution, national health reform is an opportunity, not a guarantee. Rhetoric will need to be matched with funding for data collection, building consensus on measure use, and the integration, alignment, and harmonization of measures in different programs. And, of course, declarations of cultural change in hotel meeting rooms will have to be reflected in real change in hospitals and exam rooms.

The journey from aspirational to operational for patient-derived measures will not be a smooth road, but it is one that promises unique clinical, economic, and ethical gains. The rallying cry of the disability rights movement, “Nothing about us without us,” can be the model for a new paradigm of care delivery and continuous improvement. Though the process is still unfolding, providers and others are finally beginning to understand the profound impact of seeing health care “through the patient’s eyes.”⁵⁷

Table 2. Key ACA Provisions Related to Quality Measurement and Reporting

Program/Provision	Quality Measurement and Reporting Activity		
	Measure Development and/or Revision	Data Submission	Public Reporting
<i>Provisions that specify that “patient-centered” measures (a) must be used</i>			
SEC. 3005. Quality Reporting for PPS-Exempt Cancer Hospitals (b)		X	X
SEC. 3013. Quality Measure Development (c)	X		
SEC. 3022. Medicare Shared Savings Program		X	X
SEC. 3023. National Pilot Program on Payment Bundling	X	X	
SEC. 3201. Medicare Advantage Payment		X	X
SEC. 3502. Establishing Community Health Teams to Support the Patient-Centered Medical Home		X	X
SEC. 3503. Medication Management Services in Treatment of Chronic Disease		X	
SEC. 4108. Incentives for Prevention of Chronic Diseases in Medicaid		X	
SEC. 10202. Incentives for States to Offer Home and Community-Based Services as Long-Term Care Alternative to Nursing Homes		X	
<i>Provisions related to quality measurement that DO NOT specify that “patient-centered” measures must be used</i>			
SEC. 2701. Adult Health Quality Measures	X	X	X
SEC. 2703. State Option to Provide Health Homes for Enrollees with Chronic Conditions		X	
SEC. 3001. Hospital Value-Based Purchasing		X	
SEC. 3002. Improvements to the Physician Quality Reporting System (d)		X	
SEC. 3004. Quality Reporting for Long-Term Care Hospitals, Inpatient Rehabilitation Hospitals, and Hospice Programs		X	X
SEC. 3011. National Strategy for Quality Improvement in Health Care (e)			
SEC. 3014. Quality Measurement (f)			
SEC. 3015. Data Collection, Public Reporting		X	X
SEC. 3021. Establishment of Center for Medicare and Medicaid Innovation Within the Centers for Medicare & Medicaid Services (g)			
SEC. 3024. Independence at Home Demonstration		X	

Notes: Quality measurement is a recurring theme throughout the ACA. Not all provisions specify that quality measurement must include “patient-centered” measures. However, many provisions lacking this explicit requirement may be interpreted to include them as part of a larger measure set. “Quality Measurement and Reporting Activity” indicates actions to be taken by providers, states, and/or the Secretary of HHS as required by the ACA.

- a) “Patient-centered” measures refer to assessments of patient experience, satisfaction, engagement, perception, perspective, and/or patient-centeredness.
- b) This refers to cancer hospitals not covered by the prospective payment system by which general acute-care hospitals are paid.
- c) Section 3013 requires the Secretary of HHS and other agencies to identify gaps in quality measurement and existing measures that need improvement, and to support the development, improvement, updating, or expansion of certain quality measures.
- d) This program was formerly known as the Physician Quality Reporting Initiative.
- e) Section 3011 outlines a plan to create a national strategy for quality improvement, which includes steps to minimize duplication of effort in quality measurement, set benchmarks for achieving national priorities, and align the quality improvement and patient safety efforts of public and private payers.
- f) Section 3014 outlines the duties of the “consensus-based entity” tasked with convening multi-stakeholder groups to provide input on the selection of quality measures and performance measures for public reporting, value-based payment and other programs.
- g) Section 3021 allows the Centers for Medicare & Medicaid Services to identify, test, and spread new models of care and payment that improve quality and reduce costs. Though this section in the ACA does not explicitly mention it, quality measurement has been an integral part of the demonstration projects developed by the new “Innovation Center.”

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Notes

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- ³ The Code of Ethics was revised at the June 1957 AMA meeting, effective Jan. 1, 1958, and that section was removed. See “History of AMA Ethics.” Chicago: American Medical Association, 2011, www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/history-ama-ethics.page (accessed January 2012).
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- ¹⁹ Edgman-Levitan S and Cleary PD. “What Information Do Consumers Want and Need?” *Health Affairs*, 15(4): 42–56, 1996.
- ²⁰ The expectations regarding the relationship between a business and a consumer are quite different than those between a physician and a patient. However, the language has become so ingrained that the terms are often used interchangeably. For a discussion of the difference between commercial and professional ethics, see Berenson R and Cassel C. “Consumer-Driven Health Care May Not Be What Patients Need—Caveat Emptor.” *JAMA*, 301(3): 321–23, 2009.
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- ²³ Federal Register, Rule by the Centers for Medicare & Medicaid Services. “Medicare Program; Medicare Shared Savings Program: Accountable Care Organizations.” Final Rule, November 2, 2011. 42 CFR Part 425 [CMS-1345-F], <http://federalregister.gov/a/2011-27461> (accessed January 2012).
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- ²⁹ U.S. Congress. *Patient Protection and Affordable Care Act*. See Sec. 3014.
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- ³¹ The ACA requires a “consensus-based entity” to provide input on measures, and the National Quality Forum meets those standards. See Office of Management and Budget. “Federal Participation in the Development and Use of Voluntary Consensus Standards and in Conformity Assessment Activities.” *Federal Register*, Circular No. A-119. February 10, 1998, www.whitehouse.gov/omb/circulars_a119_a119fr (accessed January 2012).
- ³² National Quality Forum. “Measure Applications Partnership.” www.qualityforum.org/Setting_Priorities/Partnership/Measure_Applications_Partnership.aspx (accessed January 2012).
- ³³ The MAP Coordinating Committee is co-chaired by George J. Isham, MD, chief health officer and plan medical director at HealthPartners, in Bloomington, Minn., and Elizabeth A. McGlynn, PhD, MPP, director, Kaiser Permanente Center for Effectiveness & Safety Research, in Oakland, Calif. For a full list of Coordinating Committee members and meeting schedules, see www.qualityforum.org/Setting_Priorities/Partnership/Measure_Applications_Partnership.aspx (accessed January 2012).
- ³⁴ National Quality Forum. “Measure Applications Partnership (MAP) FAQs.” www.qualityforum.org/Setting_Priorities/Partnership/Measure_Applications_Partnership.aspx (accessed January 2012).
- ³⁵ Federal Register, Rule by the Centers for Medicare & Medicaid Services.
- ³⁶ The seven measures related to patient/caregiver experience are: getting timely care, appointments and information; how well your doctors communicate; patients’ rating of doctor; access to specialists; health promotion and education; shared decision-making; and health status/functional status. All are CAHPS measures.
- ³⁷ Federal Register, Rule by the Centers for Medicare & Medicaid Services.

³⁸ Department of Health and Human Services. "Hospital Compare." Washington, DC: Department of Health and Human Services, 2011, www.hospitalcompare.hhs.gov (accessed January 2012).

³⁹ Conn J. "Getting Satisfaction." *Modern Healthcare*, 35(50): 6–13, 2005.

⁴⁰ For examples, see corporate websites: www.pressganey.com, www.nationalresearch.com.

⁴¹ See, for instance, www.patientslikeme.com or www.myautismteam.com. These websites are very different than the general ratings sites such as Yelp (www.yelp.com) or Angie's List (www.angieslist.com), which also have sections for rating health care providers and services.

⁴² *Federal Register*, Rule by the Centers for Medicare & Medicaid Services. CMS says the reduction in the measure set from 65 to 33 was in response to comments and notes that the actual number of measures could be seen as only 23 "when accounting for the patient experience survey modules scores as one measure and the all or nothing diabetes and CAD [coronary artery disease] measures scores as one measure each."

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