



I N F O R M A T I O N

t h e r a p y

*Turning on the Light:
Illuminating the Care Experience
Through a New Consumer Paradigm
for Quality Measurement*

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Executive Summary

Consumers are often “in the dark” when it comes to understanding the quality of care delivered by providers and health plans. The little information about provider quality that does exist is hard to understand, and it’s frequently not clear how the ratings were calculated. Opening the “black box” of health care performance measurement will require a consumer focus, innovative thinking, provider commitment, and an investment of scientific and practical resources.

There’s no doubt performance measurement challenges are substantial—particularly because measurement science and evidence-based medicine are still in the nascent stages of development. However, the health care community has failed to take advantage of the many opportunities for advancement that do exist. The areas where scientific limitations hinder current comparative performance measurement offer untapped and valuable opportunities for benchmarking and learning.

Instead of throwing up our hands, we should be developing a robust strategy for actively advancing the state of performance measurement. In particular, where evidence-based medicine does not offer clear answers for how care should be delivered, we should be seeking answers from the consumer.

The opportunity exists to involve users of health care in measuring how providers and other elements of the health care delivery system meet their needs, support their decision making, and guide them to better health. In particular, we can embrace new paradigms for quality assessment that measure how providers and systems of care are using information to aid consumers in decision making and in navigating the delivery system.

This measurement can drive the health care system to:

- Deliver better quality.
- Improve efficiency.
- Lower malpractice risk.

Background: The State of Performance Measurement

Significant Challenges Exist

Measuring the quality of health care presents myriad scientific, technical, and feasibility challenges. Many of the items of greatest importance to end-users occur infrequently enough that sufficient numbers make robust comparisons impossible. Much of what we try to measure can be influenced as much (or more) by factors other than quality—such as demographic factors, health status, severity of illness, and other variables—and meanwhile, the science of risk adjustment is still evolving. For those things that we can validly measure, we still need to do the labor-intensive work of collecting data, yet the data is often questionable. Without widespread, sophisticated clinical information systems, this data collection requires enormous motivation and commitment on the part of providers, health systems, and health plans.

All of that assumes, too, that we know what we want to measure. Without a doubt, a significant goal of quality measurement is to determine how well the system delivers care according to the best available scientific evidence; of course, that's easier said than done. Despite enormous scientific advances and the publication of tens of thousands of randomized clinical trials each year, a majority of care delivered still has no solid evidence base.

Progress Being Made

The good news is that progress is being made on a number of these fronts. In the 1990s, significant advances were made both in standardizing the specifications for measuring quality and in creating more robust measures of performance. The National Committee for Quality Assurance (NCQA) developed a consensus process for creating and refining performance measures. The measures in HEDIS provide valuable insights regarding consumer satisfaction, chronic disease management, and preventive care for 75% of Americans enrolled in managed care organizations.

NCQA also collaborated with federal government agencies, voluntary health organizations such as the American Diabetes Association (ADA), consumer groups such as the Foundation for Accountability (FACCT), and others to advance performance measurement in other levels of care delivery (besides the health plan). Collaboration with the Health Care Financing Administration (now the Centers for Medicare & Medicaid Services, or CMS) helped to standardize measurement of the care of Medicare beneficiaries. The ADA and NCQA moved the same diabetes performance measures into the physician community through the Diabetes Physician Recognition Program.

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Standardized measurement facilitated the growth of a new breed of pay-for-performance programs that have grown considerably in the last few years. Projects such as Bridges to Excellence aim to reward individual physicians and practices for providing better care. These rewards are important not just for the incentives they provide for delivering evidence-based care but also for the motivation they provide for robust data collection. Efforts by CMS, the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and private companies have also sparked a movement for hospital quality comparisons.

Measuring Quality When We Lack Evidence of Best Practice

Virtually all of these real-world quality measurement experiments are gradually changing the landscape, but they don't address the fact that a majority of what providers do is not evidence-based. Researchers estimate that decent evidence exists for only 10% to 40% of what clinicians do every day in their practices. Given the gap in

scientific knowledge, we need to answer the question: How do we gain more information about the other 60% to 90% of medical care?

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The path to finding answers lies, in part, in engaging the consumer. When science offers uncertain direction, clinicians should be bringing the best information they have to the point of care and working with their patients to arrive at the right approach to care for each individual. This shared approach to decision making has considerable value in its own right, because it helps to elevate the care experience. Although engaging consumers in care delivery is no panacea—and health care leaders need to address many other systemic problems in the health care delivery system—a whole body of research has emerged that demonstrates the positive impact of consumer engagement on a range of outcomes.¹

This patient-centered approach to care and treatment decision making should usher in a shift in measurement strategies, moving from an almost exclusively biology-focused model to a model that places emphasis on the consumer perspective on outcomes as well. Although some scientists might be concerned about relying on subjective assessment, the fact remains that much of modern health care delivery is not objective. Therefore, the question becomes whether we base subjective assessment on the desires of health care professionals or on the needs, values, and preferences of the consumer. We should certainly continue to apply objective measurement to those areas where an established evidence base exists. However, we can and should complement those scientifically robust clinical domains with other forms of measurement in realms of care where “appropriate” care is at present best determined on a personal basis.

The patient-reported measurement paradigm may be more useful and/or necessary in certain kinds of conditions than others. It is especially valid where there is less clarity (less of an evidence base) about what should be done for all patients. The greater the scientific uncertainty, the more we should factor in the values and preferences of individuals. For example, strong evidence exists regarding the value of screening people with diabetes for kidney problems, so it makes sense that we measure this for everybody with this chronic condition. In contrast, the decision about how to treat and manage slow-developing prostate cancer remains controversial; the best “outcome” depends on many factors relating to a series of trade-offs that are largely a matter of personal preference.

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Although the field of patient-reported measurement also has considerable room for scientific advancement, several valuable tools already exist. Consumer satisfaction surveys (e.g., the CAHPS survey developed by the U.S. Agency for Healthcare Research and Quality), health status instruments (e.g., SF-36), and tools to address shared decision making are now commonly used with fairly standardized reporting.

Considerable opportunity exists for measuring and reporting what we can evaluate. By measuring as we go—that is, by evaluating care as we refine the instruments—we can create great opportunities for benchmarking and ongoing learning that will not only advance the field but will drive better care experiences for consumers along the way.

Health care leaders can seize the opportunity now to create a robust strategy to move forward an agenda that revolves around a commitment to measuring the impact of providing greater and more targeted information to consumers in ways that facilitate better decision making. We can initiate more rigorous development of measures that evaluate patient values and preferences, and we can do more to measure decision quality. (This will be a focus of a CIT white paper to be released in early 2005.)

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As an example of strategies to head in this direction, NCQA recently released new draft accreditation standards in response to the proliferation of new information technologies, enhanced use of the Internet, and shifting patient expectations. NCQA recognizes that a robust accreditation system must reward innovation in addressing these trends that are rapidly transforming the health care system. Among other things, these new “Member Connections” accreditation standards specifically attempt to reward market leaders that leverage new technologies to promote consumer self-management of chronic disease. For instance, in the area of self-management, the Member Connections standards assess whether a health plan conducts health risk appraisals and offers interactive tools on its Web site related to issues such as smoking cessation, exercise, immunizations, and screenings. The standards also examine whether evidence-based guidelines are the basis for such tools, and how often the tools are tested and updated.

Engaging Consumers in the Quality Movement

A considerable body of research suggests that con-

sumers make only limited use of performance data in selecting their providers and health plans. Other research, however, indicates that this finding is not necessarily due to a lack of interest in such tools.

So why don't consumers use the same kind of information to choose their health care providers as they do for buying their dishwashers? Perhaps it's because limited information exists that meets their needs. Much of what consumers want to know just isn't available yet. Moreover, where it exists, it may not be obvious where to find it. In most cases, information about treatment and care management decisions is divorced from performance data about providers. We need to make it easier for consumers to make informed decisions by marrying the different types of information that they need. Vehicles that offer “one-stop shopping” for consumer decision making will facilitate greater usage.

We also have to make sure that we provide consumers with the right information—the performance data that is both meaningful to them and encourages them to make better decisions. Such measures will engage consumers directly and make them feel a greater sense of self-efficacy.

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The information must also be understandable to the average consumer. That doesn't necessarily mean “dumbing it down.” Rather, more emphasis should be placed on using the best consumer research we have to make it graphically appealing and easy to digest. In some cases, information is inherently complex, which means we have to develop better tools and/or better processes to convey that information to consumers.

One such option is to focus more attention on the role that physicians and other health care professionals can play as care guides. One of the most important roles that clinicians can play is helping to put complex information into a personal context for their patients. Physicians and other care providers can clarify the health information that confuses their patients, and then clinicians can help their patients to interpret what that information means for their particular circumstances.

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In modern health care, where literally tens of thousands of randomized clinical trials are published in the peer-reviewed literature each year, no physician can be absolutely current on the latest evidence. However, physicians have a unique role to play in contextualizing the evidence for their patients. They can guide consumers in how to use different pieces of information to make better, more informed decisions.

New Measurement Strategies to Support Malpractice Reform

Debate over how to resolve the “malpractice crisis” in the United States continues to be polarized. There is no doubt that this country has problems with both escalating provider malpractice insurance costs and accountability for true medical errors. Neither side in the legislative debate over malpractice reform has proposed solutions that address the underlying issues or the concerns of consumers. Although we need to ensure that clinicians are accountable for their actions, we cannot ignore the fact that rising malpractice insurance premiums are creating real barriers to advancing a number of key U.S. health care priorities.

In order to have malpractice reform, we also need medical care reform. The status quo for informed consent does little to “inform” before consent takes place.

We need performance measures that address how well clinicians perform true informed consent. Therefore, measurement of shared decision making could be part of the solution to the malpractice crisis.

Research suggests that providers who effectively provide the right information about treatment decisions to their patients likely will have substantially less malpractice risk. A study in the *Archives of Internal Medicine* found that four types of communication problems were present in more than 70% of plaintiff depositions: deserting the patient, devaluing patients’ views, delivering information poorly, and failing to understand patients’ perspectives.² An experimental design by Lester and Smith found that poor communication by the physician yielded greater litigiousness when clinicians provided identical diagnoses and treatments.³

In a world where clinicians truly inform their patients, lawsuits are extremely unlikely because consumers have faith that their providers are doing whatever they can to advise the patients of the risks and to do whatever can be done to prevent them. When clinicians prescribe appropriate information and offer their patients an opportunity to discuss it, we will have far fewer lawsuits and far better care.

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The development of measures that address this provision of information and the communication around it can catalyze progress in this direction. Such measures can provide new insights into the nature of clinician-patient interaction that can help to improve consumer knowledge and overall experience with care. Researchers have already laid a solid foundation for this measurement approach, and a robust strategy to advance it further will generate profound changes in the quality and efficiency of health care.

Conclusion

The health care community has a challenge and an opportunity to address the limitations in performance measurement and evidence-based medicine. Where scientific gaps exist in figuring out exactly how care should be delivered, we should be tapping into consumers to understand better how well clinicians are meeting their needs.

We should design ways to measure the extent to which providers take into account their patients' individual values, attitudes, and beliefs. We should hold clinicians and systems accountable for the way in which they use information to aid consumers in effective decision making and navigation of the health care delivery system. Such measurement can stimulate improved clinical quality, increased efficiencies, and reduced malpractice risk. ●

ENDNOTES

1. For more details on this body of research, see Gwinn B, Seidman J. The Ix Evidence Base: Using information therapy to cross the quality chasm. March 2004. Available online at www.informationtherapy.org/rs_white_papers.html.
2. Beckman HB, et al (1994). The doctor-patient relationship and malpractice. Lessons from plaintiff depositions. *Archives of Internal Medicine*, 154 (12): 1365–1370.
3. Lester GW, Smith SG (1993). Listening and talking to patients. A remedy for malpractice suits? *Western Journal of Medicine*, 158 (3): 268-272.

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