

## Summary

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

### Timely Analysis of Immediate Health Policy Issues

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Nearly a decade after the Institute of Medicine designated “patient-centeredness” as one of six goals for a 21<sup>st</sup> 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. 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.

Although questionnaires asking patients about emotional support, communication, and “maintenance of [a hospital] patient’s self-esteem” go back at least to the late 1950s, the context has changed radically. The ACA requirements and similar efforts taking hold in the private sector represent an unsung transformation in the patient’s role based on three separate ideas.

The first is *ethical*, building on the concept of patient autonomy as a human right that supersedes physician beneficence. The second idea is the *economic* one of health care as a marketplace filled with consumers and providers weighing costs and benefits. The third idea is for an explicit

*clinical* role for patient-reported information, where it begins to be collected in standardized formats to provide feedback about ongoing treatment decisions. These separate threads are intertwined in the ACA. Translating them into implementable change is a critical challenge providers face in meeting ACA mandates.

In *patient satisfaction* surveys, patients rate care. In *patient experience of care* surveys, on the other hand, patients report what they objectively observed about their care in an attempt to obviate the influence of prior expectations that are a function of age, socioeconomic status or other factors. The family of surveys known as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) has emerged as a common thread connecting disparate parts of the health care system and will play a critical role in assessing the patient experience of care. CAHPS instruments are divided into ambulatory surveys (including health plans) and facilities surveys (for institutions such as hospitals). Supplemental items, related to specific conditions or aspects of care, can be integrated into the “core” instruments, and questions are under development for specific areas of policy interest, such as patients’ experiences with non-physician providers at medical groups.

The ACA also refers to *patient engagement* and *shared decision-making*. Consumer advocacy groups talk about *patient activation*. However, distinctions among terms and their relationships to one another are often unclear in common usage.

Although there are worries about the growth of patient-centered measurement and its costs as a result of the ACA, the law explicitly seeks integration and alignment of measures with other programs. In addition, there is growing evidence pointing to clinical and cost benefits from these measures, including greater patient adherence to medical advice, fewer complaints and grievances, fewer and less serious malpractice claims, and improvement in patient health and functional status outcomes. Equally important, patients’ satisfaction with their care is a valuable outcome in and of itself.

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, and the National Quality Forum has created a special Measure Applications Partnership to do so. This private-public partnership has proposed 366 possible measures for HHS to use in its 2012 rulemaking.

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Despite government-led standardization, private firms continue to offer surveys and consulting services. At the same time, web-based entrepreneurs are bypassing traditional methods of collecting patient experience data and could one day exert a powerful influence on consumers' choice of providers.

The increased emphasis on a patient-centered care system 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. There is also increasing acceptance of previously foreign business concepts such as value-based competition based on customer needs.

More broadly, chronic disease cannot be treated effectively without patient participation and cooperation. 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.

A serious and sustained effort to build a patient-centered health care system is starting to gain momentum. Still, while the ACA may signal a turning point, national health reform is an opportunity, not a guarantee. Rhetoric will need to be matched with funding for data collection, consensus building 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 changes in hospital 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."

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## **About the Author and Acknowledgements**

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