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# Overhauling Quality Measurement in the US: Measure What Matters

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**I REMEMBER** a past US election cycle when the focus on the economy and on health commanded headlines. The refrain “It’s the economy, stupid” was a blunt reminder that a better future demanded focus on our common desire to thrive. The economy remains a center point of political discourse in 2024, specifically the economic

impacts of health care on—and the deteriorating health of—our citizens. The US is not alone: Rising costs and greater disease burden are challenging societies and economies globally.<sup>1,2</sup> Yet it is a uniquely American problem that our hefty health care spend continues to rise alongside declining

public health, safety, and equity results. Disrupting the status quo is no longer a choice—it’s a necessity. We must radically rethink our approach to health care, prioritizing outcomes over outdated processes. In a political landscape fraught with division and fear, the uncertainty surrounding our upcoming election only amplifies the urgency for transformative change in US health care. The stakes have never been higher.

## PATIENT CENTRICITY DEMANDS MEANINGFUL OUTCOMES

Ongoing debate and considerable investment have focused on testing “best” payment and access models,

establishing safety standards and public health programs, and, more recently, technological solutions that promise to speed care, predict disease risk, or increase the precision of identifying what treatment will work best for an individual. To truly unlock the promise of these groundbreaking trends, we must focus on achieving the outcomes that matter most to the people who need care. Everyone deserves to live with the best possible health and a quality of life that is meaningful to them. It's time to demand results that genuinely transform lives.

Unfortunately, our health enterprise buries these goals under layers of regulation, opaque payment and pricing, and quality measurement that focuses on processes of care and costs over meaningful, patient-centered health outcomes. Prioritizing outcomes enables providers to tailor treatments to individual needs, enhances patient engagement and shared decision-making, improves trust and patient satisfaction, and leads to more rational and efficient use of labor and resources to achieve the desired results for both clinical health and life quality.

A rising tide of patients, caregivers, and family members—both as individuals and through various well-established organizations—is demanding action by policy makers in all sectors of government and private health care to stanch the hemorrhaging of our sick-care system. They point to the growing evidence that we are getting sicker—often with disproportionate impact based on social and political determinants of health—and to the increasing economic burden both in the cost of care and the impact of poor health outcomes on educational and income attainment. Their impatience is justified. Our resistance to rapid, fundamental, accountable rebalancing in our quality measurement system is not.

## EVIDENCE OF NEW THINKING AND ACTION

There are signs of change. A recent study published in *NEJM Catalyst Innovations in Care Delivery* found that more than 83% of patients prioritized the outcomes of their care over the experience of receiving care when discerning the quality of their medical teams.<sup>3</sup> After decades of advocacy, there continues to be a steady shift in dialogue and appreciation for the expertise and contribution of people with lived experience across health conditions. The FDA has partnered with patients and families to redefine clinical trials to emphasize end points important to patients, which has the potential to influence what outcomes are prioritized in clinical care and to enhance the patient-centricity of the very data we use to make decisions about innovations and their use. Policy makers at the Center for Medicare and Medicaid Innovation have emphasized the growing importance of patient-reported outcomes as drivers of delivery system and payment reform as part of their Quality Pathway.<sup>4</sup>

The marketplace is also turning its attention to outcomes. Medical technology and life science companies invest heavily in patient engagement and research to determine the outcomes and needs most important to the diverse patient communities affected by both acute and chronic conditions. Burgeoning digital technology, data analytics, and now artificial intelligence-focused companies promise accelerated access to insights and answers that are *patient reported*, *patient centered*, or *patient activating*. And payers and purchasers, once distant from collaborating directly with patient communities, are realizing the imperative of understanding and acting on the insights and priorities of the lives they cover.

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This emerging alignment presents an important opportunity, but the challenge is sustaining the attention and accelerating momentum to fundamentally change how we measure and reward value, with patient-prioritized outcomes at the center. Measurement of clinical and patient-reported outcomes is not yet mainstream in the US primarily because our policy and payment systems do not require transparency and a focus on outcomes, nor do they align with outcome measurement standards. Moreover, the overwhelming regulatory and data barriers choke out any focus on meaningful measures of whole-person health and attention to the care structures and payment incentives that best achieve them.

## A BETTER WAY: STANDARDIZED OUTCOMES MEASUREMENT

After 30 years as a self-advocate and professional championing the voice and lived experience of patients and patient communities, I have the privilege of engaging in a global conversation on how to achieve value for all stakeholders in the delivery of

and access to health care, based on standardizing clinical and patient-reported outcomes that are defined as important in collaboration with patients. The International Consortium for Health Outcomes Measurement (ICHOM) has been leading this charge for more than a decade, building on the seminal ideas and experience of Elizabeth Teisberg, PhD, and Michael Porter, PhD,<sup>5</sup> and advancing the concept of value benchmarked by patient-centered outcomes through a worldwide network of clinical, research, patient, payer, and policy champions. This community of practice has proven the concept that focusing on both clinical and life quality outcomes yields actionable data—usable in real time to drive change in clinical practice, care integration and pathways, whole-health status, and greater efficiency in the use and sustainability of our scarce health care resources.<sup>6</sup>

In our current state of increasing costs, disease burden, and finite resources, consistently measuring health outcomes is an essential tool for accountability and efficiency. Shifting our focus to measuring the clinical and life quality outcomes that matter most to patients is the fundamental change we need. This approach will enhance the data we use to inform providers—and ourselves—about whether we're improving health and functioning and, if not, guide us to understanding why. Utilizing standardized outcomes measurement will improve the consistency and comparability of health data. Doing so facilitates identifying patterns of care; reducing variations in care delivery; comparing results across different settings, systems, and geographies; improving clinical and real-world research; and gaining insights that drive innovation and optimize health spending.

## OUTCOMES DRIVE A LEARNING HEALTH CARE SYSTEM

On a global level, value-based health care is driving system reform and bringing together patients, payers, clinical leaders, and policy makers to establish outcome measurement as a backbone and critical element of change. Learning from early adopters in the US and other nations reveals the advantages and challenges of measuring health outcomes. Data collection can be complex and resource intensive, requiring robust technological infrastructure and standard methodologies. Issues of data privacy, patient confidentiality, and ethics arise in the responsible use of outcomes data. Cultural context, language, and health literacy are vital factors in ensuring patient self-reporting and trust.

Although these issues are certainly complex, there are growing examples of sustained success in Europe and Canada but also increasingly in Africa, Asia, Latin America, and the Middle East. Beyond ICHOM, organizations such as PROMIS Health Organization, OMERACT, COMET Initiative, and others champion a similar focus on outcomes that matter to patients. From these trailblazing organizations and initiatives, a clear blueprint for success emerges: policies and payment models that reward outcomes over processes; clinical champions empowered to

work as cohesive teams, armed with outcomes data to fine-tune their care strategies; health system leaders and purchasers who prioritize long-term health and total cost of care; and patients, families, and caregivers who are activated and empowered.

The message is loud and clear: It's time to set aside outdated, process-heavy models and embrace a future where tangible health outcomes are king. Clinical leaders must be given the autonomy and tools to innovate, driving forward a patient-centered approach that delivers real results. Health systems and payers need to shift their focus from short-term gains to long-term health benefits and cost efficiencies, recognizing the true value of sustained health improvements. And most importantly, we must ignite a movement where patients and their support networks are not just participants but also powerful agents of change in their own health journeys.

The revolution in health care is upon us, and these universal lessons are the keys to unlocking a system that truly works for everyone.

## VISION AND LEADERSHIP

A deep and well-established quality measurement ecosystem in the US makes radical change more than challenging. Measure developers and alignment initiatives and coalitions have done more to entrench inertia than to resolve the challenges and forge a truly integrated and shared approach to measuring and achieving quality. To rebalance a US strategy that divests from myriad process measures and invests in clinical and patient-reported outcomes, a unified vision and clear leadership are needed. We need an executive-level challenge to all stakeholders to prioritize measuring the outcomes of health care, similar to the leadership commandments associated with the Cancer Moonshot or the recent commitments to women's health, rare disease research, or disability rights. The White House and HHS should infuse focus and coordinated effort on the outcomes that are most impactful to the health of our people. Maternal mortality and morbidity may be the place to start because they are perhaps the most shocking examples of poor outcomes, fragmented approaches to care, and inequity. Rather than the current (although noble) approach to elevate social and community supports and expand the types of benefits and health professionals who can work with pregnant people, HHS could identify the outcomes that all entities involved in care are required to measure and report. Standardized measurement and transparency must be critical elements of this effort to ensure accountability by all stakeholders and to create a culture of rapid learning and shared knowledge. We've seen successful examples of a unified approach before, including patient, family, and clinician collaboration to drive better outcomes in cystic fibrosis<sup>7</sup> and data collection and public reporting for health care-associated infections.<sup>8</sup> In both cases, the path was not easy, but the consistent expectation of a data-driven approach, fearless and relentless transparency, and a focus on how the patient was

actually faring achieved measurable and sustainable results. Patients with cystic fibrosis today can count on more effective care to extend their life and increase their ability to live it well. Patients undergoing surgery or entering a health care facility are not only more aware of infections and how to prevent them, but they also can evaluate where and from whom they receive care with insight on outcomes. Federal leaders have the power to identify our most pressing health issues as a nation and demand that we get to the essence of measuring what we should be delivering to all citizens: good outcomes.

### EMBRACING THE OUTCOMES IMPERATIVE

Outcomes measurement and its use in data development, research, and performance and payment design are the action needed to do more than talk about patient and community health, cost-effectiveness, and equity. The science-based tools exist to help all actors measure what matters to people receiving care, regardless of setting, geography, socioeconomics, or health conditions. Although challenges exist, there are solutions and practical examples of sustainable change. ICHOM is a resource and forum for change, fostering international consensus on the science and practice of patient-centered outcomes measurement.

As the US charts its course through the next political era, it is crucial that we boldly allocate resources and prioritize what truly impacts patients. When faced with complexity, feasibility concerns, or entrenched norms, we must proclaim: “It’s the outcomes, stupid.”

### AUTHOR INFORMATION

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