

Standardizing Patient Outcomes Measurement

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The arc of history is increasingly clear: health care is shifting focus from the volume of services delivered to the value created for patients, with “value” defined as the outcomes achieved relative to the costs.¹ But progress has been slow and halting, partly because measurement of outcomes that matter to patients, aside from survival, remains limited. And for many conditions, death is a rare outcome whose measurement fails to differentiate excellent from merely competent providers.

Experience in other fields suggests that systematic outcomes measurement is the sine qua non of value improvement. It is also essential to all true value-based reimbursement models being discussed or implemented in health care. The lack of outcomes measurement has slowed down reimbursement reform and led to hesitancy among health care pro-

viders to embrace accountability for results.

If we’re to unlock the potential of value-based health care for driving improvement, outcomes measurement must accelerate. That means committing to measuring a minimum sufficient set of outcomes for every major medical condition — with well-defined methods for their collection and risk adjustment — and then standardizing those sets nationally and globally.

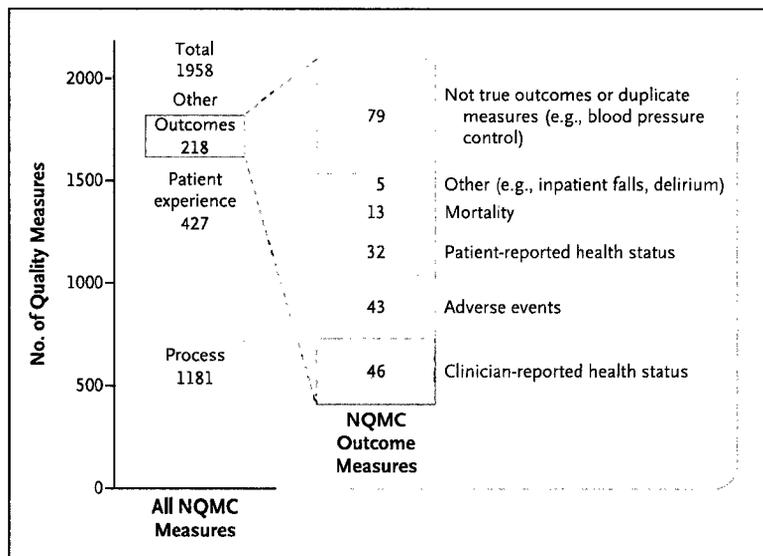
Why has arriving at the essential measures of performance been so difficult in health care, when it seems to occur naturally in other fields? First, in health care we’ve allowed “quality” to be defined as compliance with evidence-based practice guidelines rather than as improvement in outcomes. Of the 1958 quality indicators in the National Quality Measures Clearinghouse, for

example, only 139 (7%) are actual outcomes and only 32 (<2%) are patient-reported outcomes (see bar graph).² Defaulting to measurement of discrete processes is understandable, given the historical organization of health care delivery around specialty services and fee-for-service payments.

Yet process measurement has had limited effect on value. Such measures receive little attention from patients, who are interested in results. Process measures don’t truly differentiate among providers, so incentives for improvement are limited. Nor does improving process compliance from 95% to 98% matter much for outcomes. Yet the effort required to measure processes and ensure compliance consumes organizations’ resources and attention, leading to clinician skepticism about the value of measurement, which spills over to outcomes measurement.

Second, the limited outcomes measurement that has occurred has been led overwhelmingly by specialty societies. But outcomes are not strictly related to individual specialties or procedures; they reflect the overall care for a patient’s medical condition, in which multiple specialties are usually involved. What generally matters to patients are outcomes that encompass the whole cycle of care — including health status achieved (e.g., survival, functional status, quality of life); the time, complications, and suffering involved in getting care; and the sustainability of benefits achieved (e.g., time until recurrence).

Specialty societies naturally



Categories of Quality Measures Listed in the National Quality Measures Clearinghouse (NQMC).

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focus on their constituents, often choosing measures that physicians can reliably control. The perspective expressed, for example, in a cardiology society's statement that "outcome measures are highly desirable but often difficult to incorporate into performance measure sets because of vulnerability to influences outside the provider's control"³ distances providers from the work of improving patients' actual results and contributes to outcomes-measurement paralysis.

Third, efforts at outcomes measurement have overwhelmingly focused on clinical status (e.g., survival and "objective" outcomes that are readily captured by laboratory tests) and left out functional status, even though improving functional status is why patients seek care. Billing data also don't capture suffering due to the delays, chaos, confusion, and complications that often characterize health care. These omissions reflect clinicians' inclination to focus on readily accessible data, as well as the fact that many outcome measures developed to date have emerged from controlled clinical trials, which often have a single primary clinical end point. Patient-reported outcomes are beginning to be measured but are not yet routinely captured for most conditions.

Finally, progress on outcomes measurement has been slowed dramatically by the "let a thousand flowers bloom" approach, in which each organization reinvents the wheel, tweaks existing measures and risk factors, or invents ones of their own. Sensitivity to physicians' concerns about being judged unfairly results in a tendency to exclude patients from outcomes comparisons instead of

incorporating accepted risk-adjustment methods. This approach reduces the percentage of patients whose data are included in performance measurement and compromises comparability with data from other providers.

This history has led to a patchwork of inconsistent outcomes measures and definitions used by various provider organizations, specialty societies, payers, countries, and even individual clinicians. There have been no effective mechanisms for standardizing outcomes measures regionally or nationally, much less globally. Each organization that sets out

more efficiently, and allow comparisons that will accelerate care improvement.

Some steps have already been taken along this path. Guidelines from professional societies are starting to incorporate more outcomes measures, albeit ones still focused on procedures rather than medical conditions. There are a few examples of societies collaborating on broader sets of outcomes for conditions, though progress remains slow.

There is also a new institutional approach that offers a promising proof of the concept that standardization of outcomes-

A new institutional approach offers a promising proof of the concept that standardization of outcomes-measure sets can be achieved rapidly for a growing range of conditions.

to measure outcomes thus faces an arduous process of agreeing on what to measure and how, and then convincing reluctant providers to go along with it. The ability to compare performance, spark competition, and foster learning is compromised.

The time has come to change this trajectory. Providers, payers, patient-advocacy groups, and regulators can come together to create a process to agree on a minimum sufficient set of outcomes for each important medical condition — including rigorous definitions, risk-adjustment factors, and methods. Then we can agree on standardizing these measures both nationally and internationally. The establishment of standards will speed up measurement, allow providers to collect and share data on outcomes

measure sets can be achieved rapidly for a growing range of conditions. The International Consortium for Health Outcomes Measurement (ICHOM) has convened groups of experts on specific conditions, together with patient representatives, to outline minimum standard outcome sets and risk factors using a structured process. ICHOM has approved or is in the final stages of approval of more than 20 sets covering about 45% of disease burden in the United States and other high-income countries, with many more to come (see table). The international nature of the effort has allowed participants to see that patients with a given condition have the same or similar needs everywhere. Reaching agreement among international groups of clinicians on condition-

International Consortium for Health Outcomes Measurement's Standardized Outcome Sets.*

Standard Sets Complete			Under Consideration for 2016 and Beyond
2013	2014	2015 (Final Approval Pending)	
1. Localized prostate cancer	5. Parkinson's disease	13. Breast cancer	22. End-stage renal failure
2. Lower back pain	6. Cleft lip and palate	14. Dementia	23. Oral health
3. Coronary artery disease	7. Stroke	15. Frail elderly	24. Brain tumors
4. Cataracts	8. Hip and knee osteoarthritis	16. Heart failure	25. Drug and alcohol addiction
	9. Macular degeneration	17. Pregnancy and childbirth	26. Bipolar disorder
	10. Lung cancer	18. Colorectal cancer	27. Burns
	11. Depression and anxiety	19. Overactive bladder	28. Melanoma
	12. Advanced prostate cancer	20. Craniofacial microsomia	29. Head and neck cancer
		21. Inflammatory bowel disease	30. Pediatric oncology (conditions to be determined)
			31. Rheumatoid arthritis
			32. Liver transplantation
			33. Congenital hand malformations
			34. Chronic rhinosinusitis
			35. Congenital hemolytic anemia
			36. Rotator cuff disease
			37. Malaria

* The standard outcomes sets completed or pending in the first 3 years cover conditions accounting for 45% of the global burden of disease.

specific outcomes sets has been surprisingly straightforward.

ICHOM working groups understand that their role is not to devise new outcomes measures but to agree on which well-validated ones, including patient-reported measures, everyone should use. These standards are putting providers, payers, patients, and information technology vendors on a common path for tracking what needs to be tracked, making implementation of outcomes measurement easier and more efficient. Organizations may collect additional measures, but everyone is encouraged to deploy the minimum set.

We think the feasibility of outcomes standardization is now clear, and broad adoption of the standard sets is beginning. The experience thus far demonstrates that respected clinicians are eager to participate, the process of agreeing on standards is practical and effective, and standard

sets can be well documented and published in respected journals.

As adoption of these sets spreads rapidly, the tools and methods for implementing them efficiently are being developed. Information technology vendors are creating software solutions to automate outcomes-data collection and aggregation and have begun embedding the standard sets in electronic medical records. A data platform to allow voluntary provider benchmarking and learning on a condition-by-condition basis is under development.

We predict that a time will soon come when it will be hard to believe that measurement of outcomes that mattered to patients was rare in 2016 — and organizations that measured them each did it in their own way. Universal measurement and reporting of outcomes won't happen overnight. But we believe that agreeing on and implementing respected standard sets of out-

comes for each medical condition is a practical and decisive step in accelerating value improvement in health care. This is an agenda whose time has come.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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