

Engaging Consumers in the Quality Measurement Enterprise

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Preface

Community Catalyst’s Center for Consumer Engagement in Health Innovation has observed that quality measurement work is less successful when consumers and communities are not involved, or when they have been involved superficially. When consumers and communities notice that the process is not working well for them, they are less likely to support implementation and use of quality measures. In our experience, consumer engagement in all stages of quality measurement can address these concerns, but success depends on both measurement leaders and consumer advocates. In this report, we explored quality measurement in discussions with consumer advocates. The recommendations in this report can help the leaders of quality measurement efforts and consumer advocates work together to improve the development, implementation, and use of quality measures.

This work was sponsored by Community Catalyst’s Center for Consumer Engagement in Health Innovation, for which Ann Hwang serves as director. The research was conducted in RAND Health, a division of the RAND Corporation. A profile of RAND Health, abstracts of its publications, and ordering information can be found at www.rand.org/health.

Table of Contents and Figure

Contents

Preface	iii
Summary.....	vi
CHAPTER ONE	
Introduction	1
Approach	3
Organization of This Report.....	4
CHAPTER TWO	
Key Steps in Creating and Using Quality Measures	5
Setting Priorities: What General Things Should We Measure?	6
Creating Measure Concepts Within a Priority Area: What Specific Things Should We Measure?	6
Specifying Measures: How Exactly Will We Measure These Concepts?.....	7
Testing and Endorsing Measures: Are They Measuring What We Intended Them to Measure?.....	8
Using Measures to Improve the Care Available to Community Members	9
Maintaining Measures	10
Comment	11
CHAPTER THREE	
Barriers to Consumer Participation and Potential Solutions	13
Barrier 1: “Unequal Power”	13
Example 1.1: Unequal Time and Resources	14
Example 1.2: Power Dynamics	14
Potential Solutions	14
Barrier 2: “Limited Menus”	16
Example 2.1: Setting Priorities or Using Measures?	16
Example 2.2: Absence of Measures That Consumers Want	17
Potential Solutions	17
Barrier 3: “Critical Mass”	18
Example 3.1: A Seat at the Table.....	18
Example 3.2: The Lone Voice	18
Potential Solutions	19
Barrier 4: “Flat Footed”.....	19
Example 4.1: Highly Technical Request for Input.....	20
Example 4.2: Inadequate Training, Preparation, and Time to Respond	20
Potential Solutions	20
Barrier 5: “Closed Doors”	21
Example 5.1: Plans.....	21

Example 5.2: Providers	22
Potential Solutions	22
Barrier 6: “Dual Focus”	22
Example 6.1: System Capacity	23
Example 6.2: Knowing Where to Go But Not How to Get There	23
Example 6.3: Problems Stemming from Measures or Details of Implementation	23
Potential Solutions	24
CHAPTER FOUR	
Recommendations	25
Recommendations for Quality Measurement Leaders	25
Clarify the Goals of Quality Measurement	25
Affirm the Importance of Consumer-Centeredness to Their Work	25
Emphasize Openness to New Views.....	26
Offer Financial Support.....	26
Ensure Adequate Consumer Representation.....	27
Involve Consumers Early.....	27
Train Consumers and Offer Technical Assistance.....	28
Develop Tools to Support Ongoing Consumer Input	28
Assess and Learn from Experience.....	28
Recommendations for Consumer Advocates	29
Focus National Attention on Consumer-Centered Quality Measurement	29
Assess the Extent to Which Quality Measurement Processes Are Open or Closed to Consumers	
Nationally	30
Convene Independent and Public Reviews	30
Build and Share Knowledge and Technical Expertise.....	30
APPENDIX	
Discussion Questions for Representatives of Consumer Advocacy Organizations	31
Acknowledgments	32
Abbreviations	33
References	34
Figure	
2.1. Quality Measure Life Cycle	5

Summary

Quality measurement is critical for helping providers, purchasers, payers, and consumers of care identify high-quality care and improve the quality of care. The opportunities and challenges for consumers to engage in quality measurement warrant careful examination. This report addresses concerns of consumer advocates about making quality measurement more consumer-centered. The report explores the experience of consumer advocates in engaging with quality measurement, identifies barriers to effective consumer engagement, and suggests ways to address those barriers. This report is intended for decisionmakers in quality measurement organizations and for consumer advocates.

We invited representatives of community organizations from across the country to participate in small group discussions about their experiences working with quality measurement agencies and institutions and their recommendations for addressing consumer concerns about the process. Discussions were moderated jointly by the RAND project team and Community Catalyst's Center for Consumer Engagement in Health Innovation staff, and followed a structured question-and-response format. Thirteen participants from nine states joined the discussions.

This report offers an overview of the life cycle of quality measurement, focusing on six stages: setting priorities, creating measure concepts, specifying measures, testing and endorsing measures, using measures, and maintaining measures. At each stage, we explore opportunities for consumer engagement.

The report also describes six barriers that emerged in our conversations with consumer advocates about their experience with quality measurement. Some barriers are most pertinent to one or two stages in the quality measurement life cycle, but others address general issues that span the entire life cycle. Participants in our discussions described several barriers that make consumer involvement in quality measurement challenging. Consumer advocates report

- having less power relative to other stakeholders involved in quality measurement
- being invited to the measure development process after much of the work is complete, or when only a limited measure set is available for consideration
- being asked to represent the views of all consumers in quality measurement work
- having inadequate time and resources to respond to requests for involvement in the quality measurement process
- being closed out of some parts of the quality measurement process
- having difficulty focusing on both the big picture and the details of quality measurement.

Participants also describe potential solutions to these challenges. We synthesized these potential solutions into nine recommendations for quality measurement leaders and four recommendations for consumer advocates. Quality measurement leaders should

1. clarify the goals of quality measurement
2. affirm the importance of consumer-centeredness to their work
3. emphasize openness to new views
4. offer financial support to consumer participants
5. ensure adequate consumer representation
6. involve consumers early in the process
7. train consumers and offer technical assistance
8. develop tools to support ongoing consumer input
9. assess and learn from experience.

Consumer advocates should

1. focus national attention on consumer-centered quality measurement
2. assess the extent to which quality measurement processes are open or closed to consumers nationally
3. convene independent and public reviews of quality measurement work
4. build and share knowledge and technical expertise about the process.

When consumers and communities notice that the process is not working well for them, they are less likely to support implementation and use of quality measures. The recommendations in this report can help the leaders of quality measurement efforts and consumer advocates work together to improve the development, implementation, and use of quality measures.

Chapter One

Introduction

Quality measurement is critical for helping providers, purchasers, payers, and consumers of care identify high-quality care and improve the quality of care. As the nation's health care system moves increasingly to one where payment is tied to value, the demands placed on quality measurement are ever increasing. The shift to value-based payment—with substantial incentives for providers to cut costs of care—asks much of quality measures. Quality measurement is the chief bulwark against stinting on necessary services and is needed to ensure that payment models have neutral or positive effects on the quality of care. The Institute of Medicine (IOM) in 2013 recommended that public and private payers promote patient-centered care through quality measurement, reporting programs, and payment models (IOM, 2013). These responsibilities create substantial challenges for the current system of designing, testing, and implementing quality measures (Health Care Payment Learning and Action Network, 2016).

In this context, the opportunities and challenges for consumers to engage in quality measurement warrant careful examination. Consumers are the ultimate stakeholders in quality measurement. They have a viewpoint that is inherently distinct from that of all other stakeholders: Consumers are best able to articulate what types of care, what health outcomes, and what types of measures are most meaningful to them; capturing their voice is critical to defining, measuring, and achieving patient-centered care, defined by the IOM as “care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (IOM, 2001).

Several frameworks for patient and stakeholder engagement in community-based participatory research and patient-centered outcomes research have been published in the last five years (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Methodology Committee of the Patient-Centered Outcomes Research Institute, 2012; Deverka et al., 2012; Concannon et al., 2012; Patient-Centered Outcomes Research Institute [PCORI], 2015). This report is meant to be a practical extension of the concepts in these frameworks to the context of quality measurement.

There is increasing recognition of the importance of patient-centeredness—which has been described as a “shift of power that is fundamental to both the definition and pursuit of quality”—in quality measurement and improvement (Berwick and Fox, 2016). The National Strategy for Quality Improvement in Healthcare (National Quality Strategy, or NQS) has “ensuring that each person and family are engaged as partners in their care” as one of its six priorities (U.S. Department of Health and Human Services [DHHS], 2011).

To achieve the goal of person-centeredness, all steps of quality measurement—including prioritizing, developing, validating, using, and assessing quality measures—require robust consumer involvement.

Prior efforts to include consumers in the quality measurement process include Aligning Forces for Quality (AF4Q), a 2006 initiative of the Robert Wood Johnson Foundation designed to transform care on a regional level. Sixteen AF4Q communities consisted of alliances of providers, consumers, and payers. These alliances involved consumers in designing performance reports, integrated consumers into quality improvement efforts, and encouraged consumers to use the performance reports (Mende and Roseman, 2013; Ness, 2012). In another example, DHHS in 2008 funded collaboratives of community purchasers, health plans, providers, and consumers—called chartered value exchanges—to advance quality measurement and reporting (DHHS, undated).

Despite these and other efforts to involve consumers over many years, concerns remain that current quality measurement does not provide consumers with information they need for decisions about their own care (National Quality Forum [NQF], 2014). The experience of Community Catalyst, the sponsor of this report, and its network of consumer advocacy organizations support this conclusion; consumer advocates find the quality measurement enterprise challenging, time-consuming, and less than satisfying. Related to these concerns, there is a lack of published literature on consumer involvement in the quality measurement process, a gap we seek to address with this report.

Community Catalyst is a national consumer health advocacy organization that works with state advocacy partner organizations in 40 states and has been involved in quality measurement through the NQF, technical expert panels (TEPs), and technical assistance to state partners. Community Catalyst and its state partners provide input on quality measures in the context of programs such as State Innovation Model grants, accountable care programs in Medicaid, patient-centered medical home initiatives, and programs to integrate care of individuals dually eligible for Medicare and Medicaid.

We developed this report to address concerns of consumer advocates about quality measurement in this new health care context. The objective of this report is to gain a better understanding of the current experience of consumer advocates in quality measurement, to identify barriers to effective consumer engagement, and to suggest ways to address those barriers. This report is intended for two audiences:

1. **decisionmakers in quality measurement organizations.** These may include funders of quality measurement research; researchers of measurement methods and the use of quality measures; policymakers with responsibility for selecting quality measures to support payment policy, performance assessment, or quality improvement activities; payers who are responsible for using quality measures in

payment; and clinicians and health systems that are involved in implementation of quality measurement.

2. **consumers and consumer organizations that are participating or wish to participate in quality measurement, particularly consumer health advocacy organizations.** In this report, we use the term “consumer advocates” to refer to individuals who are professional, paid representatives of a consumer perspective, typically working under the auspices of a nonprofit consumer advocacy organization. “Consumers” refer to beneficiaries or community members who are not professional consumer representatives.

We hope this report can help improve consumer engagement in quality measurement across the nation.

Approach

To identify opportunities to improve consumer involvement in quality measurement, we talked directly with representatives of consumer advocacy organizations. We used a purposive convenience sampling design to gather the views of consumer advocates who had differing levels of experience with quality measurement, and who represent a variety of regions and populations across the United States. The goal was to identify what was—and was not—working to sustain *their* involvement in quality measurement, and to identify potential solutions for improving the process.

We invited representatives of consumer health advocacy organizations from a pool of approximately 90 consumer advocacy organizations with which Community Catalyst works most closely. Invitations were sent to 16 representatives of 13 of these organizations. We focused on state-based advocates because states have implemented a broad range and large number of innovative health care programs, creating both the need and the opportunity for innovation in quality measurement.

Thirteen representatives from ten organizations across nine states (Alabama, California, Georgia, Illinois, Massachusetts, Michigan, Minnesota, New York, and Pennsylvania) accepted the invitation to participate. Participants came from four organizations focusing on general health care issues, two representing persons with disabilities, two primarily representing racial and ethnic minority populations, one focused on maternal and child health, and one that addresses a wide range of poverty-related needs and issues.

We held four community discussions with one to five participants each in the summer of 2016: three by teleconference and one in person at Community Catalyst’s office in Boston, Massachusetts. Each discussion lasted one hour. Discussions were moderated jointly by the RAND project team and Community Catalyst’s Center for Consumer Engagement in Health Innovation staff, and followed a structured question-and-response

format (see the Appendix). We started off by asking participants to describe their experience in quality measure development and implementation, including

- how they learned about opportunities to work on quality measurement, whether by invitation or not
- how they were involved, such as serving on a TEP, responding to requests for information, or other activities
- what kind of work they engaged in, such as setting priorities, specification and development, validation, implementation, or assessment of quality measures.

The majority of time in each discussion was focused on assessing participants' experiences with quality measurement organizations and institutions. We asked participants to describe aspects of these engagements that met their expectations and aspects that did not, and whether they felt prepared to represent the views and experiences of health care consumers. Finally, we spent part of each discussion on participants' recommendations to improve engagement of consumers in the quality measurement process.

Two note takers documented the discussions, and both sets of notes were consulted to identify the major barriers described by consumer advocates as they have attempted to engage with the quality measurement enterprise. The barriers, illustrative examples, and potential solutions described in Chapter Three were shared with discussion participants. Written comments from participants were addressed in revisions of the report.

A panel of nine quality measurement experts (see Acknowledgments) was then convened to review and comment on this report. A presentation on major findings was made and experts were invited to comment on the project's goals, the quality measurement life cycle, the barriers to consumer involvement, and the recommendations. During the meeting, participants were asked to assess the report's recommendations. Oral and written comments were addressed in revisions to the report.

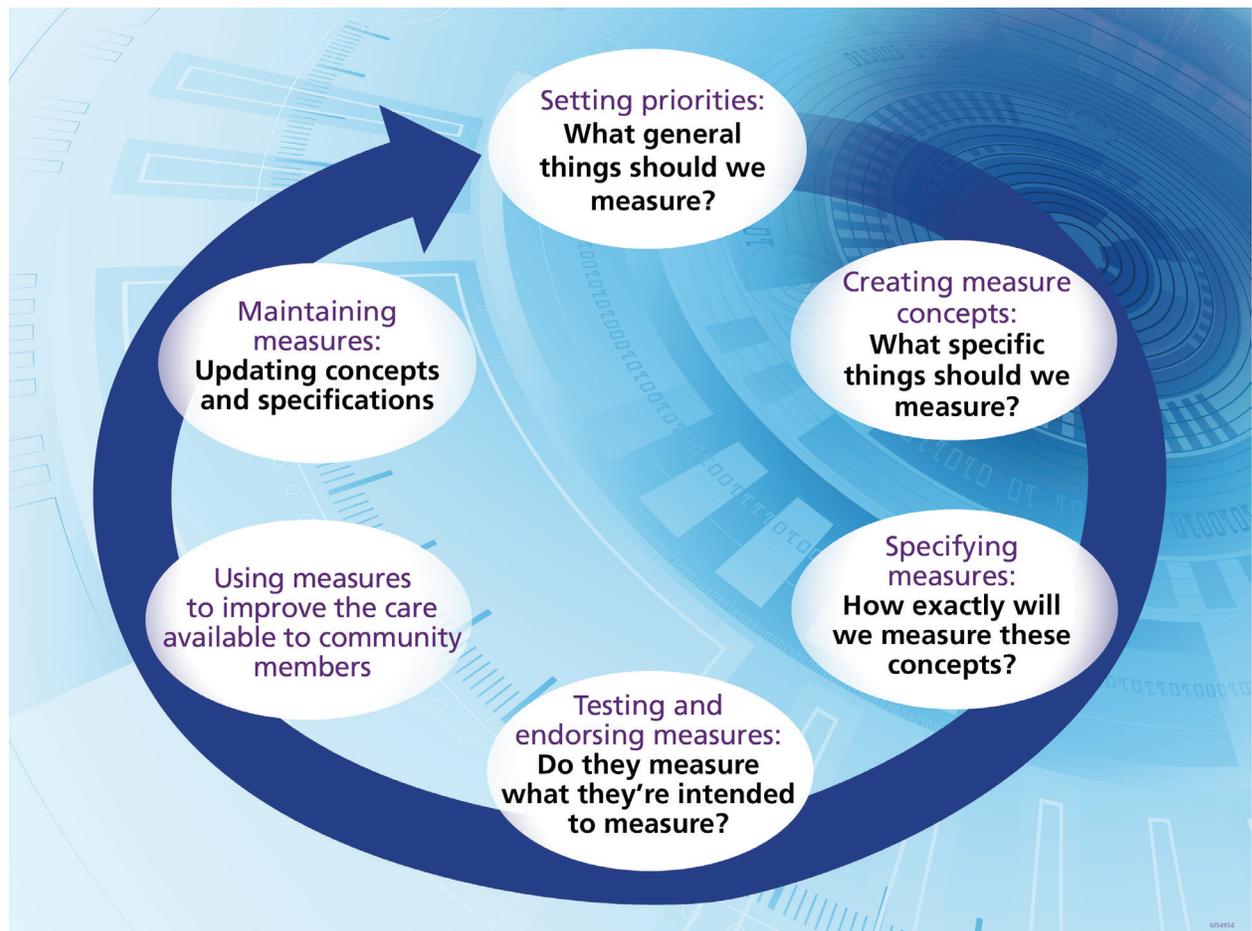
Organization of This Report

The remainder of this report is organized into three chapters. In Chapter Two, we describe typical stages of a measure development process and identify opportunities for consumers to engage in the process. In Chapter Three, we share the perspectives of our focus group participants regarding barriers to effective involvement in quality measurement. In Chapter Four, we organize potential solutions to these barriers—including those expressed by the focus group participants directly and those identified through our own syntheses of these discussions—into recommendations that quality measurement leaders and advocates can use to improve consumer involvement in quality measurement.

Key Steps in Creating and Using Quality Measures

In this chapter, we present an overview of the life cycle of quality measures to set the stage for exploring how consumers can be involved and what barriers they may face. Based on prior work (Friedberg and Damberg, 2011), we describe six stages: setting priorities, creating measure concepts, specifying measures, testing and endorsing measures, using measures, and maintaining measures. At each stage, we examine the opportunities for consumer engagement. Figure 2.1 displays these stages.

Figure 2.1. Quality Measure Life Cycle



Setting Priorities: What General Things Should We Measure?

To guide the overall direction of quality measure development and use, government and private organizations can make efforts to achieve consensus on which areas to prioritize for quality improvement. At this stage, initial decisions are made regarding which aspects of care will be prioritized and for which populations. Decisions emerging from these priority-setting efforts can influence subsequent investment in new measures and help determine how new and existing measures are used.

General priorities include such things as the decisions to measure diabetes care, dementia care in long-term care settings, or congestive heart failure orders at discharge from inpatient hospitalizations. Examples of such priority-setting efforts include the NQS of the Secretary of the Department of Health and Human Services (Agency for Healthcare Research and Quality [AHRQ], undated-b), the National Priorities Partnership (NPP) of the NQF (undated-c), and the Measurement Advisory Panels (MAPs) of the National Committee for Quality Assurance (NCQA, undated-a, undated-b). These efforts can overlap. For example, the NQS, which was mandated under the Affordable Care Act of 2010 (DHHS, 2011), gathered input from more than 300 groups, including the NPP—which, in turn, includes the NCQA among its approximately 50 member organizations (NQF, undated-d).

Participation in priority-setting efforts does not require clinical or methodological expertise. Advocacy that truly reflects the priorities of consumers and communities is highly valuable at this stage. Specific opportunities for engagement include but are not limited to the NPP of the NQF and MAPs of the NCQA.

Creating Measure Concepts Within a Priority Area: What Specific Things Should We Measure?

Once general priorities for measurement are identified, the next step is to create measure concepts that can serve as the basis for developing specific measures. When priorities involve clinical outcomes, measure concepts are frequently based on scientific evidence and clinical guidelines. For example, the NQS included “prevention and treatment of leading causes of mortality” among its priorities, with a goal of preventing and reducing the harm caused by cardiovascular disease (DHHS, 2011). Measure concepts corresponding to this goal include assessments of processes of care, such as the percentage of patients receiving guideline-concordant cardiovascular care (e.g., the percentage of patients with heart disease whose blood pressure is well controlled), or assessments of the outcomes of care, if they can be measured directly (e.g., mortality rates or patient-reported outcomes). Historically, there have been few measure concepts generated directly by patients.

For priorities involving patient-centered care, measure concepts might include provider capabilities (e.g., having electronic health records that integrate patient-generated data), as well as patients' experiences of care.

Consumer advocates can create measure concepts on their own or in partnership with measure developers. Creating measure concepts requires knowledge of specific opportunities to improve care within a given priority area and benefits from reasonably specific ideas for how these might be improved. Consumer advocates who closely follow the scientific literature on treatment of their highest-priority conditions are likely to be well positioned to create measure concepts. Advocates' roles in this activity are especially important when they represent communities with health interests that are not widely prevalent in the general population. Without careful attention by advocates, these interests may be missed by measure developers who focus on the most-prevalent health conditions. Publishing measure concepts and promoting them to those who can commit resources to subsequent stages of measure development—such as AHRQ, Centers for Medicare and Medicaid Services (CMS), or foundations involved in measure development—might be an effective strategy for such advocates. Such measure concepts can be published in the “gray literature” (e.g., memos and reports on a community organization's website) or in peer-reviewed journals. Submitting a manuscript to a peer-reviewed journal takes practice and expertise, and working with an experienced academic can be helpful for crafting an argument and navigating the process.

In high-priority areas lacking scientific evidence, consumer advocates can also seek to steer research resources to produce the evidence that can form the basis for new clinical guidelines and measure concepts. Opportunities to influence the clinical research agenda include National Institutes of Health Advisory Committees (National Institutes of Health, undated) and PCORI Advisory Panels (PCORI, 2016).

Specifying Measures: How Exactly Will We Measure These Concepts?

Before a measure concept can be tested and used to improve care, it must be translated into detailed specifications. Measure specifications are rules that describe the data required and methods for calculating a quality measure. These methods include definitions of denominators (i.e., which patients and which health events to include or exclude), numerators (i.e., which health events count as better or worse care), time frames for measurement, and methods for adjusting measures by clinical severity of the population (Friedberg and Damberg, 2011).

Where can one find examples of measure specifications? The National Quality Measure Clearinghouse (NQMC)²³ maintained by the AHRQ provides summaries of specifications for thousands of quality measures (AHRQ, undated-a), although in many

cases the full, detailed specifications must be obtained from the measure developer directly (e.g., for NCQA Healthcare Effectiveness Data and Information Set, or HEDIS, measures). Full specifications of CMS Hospital Quality Initiative measures (reported on the “Hospital Compare” web page) are available for free download and give a good sense of the degree of detail involved (CMS, 2016a, 2016b).

Specifying quality measures requires expertise in quality measurement methods and in the types of data underlying the measure (e.g., health plan administrative claims data or patient survey data). Consumer advocates can make valuable contributions to measure specifications, even if they lack such methodological expertise in-house. This is because value judgments (i.e., decisions for which there is not a single, correct scientific answer) are nearly inevitable when translating measure concepts into detailed specifications (Friedberg and Damberg, 2011). Such value judgments include determining which specific care scenarios do and do not meet the intent of the measure concept, and whether and how to perform case-mix adjustment. By working closely with measure developers, consumer advocates can help ensure that measure specifications match their measure concept as closely as possible. Participation on technical expert and advisory panels for measure development are possible ways to do this.

Many government and private organizations develop quality measure specifications. These include CMS, AHRQ, NCQA, health plans, health systems, researchers, and provider professional societies.

Testing and Endorsing Measures: Are They Measuring What We Intended Them to Measure?

Testing a measure means assessing its validity and reliability. Validity means that the measure assesses what it is intended to measure (Friedberg and Damberg, 2011). Reliability is the signal-to-noise ratio in a measure—the degree to which *apparent* performance differences between providers are *true* differences, rather than being due to chance—i.e., some providers just being luckier or unluckier than others (Friedberg and Damberg, 2011). Because measure specifications are complex and some degree of measurement error is unavoidable, assessing a measure’s validity and reliability is highly advisable before using it in a high-stakes manner (see next section).

To test validity, performance of the measure can be compared with a “gold standard” or with performance on other measures that are strongly related to the measure concept. For example, if a new measure based on administrative claims data says that Surgeon A has a lower complication rate than Surgeon B, examination of detailed clinical records should also find that Surgeon A has a lower complication rate than Surgeon B, if the new measure is valid.

Measure testing also includes assessment of reliability. Measures that are valid but unreliable might be true assessments of provider performance *on average* but still be inappropriate for high-stakes use because provider-to-provider differences in calculated performance mostly occur at random. An intuitive sign of an unreliable measure occurs when measured performance for a given provider fluctuates wildly from year to year, even if the provider is not doing anything differently.

When a measure has acceptable validity and reliability, its developers can seek endorsement from a measure-vetting body, such as the NQF. Such endorsement can help potential users of the measure have confidence in its accuracy. When a measure fails to receive endorsement, the vetting process can give measure developers useful guidance on how to improve or better demonstrate its validity and reliability. This process may be carried out iteratively over more than a year.

While testing a performance measure requires expertise in performance measurement and statistics, endorsement also requires input from stakeholders who have other kinds of expertise, including the experience of being a consumer. This is because statistics and measurement science alone cannot determine how much accuracy is good enough for a given use of the measure. For example, there is no mathematically “correct” answer for how much measurement inaccuracy is too much (i.e., the point at which an inaccurate report becomes worse than no report at all). Consumers have different tolerances for the amount of false information that might influence their choices about where to receive care, and the only way to find out is to ask them (Davis, Hibbard, and Milstein, 2007). Consumer advocates, therefore, are well positioned to provide this critical information by communicating to measure developers how much accuracy community members need from a quality measure.

Using Measures to Improve the Care Available to Community Members

Following a conceptual model developed by Dana Safran (2008), quality measures can be used in high-stakes and lower-stakes ways to improve the quality of care. High-stakes uses include financial incentives such as pay-for-performance (P4P), public performance reporting—for example, web-based reports, such as Hospital Compare (CMS, 2016a) and the Healthcare Compass maintained by the Massachusetts Health Quality Partners (MHQP, undated)—and provider tiering, in which patients pay higher out-of-pocket prices to see lower-performing providers. In all of these high-stakes uses, measures are linked directly to external incentives targeting providers, patients, or both. Because inaccurate measures could misdirect patients to truly lower-quality providers and penalize truly higher-quality providers, most stakeholders have agreed that high-stakes uses require performance measures that are reasonably valid and reliable.

Lower-stakes uses of performance measures include confidential feedback to providers to help guide their quality improvement efforts and community-level public reporting to raise general awareness of quality issues and help set priorities for improvement. While accuracy is still important for these lower-stakes uses, they do not directly influence patients' choice of providers, nor do they change how providers are paid.

Many stakeholders influence how measures are used. High-stakes uses are negotiated in contracts between providers and payers and in regional collaborative efforts, such as the MHQP. They can be required under statute or regulations, such as the Medicare Access and Children's Health Insurance Program (CHIP) Reauthorization Act of 2015 (MACRA), or through state quality measurement bodies. Low-stakes uses are frequently pursued within provider organizations and offer room to experiment with measures that have not yet been validated, or could be pursued as part of an interim internal pay-for-reporting initiative. Consumer advocates whose priorities are not adequately captured by existing validated measures might be able to use such measures under development to guide quality improvement efforts, in partnership with provider, payer, and other health organizations serving the communities they represent.

Consumer groups are frequently invited to help choose measures from a menu when new reporting and performance incentives programs are being designed. At the national level, for example, the NQF's Measure Applications Partnership advises DHHS on which quality measures to use in federal programs such as Medicare (NQF, undated-b). State governments and state-level collaboratives, such as MHQP, also frequently create opportunities for community involvement in measure selection—e.g., the MHQP's Consumer Health Council (MHQP, 2016).

Deciding which measures to use for a given program is sometimes described as a prioritization activity. However, choosing from among a menu of existing measures should not be confused with the “setting priorities” phase of the life cycle for quality measures—which can identify priorities for which no quality measures exist.

Maintaining Measures

Measure maintenance involves periodically determining whether the concepts underlying an existing measure need to be modified (e.g., to incorporate new research findings or revised guidelines) and updating measure specifications to accommodate changes in the measure concept or in the underlying data (e.g., to the change from International Classification of Disease version 9 to version 10). For example, for NQF-endorsed measures, “measure stewards” (i.e., the organizations responsible for maintaining a given measure) must submit annual status reports to the NQF that either reaffirm the current measure specifications or make updates as needed (NQF, undated-a).

Updating measure concepts or specifications can interfere with efforts to track year-to-year changes in performance. Therefore, modifying a measure can involve difficult tradeoffs.

Measure maintenance might also include checking for unintended negative consequences of ways in which the measure is used, such as a worsening of disparities if P4P programs steer resources away from providers serving sociodemographically vulnerable communities. Some uses of measures might be challenging for consumers and providers alike. Such unintended consequences can be addressed by changing measure specifications, changing the way a measure is used, or removing a measure from use altogether.

In addition, measures can be retired and no longer maintained when they have fulfilled their purpose. For example, the use of beta blockers following a heart attack is no longer assessed because prior use of the measure resulted in near-universal adherence to this guideline.

Measure stewards have primary responsibility for measure maintenance, and they are frequently the original developers of the measures. However, multiple stakeholders have roles in measure maintenance because all can notify the measure owner when changes to the measure concept, specifications, or uses seem necessary. In most cases, the owner of a quality measure is listed in the NQMC entry for the measure (AHRQ, undated-a). Consumer advocates with concerns or advice about maintaining a measure can always publish their concerns in a public forum, but in many cases simply contacting the measure steward directly might be sufficient.

Comment

Not every quality measure follows the sequence outlined in this chapter. Sometimes a stage is skipped. For example, a new measure can be used before it is tested, even though such skipping might create bad incentives or misinform consumers—for example, if a measure turns out not to assess what it is supposed to. Moreover, the lengths of time within and between stages can be unpredictable. Measure developers and measure users can have differing agendas and time lines. For example, a well-specified and tested measure might lie unused for months or years, then come into use when a new government or private-sector program starts, sometimes in ways not envisioned by the measure developers.

Further, activities within one stage may be repeated based on lessons learned in other stages. For instance, use and reuse of measures (stage 4) may be informed by the emergence of newly endorsed measures (stage 3) and experience from using measures can inform maintenance of existing measures (stage 5). In other words, limitations of a new measure might not become apparent until its usage, when ideas for improved or

substitute measures come into focus. In such cases, revisiting the earliest stages of measure development can guide its refinement.

In principle, all stakeholders, including consumers, can participate in each stage of the quality measure life cycle. In practice, the ability of consumers to engage effectively in certain stages—most notably specifying, testing, and maintaining measures—depends in part on the willingness and experience of experts in quality measurement methods. Consumer involvement in technical work is also dependent on their access to the resources that are necessary to support full participation, including funding, allocated time, training, and support. The magnitude of investment required to participate throughout the whole quality measurement life cycle can be considerable, and the payoff might be uncertain, especially in the short term. In our experience, meaningful consumer engagement in all stages depends on both the ability of technical experts to work collaboratively with consumers and on ongoing support for their engagement.

Barriers to Consumer Participation and Potential Solutions

In this chapter, we present six barriers that emerged in our conversations with consumer advocates about their experience engaging in the quality measurement process. For each barrier, we offer a brief description, two or more examples, and potential solutions recommended by our participants to improve the role of consumers in quality measurement. Some barriers are most pertinent to one or two stages in the quality measurement life cycle, but others address general issues that span the entire life cycle.

Barrier 1: “Unequal Power”

Most of the stakeholders directly participating in quality measurement discussions are employed in some part of the health care sector. Their engagement with quality measurement can be sustained over many years by salary and institutional support. Because they know the process, are familiar with other stakeholders, and have the backing of an organization, they come to the discussion with status and power.

Consumers of health care typically do not have these advantages. They come to discussions about quality measures as experts in the consumer experience of care and in how to make measures understandable and meaningful to consumers, but they may lack institutional backing. This can result in a range of difficulties, such as affording the cost of transportation to and from meetings, getting time off from work, and juggling precisely the family or health care commitments that give them relevant experience to contribute to quality measurement. Consumer advocates, too, often have limited institutional backing. Consumer advocates who are dependent on external support (e.g., from grant-giving foundations) might find that funder-specific priorities exclude or restrict general operating support for preparing and attending stakeholder quality forums, many of which might occur on time lines too short for separate grant applications.

Once a quality measurement activity is under way, participants may not know or believe that consumer perspectives carry equal weight with those of physicians, researchers, nurses, policymakers, or health system and insurance executives. An inherent power differential exists between consumers and professionals who are engaged together in a quality measurement process. Imbalances of power can be especially acute during parts of the life cycle that involve such technical details as creating measure concepts, specifying measures, and testing measures.

Example 1.1: Unequal Time and Resources

Consumer advocates do not always have the time and resources to be involved in quality measurement work, or to respond effectively if they are involved. This kind of imbalance can play itself out in a number of ways. For example, one consumer advocate told us that inconsistent involvement made it challenging to know what was going on at any time or how long she would have to respond to draft documents. She said,

If you are not on an advisory committee or really following [State] board meetings month to month or involved at a level where you are in the know, then it can be very difficult to figure out when things are happening, how long you have to respond.

A consumer advocate, on the other hand, who *did* have the benefit of a salary and employment said that his organization still did not have personnel who are dedicated to quality measurement, making it challenging to maintain the organization's presence and voice consistently.

At the statewide level, where the quality measures are being developed, we've had more of a monitoring role. We've not been able to insert our perspectives into that process. . . . We just haven't had the person power to go to the meetings and make our case there.

Example 1.2: Power Dynamics

Another consumer advocate observed that participating in quality measurement work with employed and trained representatives of powerful organizations brought with it an inherent difference in power. This can make it difficult for consumers to feel they are really “at the table” with an equal voice. The advocate said,

The first four years, we were in this so-called multistakeholder group. We were creating recommendations, but you have at the table the hospital association, the medical association, the department of health, and community members. I'm sure you know that if you have a person paid to be at the table, and the community members do not have the same resources, it appears that the community is there, but the power dynamic was unbalanced and in the beginning, our voices were not as strong.

This phenomenon is often described by consumer advocates as a “power dynamic” and the implication is that power is inherently imbalanced. The imbalance may be felt by any member of a group, but it is very often felt by consumer advocates.

Potential Solutions

To address the inherent power differentials that can affect how consumers engage in quality measurement work, several considerations are important.

First, involvement of consumers is strongest when it is sustained over time (Clinical and Translational Science Awards Consortium Community Engagement Key Function

Committee Task Force on the Principles of Community Engagement, 2011), even if the intensity of engagement varies with the level of technical details from stage to stage of the life cycle. This enables the person who represents other consumers to get the lay of the land, meet the players, understand the content areas, and see the whole quality measurement process of development, validation, implementation, and evaluation from start to finish. This is especially important because the time frame of measure development can last so long.

Second, the involvement of consumers is easier to sustain when they are compensated for their time and reimbursed for their expenses. This enables a consumer to join discussions without the opportunity costs of missed income or other important pursuits. A consumer advocate told us about how her experience changed after resources were put in place to sustain her involvement:

Community members got to a point [and said,] “This is not worth it any more.” When we said that, people said, “Let’s do this in a different way.” The coalition was able to pass a bill saying that community has to be at the center. Our first project was the [State] Department of Health contracting with us to bring in the voices of the community.

Third, quality measurement organizations and institutions might consider sustaining consumer engagements not only over the long terms of individual projects, but over even longer terms covering many projects. One consumer advocate described interactions with researchers: “They zoom in, do their study, and zoom out. If you really want to build meaningful quality indicators, develop sustained relationships with consumers.” This is what is meant by the need to support a sustained relationship with consumers over time. Just like other stakeholders, consumers have an interest in seeing their work and contributions result in change. Who pays for this and where the resources come from is a challenge just like other challenges in the quality measurement process, all of which require money and resources.

Finally, involvement is set on a level playing field when everyone understands that consumers bring an expertise to the table that no one else has. Consumers are experts in their own experience and this is necessary expertise. Consumers need to understand their advocacy and representation is not only about their personal view and that they need to represent the views of a population as faithfully as they can. Consumers can best articulate to other stakeholders how some decisions may be viewed and experienced by other consumers. Further, how consumers are referred to is important. One consumer advocate for people with disabilities told us, “. . . using the word ‘patient’ disempowers us, and we repeatedly ask to be called members or persons.” Another said, “We had to educate other stakeholders to understand the consumer voice.” The individual’s experience is a kind of expertise that should be acknowledged routinely. Further, any

member of a multistakeholder board or panel, including a consumer, is capable of citing generalizable research findings in support of a position or view.

Barrier 2: “Limited Menus”

In some cases, invitations to participate in the quality measurement process are made to consumers after much of the early work has been completed. For example, invitations are often made after the measure development process is complete, or when only a limited measure set is available for consideration. Such an approach leaves consumers out of some of the most important decisions that are made in quality measurement work.

This barrier arose frequently in our discussions. Consumer advocates told us that they were typically being invited to be involved in quality measurement in the middle of the life cycle, usually at the stage in which measures are being implemented for use in a particular purpose or program. Starting the consumer engagement process at this stage was described as being too late. Because consumers have an inherently different viewpoint about the quality measures and outcomes that matter most to them, it can be especially valuable to invite consumers to weigh in when prioritizing areas for measure development, from the beginning of the life cycle.

Example 2.1: Setting Priorities or Using Measures?

The opportunities to set priorities for new measures may not happen frequently in the quality measurement cycle, but it is a necessary part of the process. *Setting priorities* is a process of assessing community needs, preferences, and experiences that could be evaluated with quality measures. *Measure use*, on the other hand, is a distinct activity aimed at choosing among a set of measures that have already been developed. Several consumer advocates described being part of a process that was ostensibly about prioritization but was really only about choosing from a predetermined list for use in a specific context:

[I serve] on a panel that is developing long-term services and supports measures. You come into a group that is trying to seek input and it is largely talking about measures already out there and prioritizing what is already out there. Occasionally you get asked what else is important to the consumer, but far too often the response is: “There is not any validated measure out there so we can’t do that.”

[There has been] remarkably little new measure development in [our state]. New measures were last developed more than ten years ago, in the early 2000s. . . . We have hit a rut.

Example 2.2: Absence of Measures That Consumers Want

Consumer advocates repeatedly emphasized they are looking for measures that address their specific concerns. When consumers are asked what they would like to see measured, other stakeholders in the quality measurement process may not be prepared to hear that consumer priorities do not come from a predetermined list of available options. One consumer advocate said that the “focus is on quality data around hospitals but not around consumer-focused needs.” Another told us,

We were asked what to recommend. They asked us to prioritize from a list. But the list didn't have some of the things we would recommend. We had an open discussion with them. Nothing about social determinants, cultural competency, other topics.

Potential Solutions

Consumers should be involved in measure development and implementation at the earliest possible stage, preferably when other decisionmakers and stakeholders are invited. Consumers' comparative advantage is knowing what their own concerns are, and this information is especially helpful when selecting priorities for measurement, the first stage of the life cycle. Not involving consumers at this stage leaves them out when they can perhaps be most helpful. One consumer advocate said that “consumers know where they want to go but they may not know how to get there.”

Realistically speaking, the life cycle of quality measurement happens in fits and starts and may not proceed strictly from step to step as this report describes. When consumers are invited, however, the next opportunity for prioritization and selection of new areas for measure development could be highlighted. It would help to communicate to all consumers when this opportunity will be coming around. In this case, having an infrastructure that can communicate with a network of consumers would be important. Such an infrastructure could serve to gather, sustain, and communicate consumer input and to transmit this information when windows of opportunities arise. This infrastructure could help mediate the mismatch between what is needed to sustain a strong consumer voice over time and the episodic and fragmented opportunities for engagement that arise in quality measurement.

Finally, when the opportunity to prioritize measures comes around, policymakers, providers, health plans, researchers, and other stakeholders in the process should be sincerely open to and prepared to hear what consumers say about the concerns they have and the types of measures they would most like to see.

Barrier 3: “Critical Mass”

Many times, quality measurement discussions occur at stakeholder committees or expert panels that tap, at best, a handful of consumer advocates who are expected to represent a broad range of consumer experiences. A multistakeholder panel, for example, may include several dozen industry representatives, each representing the interest of their specific organization—such as a behavioral health provider, a health plan, a hospital system, or a professional society. In contrast, there may be a single or a handful of consumer advocates who are expected to represent the diverse perspectives of all consumers, spanning race, age, disability, medical conditions, education, income, geographic region, gender, and sexual orientation. The inherently diffuse nature of consumer representation argues for the importance of ensuring a critical mass of consumers, whether that is direct representation or deployment of resources and tactics to ensure that a broad range of perspectives are collected and synthesized.

This barrier is related to but distinct from Barrier 1. There, the challenges are to do with the power of one consumer voice relative to any other single voice in a multistakeholder effort. Here, the challenges have to do with the representation of multiple consumer perspectives. The challenges described here relate to all steps in the quality measurement cycle.

Example 3.1: A Seat at the Table

In some cases, those who convene a committee or panel may believe that consumers are not interested in being at the table for conversations about quality measurement. One advocate noted, “The narrative is set up . . . that consumers do not have interest in quality measures so they do not need to be at the table.” This narrative sets the stage for keeping the number of consumers below the critical mass at which the diversity of consumer viewpoints can be fully appreciated.

In this environment, consumer advocates have had to work hard to change this belief. In one state where consumers were not included in a stakeholder group, an advocate noted, “We had to force ourselves into the meeting, show up, demonstrate that we had the voices of consumers.” In this context, consumers are already starting with a “leg down” in terms of the perception of their value and contributions.

Example 3.2: The Lone Voice

As one advocate noted, “we are often the only consumer voice.” In this role, another advocate noted, “My concern is that consumers are always outnumbered. There might be 30 or 40 lobbyists and one or two consumer reps. It is tough to be heard in a meaningful way when you are one small representative.”

Related to this, consumer advocates note the impossibility of a single voice representing the broad range of consumer perspectives. One advocate noted, “If you are looking at women and kids, it is very different than looking at people over 65 or people with chronic conditions.”

Potential Solutions

To ensure consumer representation that credibly reflects the views of a broader consumer perspective, several actions may need to be taken.

First, ensure that a diverse set of consumer viewpoints is represented on stakeholder groups or expert panels. This is particularly important for measure selection because priorities for one consumer may not reflect priorities of all consumers. For example, a consumer advocate working with seniors will be attuned to different issues than a consumer advocate working primarily with parents of young children.

Second, ensure a critical mass of consumer representatives. Think about the balance of different representatives, not just in terms of the number of seats at the table, but the size and breadth of the constituency they are being asked to represent.

Third, make allowances for consumers who may need time, resources, and technical support to solicit input from the broad and sometimes diffuse constituency that they represent. Several consumer advocates described successful and innovative examples in which they were able to do this by convening focus groups, “town hall” meetings, or member conference calls. For example, one advocate reported that, to inform their perspective on patient experience and satisfaction surveys, “we worked with consumers to do focus groups around what kind of input patients wanted to have in their care.” In another example, the consumer advocate invited a stakeholder committee to a consumer forum to hear directly from consumers about the different payment models and how they would affect them. Another group described its strategy for obtaining a wide range of input:

We have a community mobilization arm that we work with of different racial and ethnic groups across the state, and we have weekly calls where we talk about issues. . . . We ask for feedback as we try to advocate for different measures.

Barrier 4: “Flat Footed”

Consumer and community input is sometimes solicited, but consumer organizations are not always fully prepared to respond. One consumer advocate said, “Okay, we are at the table now. What should we ask for?”

Further, consumers do not always have adequate time to respond to requests for involvement in the quality measurement process. They might be unaware that they are being invited to join the process at a late stage, when other stakeholders are focused on choosing measures for immediate implementation and negotiating the details of their use.

In these late stages, where experience with technical details of measurement is especially valuable, consumers are at a relative disadvantage. Yet in these cases, consumers may be asked methodological questions that are difficult to answer on a tight deadline. For example, a consumer who is offering new measurement ideas (i.e., priority areas and measure concepts) might be told that the ideas have merit but are not validated, suggesting the need for technical work that the consumer is not prepared to lead. To consumer advocates, such technical requests can be “conversation stoppers.”

Example 4.1: Highly Technical Request for Input

Consumers are sometimes asked to provide input on highly technical topics with which they are not entirely familiar, or they may lack the technical expertise to respond quickly to requests that come their way. One consumer advocate said, “We were surprised by the level of detail they requested—we know the ‘what’ but not always the ‘how’.” Another told us,

This is complicated stuff—issues of statistical significance, validation, the comparison between the different instruments, what the link is between length of survey and completion rates. For us to translate this into something consumers can work with is a whole level of expertise we do not have.

Example 4.2: Inadequate Training, Preparation, and Time to Respond

One consumer advocate described being in meetings where everything happens very quickly and participants lack the information necessary to participate:

... at the same time we are trying to fly the plane, we’re trying to engage others. Sometimes we are in a meeting and they’re using words we haven’t heard before so we’re Googling this so we can insert ourselves into the conversation. This is an area where we are underresourced. We need to build the technical expertise among consumer groups.

Potential Solutions

Quality measurement leaders and managers can offer additional support and resources to prepare consumers for their involvement. As a first step, clarifying the stages of the measure life cycle can help consumers decide whether and how to participate most effectively.

Additional support might include training in the fundamentals of quality measurement, a planning meeting to prepare for interaction with other stakeholders, or other activities. As one advocate put it, “We need more [technical assistance], more engagement with other states, and a better framework for thinking about how to engage in quality [measurement work] with Medicaid to be more effective.” Comprehensive training and technical assistance may be needed to advise consumers on key questions

concerning quality measurement:

1. Why is quality measurement needed in general and project-specific terms, and why is a consumer-centered process desirable?
2. Who are the many actors in quality measurement?
3. What are the major steps in quality measurement?
4. When is the right time for consumers to engage?
5. How can consumers become and stay involved?

Further, training on measure development may not be enough to help consumers become and stay prepared for involvement. In addition to training, consumers would benefit from access to real-time assistance from measurement experts, who can act as experienced advisers and guides to the measure development life cycle. Such advisers can provide guidance on available measure concepts and measures, as well as technical information to help advocates respond to methodological questions that arise when they propose particular measure concepts or measures. Consumers also might benefit from peer-to-peer support that could help them understand how to be more effective in this challenging environment.

Barrier 5: “Closed Doors”

Some parts of the quality measurement process may not currently involve consumers. Certain communications about quality measurement efforts happen through informal channels among interested parties, and there may even be a concerted effort by some parties to keep those informal channels closed to consumers. In others cases, parts of the process that are open to consumers in one state or location may be closed to consumers in another.

Many of the concerns in this barrier are aimed at using measures (stage 5), when payers—including state Medicaid programs and health plans—and providers negotiate with other stakeholders and with each other about how a measure set will be implemented and used.

Example 5.1: Plans

One of the barriers that came up repeatedly was consumer advocates’ concern that much of the negotiation between regulatory authorities and health plans may be taking place behind closed doors. Federal regulatory procedures require publication of draft rules for public comment, but concerns about this part of the process were expressed nonetheless. “We are deeply concerned about the lack of emphasis on setting benchmarks for health plans,” one consumer advocate said.

Example 5.2: Providers

Similarly, consumer input into the launch of new provider arrangements has sometimes been overlooked. Another consumer advocate told us, “[our] PCMH [patient-centered medical home] advisory board was composed of plans, provider organizations, and health care centers but not consumers.”

Potential Solutions

This topic may need further assessment before recommendations can be made. While we heard clearly that consumers have not been included in some important discussions regarding how to use measures, it is not clear how extensive this practice is, how extensively it varies from place to place, and whether consumer involvement is always appropriate (such as in private plan–provider negotiations). Understanding the extent of variation from place to place in how open or closed the quality measurement process is could help identify opportunities for greater consumer input. By looking closely at quality measurement processes that have successfully opened doors, consumers might get a better grasp of where there are opportunities to change closed quality measurement processes.

Consumer advocates can take independent action when not invited to the table, by convening their own information-gathering activities and making them known. One consumer advocate described how the consumer perspective was left out of a quality measurement discussion: “We organized focus groups of patients on what kind of measures they would like to have. . . . We will take this back to the panel. This will be an uphill battle.”

Barrier 6: “Dual Focus”

When participating in the quality measurement process, it can be a challenge for anyone to keep track of both the big picture and the details.

The big picture is a challenge of its own: All of the measures that could be adopted have to compete among many other priorities in the quality measurement process. Knowing that clinicians, plans, and health systems cannot adopt every available measure, how do we steer toward a set that is both parsimonious and consumer-centered? Choosing a complete set that takes into account all of the relevant dimensions of quality, including consumer priorities, is a challenge.

The details present a different challenge. Some details of quality measurement may be well understood by consumers, while others are not. For instance, consumers are sometimes asked to wade into waters where they lack expertise—they are not clinicians or statisticians and so may have a hard time figuring out exactly how to specify a

particular measure—but they will have more insight into what is relevant to consumer experiences and what will be understood by their peers.

The challenges described in this barrier relate both to prioritization and to the technical details and implementation of specific measures.

Example 6.1: System Capacity

The quality measurement enterprise is vast; the number of plans, providers, and contracts that need to be scrutinized can be overwhelming. Consumers described challenges related to the capacity of their organizations to participate in this vast enterprise. One consumer advocate told us that,

Capacity [of our state leadership] is an issue. They are dealing with multiple plans and encounter data from the plans that vary in quality. [In one instance], it took long to get the data [because the state] had to go by hand through it to make sure coding was accurate. How will you scale this up?

Example 6.2: Knowing Where to Go But Not How to Get There

Consumers may believe strongly that quality problems in long-term care could be addressed by ensuring that there is meaningful consumer engagement at the health care organization level. To use an analogy, consumers may not have expertise on how to fly a plane, but they know where they want to go and are the only reliable source of information on the experience of getting there. In this case, when existing measures seem inadequate yet there is pressure to define a measure set for use in the near term, what should advocates do?

Example 6.3: Problems Stemming from Measures or Details of Implementation

When developing new measure sets, consumers may come to the table with strong ideas about what is needed. In discussing the impact of primary care, one consumer told us that the measures were wrong for people with disabilities, which created problems when using them in a high-stakes way: “If you ding my doctor because I gained weight this year, it does not reflect that I have had more days this year when I could get out [of the house].” What matters to the consumer advocate in this instance—ability to get out of the house—is a preferred measure for doctor quality.

Another explained how, even when measures were adequate, their usefulness could be constrained by data limitations:

What we’ve seen in our monitoring is that the measures look pretty good—we do not have qualms with the way they’ve outlined the quality measurement—except that we do not think that they’ve required enough in terms of data refinements that would allow us to measure and address

health disparities on an ongoing basis. We think we're lagging on data points that would be a useful tool to help us address disparities.

Potential Solutions

When convening consumers and other stakeholders to participate in a quality measurement process, clarifying the purpose and framework for measurement can help all participants achieve a common understanding of the task and how it fits into quality measurement generally. As one consumer advocate put it,

I do not feel like we have a pro-consumer framework for thinking about measures. We have a doctor framework, a state policymaker framework, but not a vision for what consumer-driven measures would look like. You have to think about what you are measuring for. Are you measuring for plan performance, for monitoring as a government regulator, or are you measuring for consumers to be able to shop?

Recommendations

In this chapter, we synthesize potential solutions identified in Chapter Three into recommendations grouped by our two major audiences. A limitation of our sampling approach is that it is impossible to know whether the recommendations we synthesize are representative of all consumers' views. This is a limitation of findings drawn from any convenience sample. However, we believe the nine recommendations for quality measurement leaders and the four for consumer advocates that are presented in this chapter can help to improve consumer engagement in quality measurement.

Recommendations for Quality Measurement Leaders

Clarify the Goals of Quality Measurement

When convening consumers and other stakeholders to participate in a quality measurement process, it is important to begin by articulating the end goals of the work. Offering information to all participants about both the “big” and the “little” pictures of quality measurement will help to start the process off on the right foot. The big picture includes clearly identifying the position of the current effort within the life cycle of quality measurement: setting priorities, creating measure concepts, specifying measures, testing and endorsing measures, using measures, and maintaining measures. The little picture includes information about the specific stage currently being worked on.

We learned from talking to consumers that many of the efforts they are invited to join are focused on the “using measures” stage, when a selected measure set is chosen for a specific purpose. When working in this stage, it is especially important to be specific about objectives: The reason for using measures in health care directly affects what is measured and how it is measured and reported. It will also be helpful to consider in advance of this stage how consumers might be involved earlier in the process.

Affirm the Importance of Consumer-Centeredness to Their Work

It is helpful to establish a consumer-centered lens. The rationale for involving consumers in quality measurement should be made clear at the outset to every participant at the table. The playing field cannot be level unless both consumers and other stakeholders understand and can describe the special expertise that consumers bring to the table: Consumers are experts in their own preferences and experiences. This kind of expertise is critical to the success of consumer-centered quality measurement and should

be acknowledged throughout the course of choosing, validating, implementing, and assessing quality measures.

A common pitfall is the unintentional undermining of consumer voices throughout the course of a quality measurement project. For instance, when a multistakeholder panel is described repeatedly as a group of technical experts and patients, the implication—intended or not—is that consumers are not experts who can play on an equal field. When this tone arises frequently in a quality measurement process, the work may be shaped by the “experts” and therefore emphasize policy, provider, or researcher priorities. All of these perspectives are valuable, but if they eclipse consumer priorities, measurement efforts may misalign with consumers’ needs and lose their endorsement.

Emphasize Openness to New Views

When opportunities to prioritize areas for measure development arise, policymakers, providers, health plans, researchers, and other stakeholders in the process should signal their preparedness to hear what consumers say about the concerns they have and the types of measures they would most like to see. Specifically, leaders of a quality measurement effort should remain open to concepts that might be challenging to develop into measures (e.g., because few legacy measures exist) but that are meaningful to consumers. Newer measures might round out the existing set. These include measures of patient experience, consumer choice and control, and quality of life.

Offer Financial Support

The involvement of consumers is easier to sustain when consumers are compensated for their time and reimbursed for their expenses. This enables a consumer to join discussions without the opportunity costs of missed income or other important pursuits. The *advocate* who represents other consumers requires time and support to get the lay of the land, meet the players, understand the content areas, and see the whole quality measurement process from start to finish. This is especially important because the time frame of measure development can last so long.

Quality measurement organizations and institutions might consider sustaining consumer engagements not only over the terms of individual projects, but over even longer terms covering many projects. Consumers lack an analog to professional societies that work over a period of decades to participate in the prioritization, development, specification, testing, and use of measures. Building this key piece of infrastructure—which could also serve as a source of technical expertise to consumer advocates nationwide—could improve the consumer-centeredness of quality measures.

Just like other stakeholders, consumers have an interest in seeing their work and contributions result in change. Who pays for this and where the resources come from is a

challenge just like other challenges in the quality measurement process, all of which require money and resources.

Ensure Adequate Consumer Representation

Establishing balance in the representation of consumers and other types of stakeholder groups is critical, including both the weight of consumer voices relative to others in a multistakeholder panel and to the diversity of consumers who are brought to the table.

Consider how many consumers have been invited to participate. Will consumer voices be drowned out because they are underrepresented in a large group discussion? If input is being solicited in a public meeting, will stakeholders with a financial interest in the outcomes of the meeting be represented in disproportionately large numbers? If so, it may help to ensure attendance of an equally large group of consumers who can articulate their preferences and experience to the community at large. Some of the most vulnerable or marginalized communities may face the greatest challenges in getting their voices heard. While long-standing relationships with community organizations can help in determining whom to invite and how to get them there, it is important to note that the location, timing, level of effort, and format of participation will influence who is willing and able to attend.

It is also important to ensure that a diverse set of consumer viewpoints is represented on stakeholder groups or expert panels. Quality measurement leaders should support consumer advocates to solicit input from their constituencies. These consumer organizations bring expertise, skill, and relationships that have enabled them to support the voices of consumers and communities. For example, one advocate reported that to inform their perspective on patient experience and satisfaction surveys, “We worked with consumers to do focus groups around what kind of input patients wanted to have in their care.” In another example, a consumer advocate invited a stakeholder committee to a consumer forum to hear directly from consumers about the different payment models and how such models would affect consumers. Another advocate used weekly conference calls with members to share information and hear feedback.

Involve Consumers Early

It can be especially valuable to invite consumers to weigh in from the beginning of quality measurement process, when other decisionmakers and stakeholders are invited. Consumers know what their own concerns are, and their concerns are especially relevant when selecting priorities for measurement, the first stage of the life cycle. Not involving consumers at this stage leaves them out when they can perhaps be most helpful.

Train Consumers and Offer Technical Assistance

Quality measurement leaders, managers, and consumers can work together to offer additional support and resources that prepare consumers for their involvement. Additional support might include codeveloped training in the fundamentals of quality measurement, holding a peer-led planning meeting to prepare for interaction with other stakeholders, or other activities.

Specifically, consumers need to know why quality measurement is needed and who conducts the work, along with the major stages, the right time to engage, and how consumers can be involved.

Further, consumers would benefit from access to real-time technical assistance and support to help them advocate their priorities. This includes advice about available measure concepts and measures and technical information to help advocates respond to the challenges that are brought up when they propose use of particular measure concepts or measures. Consumers also could benefit from peer-to-peer support in understanding how to be more effective in this challenging environment.

Develop Tools to Support Ongoing Consumer Input

Like any activity in health care, consumer involvement can become unnecessarily resource-intensive for both developers and consumers if attention is not given to efficiency and process improvement. Quality leaders should partner with consumers to look for opportunities to develop tools and resources that support ongoing consumer input that is rapid and efficient, and they should review existing processes to understand how these could be changed to overcome barriers to consumer participation. Examples include electronic platforms for recruiting, connecting, and involving consumers; establishment of an infrastructure that enables measure developers to consult with a permanently established network of consumers; and gaining consumer input through interviews, focus groups, and partnerships with consumer organizations. With all of these approaches, it will be important to assess their ability to engage hard-to-reach populations.

Assess and Learn from Experience

Consumers and quality leaders cannot assume that every attempt to involve consumers in the quality measurement enterprise will be a success. Whether due to mistakes in the design of the engagement plan or to circumstances beyond the control of the actors, things can go wrong. Those who have advocated consumer involvement in health care do so because it can improve relationships between health care professionals and consumers and because it has the potential to create far-reaching changes in the delivery system. However, consumer involvement requires money and resources, can be

challenging and frustrating, and may sometimes even seem to set a program backward a few steps.

The path to reaping hoped-for benefits of consumer involvement is littered with pitfalls and challenges. One of these is the external time line that is often imposed by policymakers who are not involved in the process at a local level. Time lines and budgets are critical to ensuring the success of any effort, but may also represent external constraints that put so much pressure on the process that consumer involvement becomes a resource cost that local leaders cannot afford. Measure development contracts may be structured to allow “no option but forward” in measure development, even when an approach that is more consumer-centered would favor revisiting an earlier step in the measure development process.

To maximize chances of success, quality leaders might approach these challenges like any other in health care, by committing to a continuous process of assessment and learning from experience. Leaders should support independent assessments of the impact of consumer and stakeholder engagement activities. Further, the assessment should point to changes that can be implemented to improve the outcomes of consumer involvement each time a new effort is undertaken.

Recommendations for Consumer Advocates

Focus National Attention on Consumer-Centered Quality Measurement

Our discussions with consumer advocates underscored that most of their involvement is focused on a later stage of quality measurement, specifically on the “using measures” stage. Starting consumer involvement at (or limiting it to) this stage misses out on an opportunity to involve consumers where their perspectives may be most valuable. Consumer involvement is needed to ensure that the quality measurement enterprise is addressing consumers’ highest priorities.

Consumer advocates can support measure development around consumer-centered priorities by engaging in national conversations around priorities and pushing for the research needed to drive measure development in these priority areas. However, there is a core piece of infrastructure that is needed to truly advance consumer-centered quality measurement. We note the absence of a national consumer equivalent of the national provider, payer, industry, and policy associations that focus on quality measurement. As a result, it can be difficult for consumers to contribute to measure concepts that ultimately move into the later steps of measure development. Such a national consumer organization could look critically at the quality measurement enterprise as a whole and understand where changes to the system and the “ground rules” might facilitate more-effective consumer involvement on an ongoing, long-term basis.

Assess the Extent to Which Quality Measurement Processes Are Open or Closed to Consumers Nationally

While we heard clearly that some quality measurement discussions are closed to consumers, it is not clear how extensive this practice is or how extensively it varies from plan to plan or from provider to provider. Understanding the extent of variation in how open or closed the quality measurement process is could help clarify where the opportunities are for more consumer input. It is possible that in many instances (e.g., negotiations between health plans and providers), consumers are not explicitly excluded, but working without consumers is viewed as the natural way of doing business. By looking closely at quality measurement processes that have successfully opened doors, consumers might know better where there are opportunities to change closed quality measurement processes.

Convene Independent and Public Reviews

Consumer organizations can take independent action when not invited to the table by convening their own information-gathering activities and making them known. One consumer advocate described organizing focus groups of consumers after being excluded from a quality measurement process. They asked consumers what kind of measures they would like to have and planned to publicize the results. Other activities might include convening a town hall meeting, hosting conference calls with a membership base, and inviting online feedback. This strategy can be effective even when the process is friendly; it can help to send individual representatives to a public meeting armed with information about what their community says is most important.

Build and Share Knowledge and Technical Expertise

Consumers contributing to quality measurement often have similar priorities and face similar challenges. Technical assistance and peer-to-peer learning can help consumers successfully make the case for consumer-centered priorities, measure concepts, and measures. Because the effort involved to “get up to speed” to feel comfortable in quality measurement arenas can be significant, it is important for consumers to have opportunities to share information, draw from a clearinghouse of customized resources, and be able to tap expert advice on performance measurement when needed. Even as consumers “learn the rules,” they also have an important role to play in assessing and challenging those rules when they prevent meaningful consumer engagement.

Appendix

Discussion Questions for Representatives of Consumer Advocacy Organizations

1. Can you describe any experiences you have had with quality measure development and implementation?
2. Where or from whom have you typically heard about opportunities to work on quality measurement?
3. From your organization's standpoint, what aspects of your involvement in quality measurement have gone best? Why?
4. From your organization's standpoint, what aspects of your involvement in quality measurement have been most challenging? Why? Where have problems arisen?
5. When existing measures do not cover an aspect of care that is important for your organization, what do you do?
6. When participating in quality measurement activities, have you been able to gather and communicate input from the entire community?
7. *Probe:* Are you limited to giving input from organizational leaders? If so, what are the factors that create this limitation?
8. For your organization, has the time and effort you've spent engaging with the quality measurement process been worth the investment?
9. Is there anything else you would want quality measurement leaders and stakeholders to understand about how to engage with patient and community organizations like yours?

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Abbreviations

AHRQ	Agency for Healthcare Research and Quality
CMS	Centers for Medicare and Medicaid Services
DHHS	Department of Health and Human Services
IOM	Institute of Medicine
MHQP	Massachusetts Health Quality Partners
NCQA	National Committee for Quality Assurance
NQF	National Quality Forum
NQMC	National Quality Measure Clearinghouse
NQS	National Strategy for Quality Improvement in Healthcare (or National Quality Strategy)
P4P	pay for performance
PCORI	Patient-Centered Outcomes Research Institute
TEP	technical expert panel

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