

Empowering New Yorkers with Quality Measures That Matter to Them

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Executive Summary

The health care consumer who needs information to help choose a new health care provider is in a tough spot these days. Frequent changes in health plan benefits, provider networks, and rising out-of-pocket costs mean that many New Yorkers will need to find new physicians at a time when they have more “skin in the game” and must pay more for the health care services they use. But relevant information, which could help consumers identify quality and price differences and find providers who match their needs, remains elusive.

Quality measurement and public reporting are attracting more and more attention as the U.S. health care system undergoes rapid change and increasingly focuses on reducing the costs associated with unnecessary care. However, even as quality measurement becomes integral to health care improvement and reform efforts, most quality measures focus on the technical and clinical dimensions of health care. Aspects of quality that the public finds meaningful, such as patients’ experiences with care and how well clinicians communicate, have received far less attention and investment by measure developers and evaluators.

To better understand what quality information is currently available, what information consumers want, and the gaps between the two, the United Hospital Fund (UHF) Quality Institute engaged in a 15-month inquiry supported by the New York State Health Foundation. Along the way, we identified and documented shortcomings in quality measurement and reporting, as well as barriers and opportunities for empowering New Yorkers with information that could help them make health care decisions.

Research has shown that for quality information to be meaningful to consumers, it must be relevant to health care decisions they or their families need to make, provide comparisons at the right level of detail, and take into account distinct priorities and information preferences.

Quality Information That Consumers Value

Characteristic	Examples
Condition-Specific Information	Five-year survival rate by stage for prostate cancer
Clinician-Level Information	Reputation, expertise, credentials, history of legal actions
Patient Experience and Patient-Reported Outcomes	Communication skills, respect, compassion, ratings by patients in similar circumstances, quality of life
Structural and Service Quality Attributes of a Practice	Health insurance plan participation, ease of access, HIT capabilities, cleanliness, helpful office staff
Characteristics of the Information Itself	Plain language, avoidance of acronyms, timeliness, ability to customize

An expanded version of this table appears as Table 1 in the report.

However, few public reports or websites enable consumers to customize their search for quality measures. In essence, the measures and tools we have lack the precision to be of much help to consumers.

While conducting internet searches from the perspective of a consumer seeking performance results on quality measures for hospitals or physicians in New York, search engines led us to a confusing array of websites. Many were difficult to navigate and understand, and the quality measures they provided were often neither current nor able to address the individual circumstances that would lead a consumer to seek quality information. It's no wonder that few consumers use quality measures and instead continue to rely on recommendations from family, friends, and their regular physician.

During the course of our project, we scanned more than 70 websites and cataloged the quality information we found on a smaller group of 32 websites for 10 common conditions and surgical procedures. The following findings were among the most striking:

- Most of the quality measures on websites provided overall performance results on clinical outcomes rather than the patient experience. The information was presented in highly technical language and not designed for a broad consumer audience.
- Performance data were seldom current and often several years old. Timely performance data, of greatest use to both consumers and clinicians, were rare.
- Websites commonly lacked condition-specific and clinician-specific quality measures, which are of great interest to consumers. Condition-specific patient experience measures, also important to consumers, were almost non-existent.
- Few websites provided information about legal actions or malpractice.
- None of the websites posted measures or quality information in languages other than English.

Based on our findings, we identified several types of measures that hold promise for informing consumer choice. These included condition- and clinician-specific measures; patient experience measures and patient reviews or narratives; patient-reported outcome measures such as quality of life and physical, emotional, and social function; and shared decision-making. Yet until quality measures can be translated for a wide range of people including older adults and people with multiple chronic conditions, low literacy and numeracy skills, and limited English proficiency, uptake will remain limited with little chance of aiding decisions.

We also pinpointed other barriers that will need to be addressed if New Yorkers are to become empowered health care consumers:

- Insufficient awareness among New Yorkers that quality varies across providers and care settings, and that quality information can help them identify better and safer sources of care.
- A lack of uniform standards or other approaches to tackle the inconsistent quality of quality information on websites including the measures themselves, as well as underlying methods and data sources that are not transparent.
- The longstanding imbalance in access to quality data among the health care system's key stakeholders.
- The need to shift the measurement field's focus toward the types of measures that resonate most with consumers.
- The relative newness of the quality measurement field, which has been underfunded, limited by available data, and driven by the priorities of payers, providers, and regulators.
- Above all, a failure to involve consumers in decisions about quality measurement and reporting.

This report underscores the deficiencies and deep gaps in quality measurement that can inform consumer choice. It also makes clear that the dramatic growth of websites and public reporting has exacerbated rather than solved the problem. While advances in technology over the next several years may bring new solutions, this report advances five strategies that hold promise for making progress now:

- Simplify quality information and prioritize the elements that interest consumers.
- Provide support to help consumers, patients, and families find and use reliable information.
- Integrate quality information from public and private sources.
- Create a standard set of measures for choice and incentivize its use.
- Innovate to advance new measures, tools, communication vehicles, and partnerships—and start by involving consumers at the outset.

As New York's health care system reform continues, consumers should not have to wait for the next generation of quality measures and "the market" to help them avoid providers that are a poor match for them. While there are no simple solutions, the strategies and findings in this report should be of interest to a

range of stakeholders who can help advance awareness of measures that matter to consumers, and perhaps even incentivize their adoption and use. Potential partners in this effort include the New York State Department of Health, payers operating in New York State, consumer advocates, the provider community, organizations involved in measure development and endorsement, sponsors of websites that provide quality information, and technology innovators.

Despite much hype, the age of the activated and information-empowered consumer, who can drive markets toward high-value providers, has not yet arrived.* As movement toward measures that are meaningful to patients and caregivers gains traction, measures for choice should be elevated and New York's consumers, patients, and families should be at the center of the conversation.

*For a comprehensive analysis of the origins and evolution of medical consumerism and why it cannot fix our broken health care system, see Tomes, N. *Remaking the American Patient: How Madison Avenue and Modern Medicine Turned Patients Into Consumers*. UNC Press Books, 2016.

Introduction

Over the last two decades, there has been dramatic growth in quality measurement and public reporting. Current quality measures, however, tend to focus on the technical or clinical aspects of health care, which do not match the information consumers look for when making decisions about where to seek care. More importantly, quality measurement and public reporting have not helped create much awareness among New Yorkers that quality of care varies among providers,^{1,2,3} or that they can seek out quality comparisons to help them choose better, safer care. To put it simply, most existing quality measures do not empower consumers—or even engage them.ⁱ

To explore this disconnect and its implications for consumer choice in New York, UHF's Quality Institute embarked on a project supported by the New York State Health Foundation (NYSHHealth) to examine what quality measures are publicly available, what quality information consumers prefer when choosing health care providers, and the gaps between the two. Our aims were to:

- better understand deficiencies in current quality measurement from a consumer perspective,
- identify measures that could help promote consumer choice,
- consider how aspects of care that consumers value might be included in measuring quality, and
- raise awareness of the nature of the gaps for informing decisions about quality measurement and reporting in New York State.

We began our inquiry in the fall of 2016 by reviewing the literature on public reporting of quality measures and consumer perspectives about quality measurement. We then interviewed experts in quality measurement (see Appendix A for a list of the experts interviewed and topics covered). With input from NYSHHealth, we formed a 17-member advisory group, which met twice during the project and provided feedback on our approach, findings, and recommendations (see Appendix B for a list of advisors). To better understand the types of quality measures for hospitals, practices, and physicians that New York consumers can access, we cataloged measures for 10 conditions on 32 websites.

The remainder of this report describes findings from the UHF Quality Institute's analyses and presents recommendations for advancing quality

ⁱ In this report, we use the term "consumers" broadly to include patients, family members, and caregivers. While cost and quality are both important aspects of value for consumers to consider in health care decisions, this report focuses specifically on quality. We also use the terms "performance data" and "quality measures" interchangeably, although we recognize that quality measures themselves are the basis for assessing, reporting, and comparing provider performance.

measures that are more closely aligned with the information that consumers prefer and value when searching for a health care provider.

Methods

To learn about quality measures that are publicly available to New Yorkers, UHF's Quality Institute scanned more than 70 websites. Even for people with expertise in quality measurement and improvement, this was no small feat.

To narrow the universe of websites to a smaller sample, we selected a group of 32 sites, including those sponsored by New York State Department of Health (NYSDOH), Centers for Medicare & Medicaid Services (CMS), health systems and payers operating in New York, commercial firms, and media. Seven websites from other states were included as models for quality information available to consumers outside of New York. Most of the measures came from commercial websites, medical societies, and national and state agencies. Much of the underlying data for these measures came from proprietary sources, making it challenging for consumers to compare across health systems and providers.

To select the conditions, we adapted an existing framework⁴ that identified four contexts representing key decision points when people are motivated to seek providers and information about medical conditions. We used two of the framework's contexts—shoppable treatments and serious chronic conditions—and added a third for a new diagnosis of cancer.

To illustrate the three contexts, we selected 10 common acute and chronic conditions and inpatient and ambulatory procedures based on state and national prevalence and utilization data:

- | | |
|-------------------------------------------------|-----------------------------------|
| 1. Asthma | 6. Congestive heart failure (CHF) |
| 2. Breast Cancer | 7. Diabetes |
| 3. Cataract Surgery | 8. Prostate Cancer |
| 4. Cholecystectomy | 9. Total hip replacement |
| 5. Chronic obstructive pulmonary disease (COPD) | 10. Total knee replacement |

The process of developing a catalog (database) of quality information for 10 conditions across 32 websites is described in Appendix C.

Results

A Crowded Landscape: Where Can New Yorkers Find Quality Measures?

New York consumers who are motivated to search for quality measures can find this information on a confusing array of websites. The large and growing number of sites on the internet pose barriers to navigation and interpretation even for sophisticated consumers. Below, we trace some potential paths for consumers who are searching for quality data about health care providers in New York.

For *hospital-level measures*, many consumers might start with their health plans to determine which hospitals are in their network. They can then learn more about hospital quality and compare performance by visiting CMS Hospital Compare, the NYSDOH Hospital Profile, Leapfrog, IPRO's *Why Not the Best*,

Consumer Reports, *U.S. News and World Report*, Healthgrades, health system websites, and others. They can also view social media sites for additional information about hospitals from their peers, including Crowd Clinical, Yelp, and Facebook.

For *physician-level measures*, New Yorkers can start with their health plan's website for a list of in-network physicians. Next, they can search the NYSDOH Physician Profile and Office of Professional Medical Conduct (OPMC). The NYSDOH Physician Profile includes information for

all licensed physicians and doctors of osteopathy who are registered to practice in the state.ⁱⁱ The OPMC website provides information about disciplinary actions and charges of misconduct for several types of clinicians.⁵ New Yorkers can also search the CMS Physician Compare website, which provides performance data from 2015 for group practices and individual physicians participating in Medicare's Physician Quality Reporting System (PQRS), although data for individual physicians is sparse. CMS plans to publicly report additional, physician level performance results on quality measures through Medicare's new Merit-Based Incentive Program (MIPS).⁶

For *patients' ratings and reviews*, there are several options—e.g., “disruptor” sites such as Yelp, Healthgrades, Zocdoc, Vitals, and RateMDs; some health system websites in New York, such as Northwell Health and Mount Sinai

“Even a highly motivated consumer will abandon a search for information if it is difficult to find or understand.”

—Yegian JM, P Dardess, M Shannon, and KL Carman. Engaged Patients Will Need Comparative Physician-Level Quality Data and Information about Their Out-of-Pocket Costs. *Health Affairs* 32(2): 328–37, 2003.

ⁱⁱ Although NYSDOH published the first surgeon-specific mortality report in the nation in 1992 (for cardiac surgery), the only outcome data for individual physicians that currently appear on its website are for cardiac surgery and percutaneous coronary interventions.

Health System, also report ratings on their physicians. Northwell Health has gone a step further and posts patient comments as well.

For *quality information on chronic illnesses*, patients can visit websites of disease-related organizations such as the American Diabetes Association and find information through patient networks, chat rooms, and forums on PatientsLikeMe, Reddit, and others.

A recent survey and series of focus groups in New York found that most consumers start a search on Google⁷, the world's most popular search engine. However, advertising, branding, and algorithms play a role in what they find there and where they click next. And there are concerns about the transparency, accuracy, and reliability of the measures, ratings, and reviews on some of the commercial sites that consumers visit most.

What Kinds of Quality Measures Do Consumers Prefer?

First, we learned that consumer needs and preferences vary when it comes to quality measures. Consumers are not all the same—some prefer to review highly detailed quality measures and other quality-related information when making care decisions, others less or none at all. For example, certain consumers may be concerned about hospital safety and infection rates, but most others are not and would not seek out this information before choosing a hospital for care not urgently needed.

“Consumers are rarely aware of official quality comparisons, such as safety or patient satisfaction ratings. This is especially true for lower-income consumers.”

—Altarum Institute, Oliver Wyman, and Robert Wood Johnson Foundation. *Right Place, Right Time*, January 2017.

Second, context and customization matter.^{8,9} For quality information to be meaningful to consumers, it must be relevant to a health care decision they need to make, enable performance comparisons at the right level of detail, and consider that consumers' priorities and information preferences vary. Yet few public reports or websites enable consumers to customize their search for quality measures based on their priorities.

Third, relationships and interpersonal skills matter. For example, how clinicians listen to and communicate with patients and families, show respect, and convey compassion factor prominently in consumers' understanding of quality.ⁱⁱⁱ A body of research demonstrates that consumers prefer information based on patients' experiences interacting with physicians and hospital staff, rather than process- and outcome-based measures of performance.^{10,11}

ⁱⁱⁱ However, research has also shown differences by race and ethnicity in how Medicare patients experience hospital care. Collins RL, A Haas, AM Haviland, and MN Elliott. 2017. What Matters Most to Whom: Racial, Ethnic, and Language Differences in the Health Care Experiences Most Important to Patients. *Medical Care* 55(11): 940-947, doi: 10.1097/MLR.0000000000000804.

Table 1 summarizes other key findings about the types of measures and dimensions of quality that consumers value.

Table 1. Quality Information That Consumers Value

Condition-Specific Information	
<ul style="list-style-type: none"> • Condition- or procedure- specific performance data at the clinician level^{12,13} 	<ul style="list-style-type: none"> • Treatment risks and options¹⁴
Clinician-Level Information	
<ul style="list-style-type: none"> • Reputation (e.g., lists of top providers, professional opinions) • Expertise and credentials (e.g., education, training, and board certification) • Demographics (e.g., age, gender, ethnicity) 	<ul style="list-style-type: none"> • Hospital affiliation • History of legal actions • Languages spoken • Photo • Physician statement/video
Patient Experience and Patient-Reported Outcomes	
<ul style="list-style-type: none"> • Doctors or other health care providers who spend time with me and do not rush¹⁵ • Doctors who listen and show they care about me¹⁶ • Doctors who clearly explain what they are doing and what I need to do later¹⁷ • Someone who treats me with respect • Someone who has compassion • Someone who is kind, caring, comforting • Someone who involves and shares information with my family members 	<ul style="list-style-type: none"> • Someone who uses plain language • Someone who communicates with me, not over me¹⁸ • Someone who presents information to me in a culturally relevant and sensitive way¹⁹ • Measures (e.g., functional, quality of life indicators) relevant to the patient’s condition that can aid treatment decisions²⁰ • Ratings and reviews by patients in similar circumstances
Structural and Service Quality Attributes of a Practice	
<ul style="list-style-type: none"> • Health insurance plan participation • Access (e.g., scheduling an appointment easily, convenient office hours, minimal wait times) • HIT capabilities (e.g., online appointments, portal access to medical record information, email/text communication) 	<ul style="list-style-type: none"> • Cleanliness • Helpful and friendly office staff • Care team members who treat each other with respect • Amenities (e.g., parking, access to public transportation)
Characteristics of the Information Itself	
<ul style="list-style-type: none"> • Measure labels and explanations in plain language, with visuals to represent data²¹ • Simple, clean formatting with limited information on a page²² 	<ul style="list-style-type: none"> • Avoidance of acronyms • Timely information

What Measures Are Available?

Quality Measures

A total of 462 measures were identified from the catalog analysis. We drew some general observations about the measures we found:

- In the majority of cases, when quality measures were reported, not all were geared towards consumers; the measures were expressed in technical language without contextual or easy-to-understand explanations and possibly above consumers' literacy and numeracy levels.
- Types of measures^{iv} found varied by condition but were mostly clinical outcome measures that focused on mortality, readmission, or complication rates.
- Except for the patient comments, all of the measures reported were at the hospital or practice level, not at the clinician level.
- A large portion of the patient experience measures, which we found on only 12 of the 32 websites, were from Consumer Assessment of Healthcare Providers and Systems (CAHPS®)^v surveys or modifications of CAHPS (such as the Hospital Consumer Assessment of Healthcare Providers and Systems, or HCAHPS).
- Breast cancer was the only condition that had patient experience measures.
- Data found on most of the websites were not current and often several years old, and the frequency of updates was unclear.
- Data sources included a mix of public and proprietary information. Although public information is easier for comparing across health

^{iv} **Structural measures** give consumers a sense of a health care provider's capacity, systems, and processes to provide high-quality care. **Process measures** indicate what a provider does to maintain or improve health, either for healthy people or for those diagnosed with a health care condition. **Outcome measures** reflect the impact of the health care service or intervention on the health status of patient. **Patient-reported outcome measures (PROMs)** include any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else. **Patient experience measures** encompass the range of interactions that patients have with the health care system, including their care from health plans, and from doctors, nurses, and staff in hospitals, physician practices, and other health care facilities. (Agency for Healthcare Research and Quality. "Types of Quality Measures." Content last reviewed July 2011. <http://www.ahrq.gov/professionals/quality-patient-safety/talkingquality/create/types.html>; U.S. Food and Drug Administration. "Guidance for Industry. Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims." Federal Register 2009; 74(35):65132-133; Agency for Healthcare Research and Quality. "What Is Patient Experience?" Content last reviewed March 2017. <http://www.ahrq.gov/cahps/about-cahps/patient-experience/index.html>)

^v The CAHPS program is funded and overseen by the U.S. Department of Health & Human Services, Agency for Healthcare Research and Quality (AHRQ). AHRQ grantees and contractors develop and maintain the CAHPS surveys, which measure patient experience in a range of health care settings—including hospitals, nursing homes, home health care, clinician and group practices, and others.

systems and providers, proprietary information can provide new insights into aspects of quality where public measures do not exist.

- Provider characteristics that represent structural aspects of quality and are also important to consumers were found on multiple websites (e.g., providers' medical education, board certification, and training).

Many of the measures found did not focus on specific conditions but instead on overall performance. These included patient experience measures (at the hospital and group practice level) as well as outcome measures such as patient safety indicators and health care-associated infection rates (see Figure 1).

Several measures for each condition overlapped and came from the same data source. Those measures that did focus on specific conditions were mostly outcome measures, and we found very few condition-specific patient experience measures (see Figure 2).

Figure 1. Quality Measures by Type (n=462)

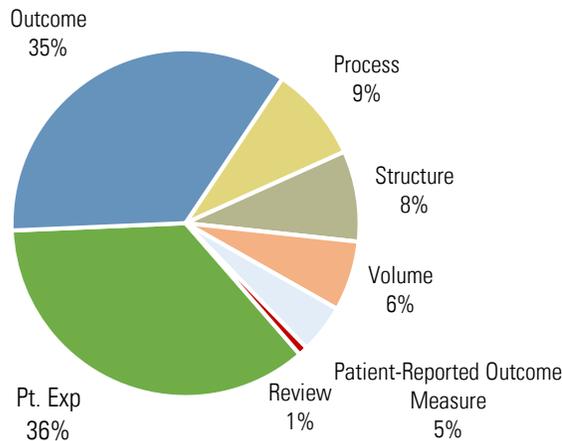
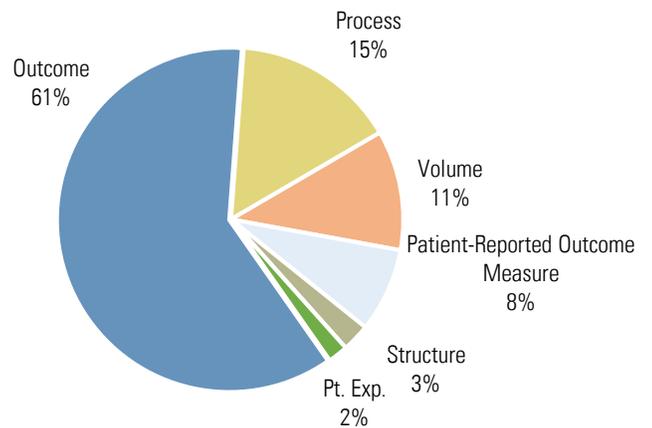


Figure 2. Condition-Specific Quality Measures by Type (n=266)



There were differences in the number and types of measures found for each condition (see Figure 3).

Across the 10 conditions we looked at, hip and knee replacement procedures had the most measures and asthma and cataract surgery had the fewest. Hip and knee replacement had a few patient-reported outcome measures, while asthma had one. Breast cancer was the only condition with several measures of patient experience. There were few volume measures across the websites.

Figure 3. Types of Measures by Condition

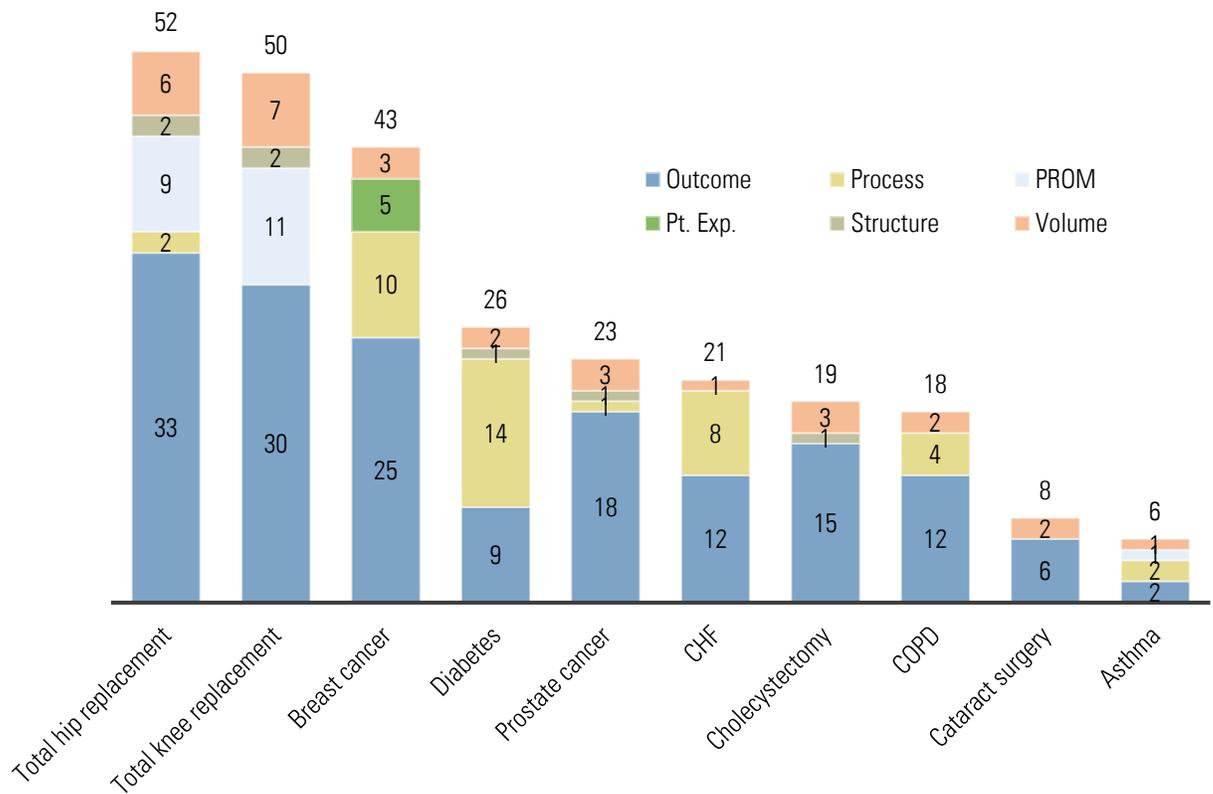


Table 2 displays some examples of condition-specific measures that might help consumers compare the quality of care across providers. Most of these measures are at the hospital level and are outcome measures, except for the asthma and knee replacement measures that are patient-reported outcome measures. The cancer measures come from hospital registry data. There is an example of a patient experience measure for a condition (breast cancer). Additional measures from the catalog that appear promising are included in Appendix C (Appendix Table 4).

Table 2. Examples of Consumer-Centric Measures by Condition

Condition	Website	Measure	Measure Level	Source (National Quality Forum #)
Asthma	Cleveland Clinic	Asthma Control Improvement	Hospital	American Academy of Allergy, Asthma, and Immunology
Breast Cancer	Beth Israel Deaconess Medical Center	5-Year Observed Survival Rates by Stage	Hospital	Beth Israel Deaconess Medical Center
Breast cancer	Beth Israel Deaconess Medical Center	Sensitivity to personal needs and concerns	Facility	Press Ganey
Cataract Surgery	Physician Compare	20/40 or Better Visual Acuity within 90 Days Following Cataract Surgery	Physician	American Medical Association-convened Physician Consortium for Performance Improvement (NQF #0565)
Cholecystectomy	Cleveland Clinic	30-Day Readmission Rate, Inpatient Laparoscopic Cholecystectomies	Hospital	Cleveland Clinic
Chronic Obstructive Pulmonary Disease	Hospital Compare	Death Rate for COPD Patients	Hospital	Centers for Medicare & Medicaid Services (NQF #1893)
Congestive Heart Failure	NYSDOH Hospital Profile	Heart Failure Mortality Rate	Hospital	Agency for Healthcare Research and Quality (NQF #0258)
Diabetes	Minnesota Healthscores	Optimal Diabetes Care	Practice	Minnesota Community Measurement (NQF #0729)
Prostate Cancer	Roswell Park Cancer Institute	Five-Year Survival, Prostate Cancer by Stage	Hospital	Roswell Park Cancer Institute
Total Hip Replacement	NYSDOH Hospital Profile	Hip Replacement Surgery Infections	Hospital	New York State HAI Report
Total Knee Replacement	Hospital for Special Surgery	Recovery following Total Knee Replacement Activities of Daily Living (2 Years After Surgery)	Hospital	Hospital for Special Surgery

Website and Provider Characteristics

None of the websites posted measures or related quality information in languages other than English. Only two of the 32 websites provided any information about legal actions or malpractice. Just four posted patient comments online, with relatively few comments per provider.

Table 3 provides details on the quality information that was easier or harder to find on the 32 websites that were cataloged. Easier-to-find information included: providers' medical education, residency, board certification, practice locations, and photo.

Table 3. Quality Information That Consumers Seek

Characteristic	Ease of Obtaining Information*
Measurement information	
Data source	Difficult
Data year	Difficult
Data frequency of update	Difficult
Information in another language	Difficult
Methodology	Difficult
Practice information	
Health plans accepted	Difficult
New patients accepted	Difficult
Provider information	
Certification	Easy
Demographics	Difficult
Hospital affiliations	Difficult
Languages spoken	Difficult
Legal action and malpractice	Difficult
Medical education and residency	Easy
Photograph	Easy
Practice locations	Easy

*Based on the proportion of websites that provided the characteristics; "difficult" meant fewer than half of the websites had this information and "easy" meant more than half did.

Gap Analysis

To identify other condition-specific measures apart from the ones cataloged, we scanned other sources of quality measures including the websites of medical societies and measure stewards, and existing core measure sets. We then created a list of "gaps" and found 91 additional condition-specific measures. While many of the additional measures found were from registry data and can be useful for quality monitoring and improvement, they are not designed to inform consumers. Upon review of those measures, only 18 seemed relevant to consumers (see Appendix C, Appendix Table 5).

In summary, our review of the literature, interview synthesis, advisory group input, and findings from the catalog and gap analyses suggests several types of measures could help fill these gaps and inform consumer choice. These include:

- Condition- and clinician- specific measures that could, for example, help a patient with asthma find performance data on clinicians who treat asthma.
- Clinician-level characteristics such as reputation, expertise, credentials, demographics, hospital affiliation, and others.
- Patient experience measures coupled with patient reviews or narratives.
- Patient-reported outcomes such as quality of life and physical, emotional, and social function.
- Shared decision-making.

However, several of these measure types have not been broadly adopted and require significant or continued development.

Discussion

UHF Quality Institute’s analysis illustrates the chasm between much of the quality data that are currently collected and reported, and the measures that interest consumers.^{23,24,25,26}

Explaining the Gaps

Several factors may help explain how we ended up with quality measures that do not meet the needs of health care consumers.

Specific Reasons to Search. Consumers tend to seek out information about provider quality when they have a particular need. However, the types of quality measures that are publicly reported are often not relevant to their circumstances.

Physician-Level Information. Although consumers think about and understand quality largely through the lens of their relationships with

physicians, few public performance reports provide results for individual physicians. Because consumers prefer condition- or procedure-specific information for individual physicians,^{27,28} other commercial sources, such as *U.S. News and World Report*, Healthgrades, Amino, and Yelp, have set their sights on filling this gap.

Diffuse Data. Comparative quality measures for both hospitals and physicians are scattered across the internet, and search engines can be a blunt tool for leading consumers to the specific information they

seek. Trying to locate and cull information from multiple websites can stump or overload even the savviest consumers.

User Interface. Consumers who are willing to travel on circuitous, information-seeking journeys can easily get stuck after arriving on a website. It can take many clicks to find quality measures, and the search for measures relevant to an individual’s condition or situation can prove frustrating or even fruitless. Those who do succeed often find quality measures that are described or displayed in highly technical language. Further, low literacy and numeracy skills can seriously limit a consumer’s ability to interpret quality information. Those who are not proficient in English are especially disadvantaged given the dearth of quality information available in other languages. Until measures can be translated for diverse populations, they stand little chance of aiding consumer choice and informing decision-making.

“The fundamental physician-patient relationship remains the core of a patient’s understanding of medical care.”

—Sofaer S, E Humphrey, L Koester, and M Mannon.
Best Practices in Transparency and Public Reporting for Wisconsin Public Employees.
American Institutes for Research, May 2015.

Influence and Consumer Skepticism. The “quality” of quality data currently on the internet is highly variable. Search engine optimization and algorithms strongly influence what a consumer finds, and some websites, while created to promote specific health care services or providers, can appear to be neutral to internet users. The sheer number of providers who promote themselves as “the best,” provider ratings that are inconsistent across websites, measures that seem aimed at reducing services or costs of care, and lack of transparent data sources all raise red flags for consumers. Many commercial sites are supported by advertising revenue from the providers they rate and are not transparent about the perceived or actual conflicts of interest that may underlie this approach.

The potential for hidden influence may be contributing to consumer skepticism of quality information on the internet. However, some surveys have found that Americans also lack trust in reliable sources of provider performance data—for example, quality information provided by state and federal agencies, medical societies, employers, and health insurance plans.^{29,30,31} It seems clear that consumers are uncertain about where to find meaningful and reliable information that can be trusted for choosing providers. This may help explain why they continue to rely on provider recommendations from family, friends, and their regular physician.^{32,33,34}

The State of the Art of Measurement Science. Measurement development is underfunded and has been limited by lack of access to proprietary data. Most of the investment in developing quality metrics has been devoted to assessing technical aspects of health care quality and facilitating clinical improvements such as hospital-wide mortality, infection, and complication rates. Other aspects of quality, such as patient experience and patient-provider relations, have received far less attention despite their obvious salience to consumers. More reliable and valid composite measures are needed to simplify provider performance results for consumers. Adequate sample size remains a barrier to measuring quality at the individual physician level—this is true for outcome and patient experience measures, as well as ratings and reviews. Timely performance data, which are most useful to consumers and providers, are rare.

System Barriers. There is a lack of consensus and perhaps even political will around measurement reform, and many stakeholders have vested economic interests. Much of the investment in quality measurement to date has been made by the government, but public funding has its limits.

Failure to Involve Consumers. Lastly but perhaps most importantly, decisions about quality measures have been driven by payers, accreditors, regulators, professional societies, and researchers, with little consumer involvement. (A notable exception is the CAHPS surveys, which measure patient experience in a variety of health care settings.)

After more than two decades of development and investment, we still do not have public quality reports or websites that consumers fully trust, are easy to navigate and understand, or could help them “separate the best from the rest” and make informed choices. Perhaps if consumers had been involved along the way in decisions about quality measurement and reporting, we would have more

measures that could inform choice. For now, quality measurement appears to have missed the mark in a fundamental way.

“We measure [providers’] performance where we can get reliable measurement, and that’s not necessarily what people look for in terms of information that can be helpful to them.”

—Barbra Rabson, CEO of Massachusetts Health Quality Partners. Quoted in *Six Things Consumers Will Know About You*, L Butcher, *H&HN*, June 9, 2015.

Despite these barriers, there is reason for optimism. The National Quality Forum (NQF) has long involved patient and consumer organizations in convenings to establish national priorities and goals to achieve safe, effective, and high-quality health care. More recently, in recognition that the patient voice is missing from existing measures, NQF has focused new attention on patient-reported outcome measures (PROMs) and has partnered with PatientsLikeMe to gather patient experience data for use in developing measures.³⁵ The

Patient-Centered Outcomes Research Institute (PCORI) is supporting the development and application of PROMs and related performance measures and ensuring that patients and caregivers are involved in those efforts. And through an effort that involves patient representatives in measure development, the International Consortium for Health Outcomes Measurement (ICHOM) has developed 20 standard sets that health care systems can use to measure and report patient outcomes.

The Essential Role of Transparency

Both effective quality measurement and increased transparency are central to moving the U.S. health care system toward paying for value and achieving the Triple Aim of better health, better care, and lower costs. However, a variety of quality data that might help inform consumer choice—such as condition-specific registry data, clinician-specific quality and cost measures, and complaints—reside in silos across the health care system where they are not accessible to the public.^{vi} This longstanding imbalance in access among the system’s key stakeholders elevates the importance of transparent public reporting. Informed decision-making cannot occur without it.

New York’s Department of Health has made a significant investment in increasing the transparency of health care quality and costs in the state through a new All-Payer Database (APD), currently in development. The APD aims to serve as a key resource for consumers and other stakeholders who need to make

^{vi} For example, in New York State, the public can access information about patient complaints filed against physicians, but not complaints against hospitals or other health care facilities.

informed decisions.³⁶ While the APD will be launched with claims and encounter data, NYSDOH plans to expand it over time into a vast data repository. How the APD will enable transparency for consumers is not yet clear, nor is the role NYSDOH will ultimately play as a steward of transparency for New York’s health care stakeholders. Potential options may include: 1) developing and sponsoring a consumer-facing website, 2) serving as a data steward and enabling and promoting broad public use, and 3) building a better platform to help New Yorkers make quality and cost comparisons through a public-private partnership.

“Consumers are the ultimate stakeholders in quality measurement.”

—Concannon TW, MW Friedberg, A Hwang, and K Wiitala. *Engaging Consumers in the Quality Measure Enterprise*. RAND Corporation, 2017.

Over the past year, two New York health systems began posting online patient ratings of their affiliated physicians. Publication of this performance information, which was

not previously available to consumers and matches their information preferences, is noteworthy and may be a potentially important advance. However, until there is greater transparency about possible conflicts of interest when hospitals and physicians report their own quality results in the absence of reporting standards and external validation, our enthusiasm remains tempered.

Two recent reports have proposed a broader and more inclusive view of transparency into the health care system. In its report, the American Institutes for Research advanced a principle of “equal access to information about health care outcomes, quality, costs, and patient experiences of care and sharing it in ways that patients can understand and use.”³⁷ The authors emphasize that transparency requires including patients in decisions about measures, methods, reporting, and use of performance results for improvement and payment.³⁸ Another report by RAND, sponsored by Community Catalyst’s Center for Consumer Engagement, outlines actual strategies for “robust consumer involvement in prioritizing, developing, validating, using, and assessing quality measures.”³⁹

How willing is the field to involve consumers, patients, and families in decisions about quality measurement and reporting? Could these varied voices converge sufficiently to drive reforms that support consumer choice?

Other Considerations

Recent research on Americans’ low use of quality and cost comparisons raises some questions about the potential for greater consumer uptake and may be a cautionary sign.^{40,41} Most people do not think about searching for a health care provider very often because they are healthy, satisfied with their sources of care^{42,43}, or feel that their choices are limited by their health plans. Can consumerism be deepened by information alone? It is certainly clear that current measures and public reporting efforts are not up to the challenge. While some experts believe that performance data cannot be used to drive consumers

to high-quality providers, others believe it can if the right information were delivered at the right time to the right audiences.

The potential for “disruptive” companies such as Yelp to advance consumer choice is gaining attention.⁴⁴ Researchers have found that high ratings of hospitals on Yelp correlated with high HCAHPS ratings, lower risk-adjusted potentially preventable readmissions, lower mortality rates for myocardial infarction and pneumonia, and lower readmission rates for multiple

“Researchers have found that health care consumers prefer to hear opinions and experiences from individual users because they trust human experience more than numbers.”

—Hibbard, JH, and E Peters. Supporting Informed Consumer Health Care Decisions: Data Presentation Approaches that Facilitate the Use of Information in Choice. *Annual Review of Public Health* 24(1): 413-433, 2003.

conditions.^{45,46,47} One study also found that Yelp narrative reviews covered 12 additional domains not covered by HCAHPS. However, there are serious doubts as to whether online physician ratings are a valid metric of physician performance. A recent study of five online platforms including Yelp found that online ratings of physicians from eight specialties were not associated with either objective measures of quality of care or peer assessment of clinical performance.⁴⁸

The jury is still out on whether ratings and reviews on Yelp or similar sites can drive consumers toward high-quality providers. Small sample sizes continue to raise red flags about possible bias, and how much consumers will use patient ratings and reviews remains unclear. On the other hand, growing interest in consumer ratings has spurred the national CAHPS Consortium to explore scientific approaches to implementing narrative elicitation^{vii}, to ensure reliability and validity. Those efforts seem promising, given the group’s measurement expertise and pioneering contributions to assessing how patients experience care.

^{vii} The CAHPS narrative elicitation protocol is currently being tested. It is a set of open-ended questions that prompt a narrative from patients about their health care experiences – five items for the Adult version and six items for the Child version. Agency for Healthcare Research and Quality. “CAHPS Patient Narrative Elicitation Protocol.” Last updated August 2017. <http://www.ahrq.gov/cahps/surveys-guidance/item-sets/elicitation/index.html>.

Looking Forward: Recommendations for Empowering New Yorkers with Quality Data

Realizing the Potential to Inform Consumer Choice

UHF Quality Institute's analysis shines a light on the deep gaps and need for quality measures that could empower choice. We recognize that this is a complex problem and that recommending more measures is not optimal, when there are already too many and providers are overburdened. There are no simple solutions and no single approach will suffice. Yet there are opportunities that may help consumers find providers that can match their care needs and preferences. With that aim in mind, we offer the following guiding principles, priorities, and strategies.

Guiding Principles

- Start with the users of information and not the measures. Bring consumers, patients, and families to the table to consider information for decision-making.
- Consider the needs of diverse populations in decisions about quality measurement and reporting, including older adults, as well as people with multiple chronic conditions, low literacy and numeracy skills, or limited English proficiency. If UHF's Quality Institute can't fully grasp the meaning and relevance of quality measures on websites, neither can the public at large and people who need more assistance.
- Explore ways to deploy information intermediaries to assist vulnerable populations and others who need help accessing and interpreting quality information.
- Make it easy for consumers to find, use, and understand measures that matter to them at key decision points.
- Develop user-friendly tools that are intuitive and can help consumers locate and customize information.
- Create standards for quality measures and the websites reporting them so that consumers can identify which sources to trust.
- Expand access to relevant datasets that are not public to help advance the state of the art of quality measurement and transparency.

Priorities

Given the scarcity of quality measures that could help consumers choose providers, measure types and dimensions of quality of greatest relevance to consumers should be prioritized:

“Patients deserve truthful, timely, and transparent measures of quality.”

—Pronovost PJ, AW Wu, and JM Austin.
Time for Transparent Standards in Quality Reporting by Health Care Organizations.
JAMA 318(8): 701-702, 2017.

- Existing measures (such as those captured by the CAHPS family of surveys) that evaluate communication, interpersonal skills, and shared decision-making—and new ones that assess key aspects of the patient/clinician relationship such as trust, empathy, caring, and compassion.
 - Measures that assess the quality of care clinicians provide and can influence. For quality reporting to engage consumers, these must include comparisons at the clinician level, and technical challenges such as adequate sample size, risk-adjustment, validity, and reliability will need to be tackled.
 - Patient-reported outcome measures that assess physical, emotional, and social function and can be used before and after a medical intervention to measure treatment effects. These measures are now being used in a few specialties and pioneering health systems, and hold great potential for informing not only treatment decisions, but also provider choice.
- Patient engagement measures to assess the level of support patients and families receive from providers to navigate the health care system and to maintain their health.
- Measures that capture broader episodes of care or quality performance over time, which could be realized through the merging of claims and electronic health record data.
- Composite measures, which are easier for consumers to understand and use to compare providers. However, more work is needed to advance the science of composites to ensure that valid methods are used to develop them.

Methods that can advance the collection and reporting of quality measures for choice in real time should also be prioritized. For example,

- Expanding and deploying patient satisfaction surveys on a larger scale and in more settings to measure patient experience at the point of care.
- Coupling patient satisfaction with online reviews or narratives as a best practice for measuring patient experience.
- Addressing technical concerns about patient reviews (e.g., validity, reliability, and dispersion).

Transparency initiatives in other states might help inform New York's approach as its work on the APD continues.

- **Minnesota:** A nonprofit organization, MN Community Measurement, works with stakeholders to curate measures on clinical quality and patient experience for select conditions. Unlike most of the other websites we scanned, measures for diabetes, asthma, and knee replacement are reported at the medical group level. MN Community Measurement also develops measures, some of which have been endorsed by NQF.
- **California:** The Healthcare Compare website, sponsored by the California Department of Insurance, works with a number of partners (UCSF, UC Davis, Honest Health, and Consumer Reports) to report quality measures for select conditions.
- **Massachusetts:** The Healthcare Compass website, developed by Massachusetts Health Quality Partners (MHQP), a nonprofit organization, reports clinical quality performance for 550 primary care offices and patient experience performance for offices that have at least three doctors. MHQP was recently awarded a contract to conduct patient experience surveys for the state's Medicaid program.

Specific Strategies

During this project, we collected many ideas about how to make progress on helping consumers find and use quality measures and other relevant quality information to select the right provider for them. Table 4 groups these ideas into five strategies for advancing consumer choice and summarizes them.

We recognize that these ideas represent a mix of short-term, long-term, and even wish-list solutions. They are meant as a starting point to build awareness about what it might take to address the deficiencies we discovered in our scan of existing quality measures. Refining these strategies will require engaging key stakeholders to identify what's feasible and related policy levers that can help foster change.

Table 4. Strategies for Advancing Consumer Choice

Simplify Quality Information
<ul style="list-style-type: none">• Highlight measures that matter most to consumers and prioritize patient experience over clinical measures.• Translate measures for the broadest possible audience and accommodate limits to people’s capacity to process information through smart website design.<ul style="list-style-type: none">○ Decrease complexity, standardize terms, and implement best practices for conveying quality information to the public.○ Target patient populations to make it easier for them to find information relevant to their search.○ Use composites to summarize provider performance across quality dimensions and enable drill downs.○ Create brief and digestible labels, descriptions, visual displays, and messages.○ Provide easy to understand explanations of data sources and methods.
Support Consumers, Patients, and Families
<ul style="list-style-type: none">• Explain the data and its importance to consumers and provide guidance on where to find reliable and valid quality measures.• Explore how various actors could serve as information intermediaries to address gaps.<ul style="list-style-type: none">○ Prioritize types of assistance and the populations that might need it the most.○ Identify potential sources of assistance, assess capacity and resource requirements.
Integrate Data
<ul style="list-style-type: none">• Partner on opportunities for integrating information from public and private sources of quality measures.• Consider creating an aggregator (site of sites) of quality measures for consumers, or ensure that websites include all data relevant to consumers for decision-making.
Standardize Measures
<ul style="list-style-type: none">• Explore policy options for creating:<ul style="list-style-type: none">○ A single set of measures for choice.○ Website content and transparency standards and a process for independent validation.• Incentivize reporting on a standard set of measures to spread adoption among payers and providers.
Innovate to Advance Measures That Matter
<ul style="list-style-type: none">• Involve consumers, patients, and families at the outset in decisions about what to measure, how to measure, how to report and interpret information, and how to design user-friendly websites.• Consider new measures to assess patient-clinician relations—e.g., compassion, trust, and empathy.• Consider new measures to assess the level of support patients and families receive from providers.• Create intuitive tools to personalize and customize quality measures and other information.• Engage consumers through channels such as mobile-friendly web platforms, kiosks, apps, and social media.• Consider the role of a NY public-private partnership with consumer representation to help promote consumer choice.

Resolving the Measurement Enterprise Dilemma

The contribution of measurement to improving the quality and safety of the U.S. health care system is unquestioned. But as the National Academy of Medicine has warned, the enthusiasm for measurement and the exponential growth of measures has led to confusion and inefficiency, and diminished the effectiveness of measurement to improve health and health care.⁴⁹

Many U.S. organizations participate in the process of developing and evaluating quality measures (see inset box). Along with payers and regulators, they have

Leading U.S. Organizations Involved in Quality Measurement

- Federal (e.g., CMS, AHRQ, Centers for Disease Control and Prevention, National Institutes of Health, Health Resources and Services Administration)
- National (e.g., NQF, National Committee for Quality Assurance, PCORI, Leapfrog Group)
- State (e.g., NYSDOH)
- Accrediting bodies (e.g., The Joint Commission)
- Professional organizations (e.g., American Medical Association, American College of Surgeons, Society for Thoracic Surgery)
- Public and private institutions (e.g., Hospital for Specialty Surgery, Cleveland Clinic, Yale University).

played a role in the rapid growth of measures—and in the rising administrative burdens associated with collecting, reporting, and monitoring performance results. Overlapping or redundant measures add little value and generate significant costs in time, effort, and money—including the inconvenience and time spent by patients completing questionnaires, the time providers spend entering quality data for payment, and the expenses for digital infrastructure and personnel needed to manage data.^{50,51} A 2015 report estimated excess administrative costs due to measurement and associated activities at \$190 billion per year.⁵²

“Not only are many measures imperfect, but they are proliferating at an astonishing rate, increasing the burden and blurring the ability to focus on issues most important to better health and health care.”

—Blumenthal, D, and JM McGinnis. *Measuring Vital Signs: An IOM Report on Core Metrics for Health and Health Care Progress*. *JAMA* 313(19): 1901–2, 2015.

The National Academy of Medicine has urged all stakeholders—including health professionals, payers, policymakers, and members of the public—to focus on measures that matter most.⁵³ A number of organizations are responding to the call for reducing disparate measurement sets and the resulting burdens and costs by refocusing quality measurement on measures that matter to patients and families.

Perspectives vary about how to reform quality measurement, with much attention now focused on metrics for value-based payment or improving health care delivery across settings. For example, some experts advocate for developing a standard set of fewer measures to assess and reward quality or for encouraging all payers to

standardize based on government measures.⁵⁴ Others propose a total reset on quality measurement that would harness sources of data beyond insurance claims to include registries, electronic health records, and patient-reported information to supplant many measures currently in use.

“Many stakeholders are invested in current measures and will not readily agree to modify or abandon them.”

—Blumenthal, D, and JM McGinnis. *Measuring Vital Signs: An IOM Report on Core Metrics for Health and Health Care Progress*. *JAMA* 313(19): 1901–2, 2015.

However, the vested interests of stakeholders, who need and use quality measures for different purposes, complicate reform. Payers want measures that can help them build provider networks, monitor the use and costs of care, and design benefits and payment incentives. Clinicians want performance measures that can guide and improve medical practice and help them understand their performance in relation to their peers. Specialty physicians and societies

have highly specified measurement needs aimed at studying treatment effects and improving technical aspects of quality. Regulators want measures to help monitor provider and system performance and assess the value of government health care expenditures. Consumers want quality measures that can help them choose effective treatments and skilled providers based on their individual preferences and priorities. Whether these various needs can be reconciled remains a central question.

Conclusion

External forces are creating a more urgent need for quality measurement approaches that consider the aspects of care that matter to consumers and promote greater public transparency. The health care environment is changing rapidly in New York State. As payment shifts from volume to value, massive delivery system consolidation is increasing the market power of providers, with uncertain effects on consumers as their out-of-pocket costs rise.

For now, the notion that “activated” or “engaged” consumers can use publicly available data on quality performance to identify and move markets toward high-quality providers remains an aspiration, at best.⁵⁵ Our analyses document several inherent problems in quality measurement and reporting that need to be addressed before real progress can be made:

“Make [existing] quality data available but don’t expect people to make complex decisions about care using abstract measures.”

—Mehrotra A, KM Dean, AD Sinaiko, and N Sood. Americans Support Price Shopping for Health Care, But Few Actually Seek Out Price Information. *Health Affairs* 36(8): 1392-1400, 2017.

- A scarcity of existing measures that can inform consumer choice.
- Lack of consumer participation in decisions about quality measurement and reporting.
- Quality information dispersed over the internet that is nearly impossible to navigate and comprehend, much less customize and compare.
- Quality measures and related information that are not standardized, and performance data on websites that raise concerns about conflicts of interest, accuracy, validity, and reliability.
- A complete lack of guidance on which sources of quality information consumers can and should trust and support for those of us who need help finding and interpreting it.
- Advances in measurement science that could produce timely performance data that interest consumers and are salient to the decisions they need to make.

Better ways of measuring and disseminating quality measures by trusted sources could help signal low quality care, inform consumer choice, and spark improvement. New York’s development of an All-Payer Database poses a unique opportunity to potentially transform quality measurement, move toward measures that matter most, and bring new levels of transparency to consumers. Still much work lies ahead before consumers have trusted information and tools they can use to find providers that meet their specific needs and possess the characteristics they value. Understanding how to empower New York consumers and help them find those providers will require continued attention, innovation, and investment. It is clear that to succeed, efforts must involve consumers, patients, and families at the outset.

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Appendix A: Expert Interviews

A list of the experts who were interviewed as part of this inquiry appears below. Topics discussed included: quality measures and other related information that consumers need and value, places where they commonly seek information, the situations and conditions that drive consumers to search for quality information and compare provider performance, the challenges involved in finding relevant and valid data on quality performance, the quality of information that can be found on the internet, the types of information consumers want that cannot be found, issues related to accuracy and trust in sources of quality measures, transparency of quality data as well as the methods used to develop them, the role of information intermediaries in assisting those who need help choosing a provider and interpreting quality measures, criteria for evaluating quality information on websites, limits to information processing and synthesizing data from multiple sources of data, and other important obstacles such as literacy, numeracy, language, and culture.

Interviews were conducted by telephone (with one exception) between November 2016 and July 2017.

- Danielle Andrews, Reena Duseja, Van Johnson, Theodore Long, and Pierre Yong, Centers for Medicare & Medicaid Services
- Bonnie Austin, Megan Collado, and Caroline Tisce, AcademyHealth
- Joseph Baker, Medicare Rights Center
- James Boswell, University at Albany, State University of New York
- Michael Constantino, University of Massachusetts Amherst
- Carol Cronin, Informed Patient Institute
- Cheryl Damberg, RAND Corporation
- Susan Delbanco, Catalyst for Payment Reform
- Andrea Ducas, Robert Wood Johnson Foundation
- Susan Frampton, Planetree
- Emilio Galan, HonestHealth
- Robin Gelburd, Michelle Scott, and Nicole Iny, FAIR Health (this interview was conducted in person)
- Natalie Helbig, New York State Department of Health
- Jaz-Michael King, IPRO

- Rebecca Kirch, National Patient Advocate Foundation
- Jacob Lippa, International Consortium for Health Outcomes Measurement
- Sally Okun, PatientsLikeMe
- Doris Peter, Yale University, formerly with Consumer Reports
- Mark Schlesinger, Yale University
- Maribeth Shannon, formerly with California Health Care Foundation
- Maya Scherer, Anthony Shih, and Linda Weiss, New York Academy of Medicine
- David Schleifer, Public Agenda
- Shoshanna Sofaer, American Institutes for Research
- Diane Stollenwerk, StollenWerks Inc., and Patients' View Institute

Appendix B: Advisory Group Members

Note: The findings and perspectives discussed in this report are those of the authors and the United Hospital Fund and do not necessarily represent the views of Advisory Group members.

Joseph Baker, JD

President
Medicare Rights Center

Elisabeth Benjamin, JD

Vice President of Health Initiatives
Community Service Society

Helen Burstin, MD, MPH, FACP

Executive Vice President and CEO
Council of Medical Specialty Societies

Kristin Carman, MA, PhD

Director of Public and Patient Engagement
Patient Centered Outcomes Research Institute

Carol Cronin, MSW, MA

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Andrea Ducas, MPH

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Director, Center for Evaluation and
Applied Research
New York Academy of Medicine

Appendix C: Catalog Methodology and Analysis

To learn more about the quality measures that are publicly available to New Yorkers, UHF's Quality Institute scanned more than 70 websites.

To narrow the universe of websites to a smaller sample, we selected a group of 32 sites, including those sponsored by New York State Department of Health (NYSDOH), Centers for Medicare & Medicaid Services (CMS), health systems and payers operating in New York, commercial firms, and media. The websites were narrowed based on whether they provided free access to quality data, included information for the conditions we selected, and had information relevant to New Yorkers. Seven websites from other states were included as models for quality information available to consumers outside of New York.

We then developed a database to collect and record the various data elements we found on the websites including:

- Quality measure labels, types, sources, and whether a measure had been endorsed by the National Quality Forum (NQF)⁸ and its number where available,
- Provider characteristics (e.g., demographic information, credentials, and photos), and
- Website features (e.g., search filters and tools enabling provider comparisons).

Quality measures and related information were abstracted and cataloged between April and July 2017.

Condition Selection

A context-based framework by Shaller, Kanouse, and Schlesinger was applied to select conditions for the catalog. The potential context for specific decision situations when consumers choose providers that are applied include: 1) people shopping for short-term treatments, 2) people with serious chronic conditions, and 3) patients with newly-diagnosed cancer. These are three circumstances where consumers are motivated to seek information about providers.

⁸ NQF is a nonprofit organization that vets and endorses quality measures, among other functions.

A mix of inpatient and ambulatory surgical procedures and acute and chronic conditions were used for this analysis. These 10 conditions were selected based on prevalence and utilization data in New York State and nationally.

- | | |
|-------------------------------------------------|-----------------------------------|
| 1. Asthma | 6. Congestive heart failure (CHF) |
| 2. Breast Cancer | 7. Diabetes |
| 3. Cataract Surgery | 8. Prostate Cancer |
| 4. Cholecystectomy | 9. Total hip replacement |
| 5. Chronic obstructive pulmonary disease (COPD) | 10. Total knee replacement |

Website Selection

A total of 32 different websites were identified and information on the websites was cataloged to understand the type of information that is available to consumers who are making choices about providers in New York. A few other state health systems and transparency websites were included to highlight what type of information could be available to consumers in New York. The categories of websites include:

- Commercial
- Federal and state agencies
- Health systems in New York and other states
- Media
- New York State Department of Health and other state transparency websites
- Payers

The websites were selected based on expert interviews and literature review except for the payers, specialty hospitals, and New York State health systems.

Payer websites were those that we had access to via our own commercial health insurance, the specialty hospitals were chosen because they fit some of the conditions we chose (breast and prostate cancer and hip and knee replacement), and for the hospitals, we selected the largest one in each of the 10 hospital referral regions in New York State as defined by The Dartmouth Atlas of Healthcare, based on data obtained from IPRO's WhyNotTheBest.org website.

Appendix Table 1. List of Websites Scanned

#	Website Type	Website Name
1	Commercial	Amino
2	Commercial	Healthgrades
3	Federal	Hospital Compare
4	Federal	Physician Compare
5	Health system – NY	Albany Medical Center
6	Health system – NY	Crouse Health
7	Health system – NY	Faxon St. Luke's Healthcare
8	Health system – NY	Hospital for Special Surgery
9	Health system – NY	Kaleida Health
10	Health system – NY	Memorial Sloan Kettering Cancer Center
11	Health system – NY	Montefiore Medical Center
12	Health system – NY	Mount Sinai Health System
13	Health system – NY	Northwell Health
14	Health system – NY	Roswell Park Cancer Institute
15	Health system – NY	Strong Memorial Hospital
16	Health system – NY	United Health Services
17	Health system – NY	Westchester Medical Center
18	Health system – Other	Beth Israel Deaconess Medical Center
19	Health system – Other	Cleveland Clinic
20	Health system – Other	Mayo Clinic
21	Health system – Other	University of Utah Health
22	Media	Consumer Reports
23	Media	ProPublica
24	Media	U.S. News & World Report
25	NY State	NYSDOH Hospital Profile
26	NY State	NYS Physician Profile
27	Patient safety	Leapfrog Group
28	Payer	Aetna
29	Payer	UnitedHealthcare Oxford
30	State model	California Healthcare Compare
31	State model	Healthcare Compass Massachusetts
32	State model	Minnesota HealthScores

Catalog Development

A database for cataloging quality measures was developed in Microsoft Access. The database contained several data elements that were grouped into three broad categories: quality measures, website characteristics, and provider characteristics.

The quality measures were recorded in the catalog with the name of the measure as written on the website, the type of measure, source of the measure, and NQF number where applicable.

The website characteristics included provider search availability, comparison across hospitals and/or provider availability, access to information in languages other than English, methodology availability and number of pages, display of ratings (e.g., symbol or number), and search filters (e.g., condition treated, location of provider, and language spoken by provider).

The provider characteristics included demographics, photo, education, certification, hospital affiliations, languages spoken, legal action/malpractice information, practice location, new patients accepted, and health plans accepted.

The quality information was collected by reviewing each of the 32 websites in the same context a consumer would access a website and search for information on a provider that treated one of the 10 selected conditions. On each website, the general website and provider characteristics were also recorded in the catalog. The quality measure type was entered based on the AHRQ definition. The methodology (if included on the website) was also reviewed to understand the data source, the year and frequency with which the data were last updated, and any other contextual factors that would help interpret the data presented on the website.

In addition, structural measures, patient experience measures and comments were also included in the catalog because these elements have been identified in the literature as ones important to consumers when seeking information.

Data Analysis

During the search for quality information, the search method was recorded so that the search could be replicated and reviewed, and the recorded information could be rechecked. Inaccuracies and errors in the recorded data were corrected or revised accordingly. The data were then exported into Microsoft Excel for analysis.

The number of condition-specific measures for the 15 websites are provided in the following table.

Appendix Table 2. Number of Condition-Specific Measures by Website

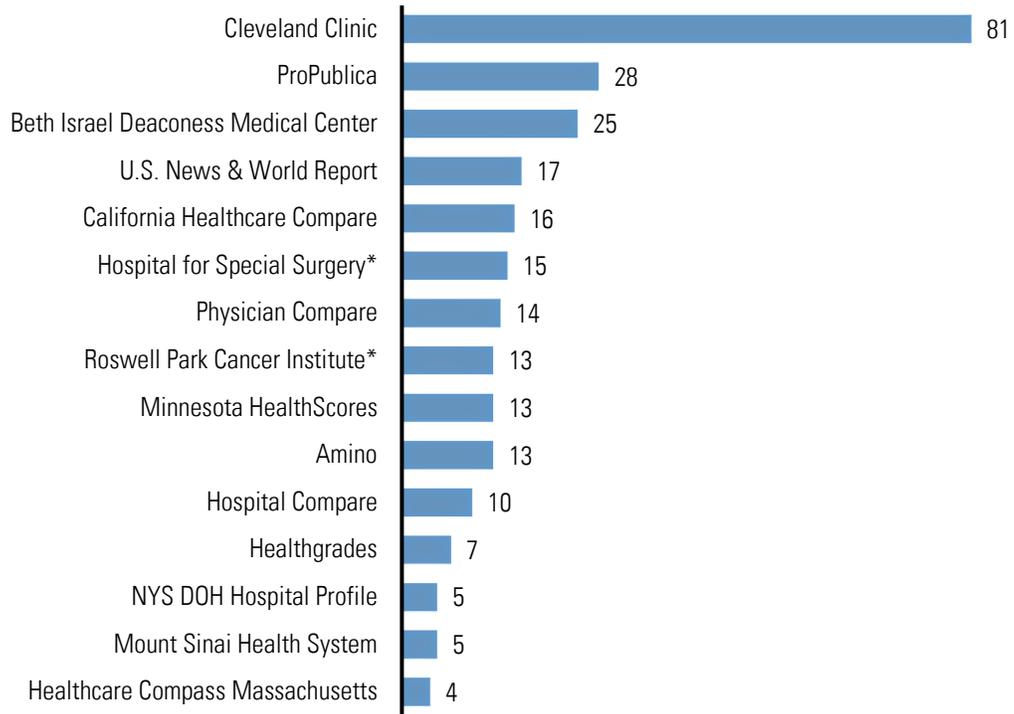
Websites with Condition-Specific Measures	Asthma	Breast cancer	Cataract surgery	Cholecystectomy	Chronic obstructive pulmonary disease	Congestive heart failure	Diabetes	Prostate cancer	Total hip replacement	Total knee replacement	Total
Amino	1	3	1	2	1	1	1	1	1	1	13
Beth Israel Deaconess Medical Center	0	17	0	0	0	0	0	1	3	4	25
California Healthcare Compare	0	0	0	0	3	0	5	0	4	4	16
Cleveland Clinic	1	13	5	9	2	4	5	8	17	17	81
Healthcare Compass Massachusetts	1	0	0	0	0	1	2	0	0	0	4
Healthgrades	0	0	0	1	1	1	1	1	1	1	7
Hospital Compare	0	0	1	0	2	3	0	0	2	2	10
Hospital for Special Surgery*	-	-	-	-	-	-	-	-	8	7	15
Minnesota HealthScores	2	0	0	0	3	2	2	0	1	3	13
Mount Sinai Health System	0	0	0	0	0	3	0	0	1	1	5
NYSDOH Hospital Profile	0	0	0	0	0	4	0	0	1	0	5
Physician Compare	1	1	1	0	2	2	6	1	0	0	14
ProPublica	0	0	0	7	0	0	0	7	7	7	28
Roswell Park Cancer Institute*	-	9	-	-	-	-	-	4	-	-	13
U.S. News & World Report	0	0	0	0	4	0	4	0	6	3	17
Total	6	43	8	19	18	21	26	23	52	50	266

Numbers in **blue** indicate which websites had the most measures for each condition.

* HSS is a specialty orthopedic hospital, and Roswell Park is a cancer institute; measures for those organizations focused on orthopedics and cancer only.

Among the 15 websites with condition-specific measures, Cleveland Clinic had the greatest number of measures across all 10 conditions, and most of those were from internal registries that are not public.

Appendix Figure 1. Condition-Specific Measures by Website



*HSS is a specialty orthopedic hospital, and Roswell Park is a cancer institute; measures for those organizations focused on orthopedics and cancer only.

The following table lists the unique sources of the 462 quality measures.

Appendix Table 3. Unique Data Sources for the Quality Measures

Category	Source	No. of Sources
Academic researchers	PROMS Tools	5
	HOOS Questionnaire	
	KOOS Questionnaire	
	ROMS Questionnaire	
	Veterans RAND 12-Item Health Survey	
Commercial	Amino	12
	CareChex	
	Consumer Reports	
	Healthgrades	
	Leapfrog	
	Press Ganey	
Health Systems	ProPublica	4
	RateMDs	
	U.S. News & World Report	
	Vizient	
NY State	Hospital for Special Surgery	4
	Roswell Park Cancer Institute	
Other States	Beth Israel Deaconess Medical Center	4
	Cleveland Clinic	
Government	Agency for Healthcare Research and Quality	5
	Centers for Medicare & Medicaid Services	
	Centers for Disease Control and Prevention	
	New York State Department of Health	
	California Department of Public Health	
Organizations	American Academy of Allergy, Asthma, and Immunology	11
	American College of Surgeons	
	American Medical Association-convened Physician Consortium for Performance Improvement	
	American Nurses Credentialing Center	
	American Podiatric Medical Association	
	American Thoracic Society	
	National Committee for Quality Assurance	
	California Healthcare Compare	
Integrated Healthcare Association		
Other States	Massachusetts Health Quality Partners	11
	Minnesota Community Measurement	
Payers	Aetna	2
	UnitedHealthcare Oxford	
Total		39

Appendix Table 4 lists some condition-specific measures from the catalog that might be of value to consumers as they search for a provider.

Appendix Table 4. Promising Quality Measures

Condition	Measure Name	Type	Steward/Number
Asthma	Asthma control improvement - minimal important difference	Outcome	AAAAI
Asthma	Optimal asthma control	Outcome	MN Community Measurement
Breast cancer	Breast conservation rate (stages 0-2)	Outcome	BIDMC
Breast cancer	5-year observed survival rates by stage (stages 0-5) and gender	Outcome	BIDMC, Cleveland Clinic, RPCI
Breast cancer	Likelihood to recommend for outpatient breast cancer care	Pt. Exp	Press Ganey
Breast cancer	Overall visit experience	Pt. Exp	Press Ganey
Breast cancer	Experience with care provider	Pt. Exp	Press Ganey
Breast cancer	Sensitivity to personal needs & concerns	Pt. Exp	Press Ganey
Breast cancer	Care providers efforts to include patients in care decisions	Pt. Exp	Press Ganey
Breast cancer	Outpatient and inpatient visits by disease group or site (breast)	Volume	Cleveland Clinic
Breast cancer	Five-year overall survival of female patients with breast cancer by race	Outcome	Cleveland Clinic
Cataract surgery	Postoperative and intraoperative complications	Outcome	Cleveland Clinic
Cataract surgery	Percent of patients who had improvement in visual function within 90 days following the surgery	Outcome	CMS (NQF #1536)
Cataract surgery	20/40 or better visual acuity within 90 days following surgery	Outcome	AMA-PCPI (NQF #0565)
Cholecystectomy	30-day readmission rate, inpatient open and laparoscopic cholecystectomies	Outcome	Cleveland Clinic
Cholecystectomy	Median length of stay, inpatient laparoscopic cholecystectomies	Outcome	Cleveland Clinic
Cholecystectomy	30-day mortality rate, inpatient cholecystectomy	Outcome	Cleveland Clinic
Cholecystectomy	Complications	Outcome	ProPublica
COPD	30-day readmission rate	Outcome	CMS (NQF #1891)
COPD	30-day mortality rate	Outcome	CMS (NQF #1893)
CHF	30-day readmission rate	Outcome	CMS (NQF #0330)
CHF	30-day mortality rate	Outcome	CMS (NQF #0229)
CHF	Hospital return days	Outcome	CMS (NQF #2880)
Diabetes	ETDRS vision improvement	Outcome	Cleveland Clinic
Diabetes	Optimal diabetes care	Outcome	MN Community Measurement (NQF #0729)

Condition	Measure Name	Type	Steward/Number
Diabetes	Relative number of inpatients age 65+ who had this procedure or condition in 2012-14	Volume	U.S. News & World Report
Prostate cancer	Prostatectomy: radical	Volume	BIDMC
Prostate cancer	Cumulative incidence of death due to prostate cancer by treatment type (low, intermediate, high intermediate, high)	Outcome	Cleveland Clinic
Prostate cancer	Raw complication rate	Outcome	ProPublica
Prostate cancer	Performed procedure	Volume	ProPublica
Prostate cancer	Complications	Outcome	ProPublica
Prostate cancer	Five-year survival by stage (I, II, III, IV)	Outcome	Cleveland Clinic, RPCI
Total hip replacement	30-day morbidity	Outcome	ACS NSQIP
Total hip replacement	30-day mortality	Outcome	ACS NSQIP
Total hip replacement	In-hospital mortality	Outcome	Cleveland Clinic
Total hip replacement	Discharged home	Outcome	Cleveland Clinic
Total hip replacement	Length of stay, days	Outcome	Cleveland Clinic
Total hip replacement	Yearly volume	Volume	Cleveland Clinic
Total hip replacement	30-day reoperation rate	Outcome	Cleveland Clinic
Total hip replacement	90-day post-op function	PROM	Cleveland Clinic
Total hip replacement	Pre-op function	PROM	Cleveland Clinic
Total hip replacement	90-day infection rate	Outcome	Cleveland Clinic
Total hip replacement	Hip-related pain and function 1 year after surgery	PROM	HOOS questionnaire
Total hip replacement	Leg-related physical function 1 year after surgery	PROM	ROMS questionnaire
Total hip replacement	Whole-body physical function 1 year after surgery	PROM	Veterans RAND 12-Item Health Survey
Total hip replacement	Rate of complications for patients	Outcome	CMS (NQF #1550)
Total hip replacement	30-day readmission rate after hip/knee replacement	Outcome	CMS (NQF #1551)
Total hip replacement	Recovery following total hip replacement activities of daily living (2 years after surgery)	PROM	HSS
Total hip replacement	Recovery following total hip replacement sports and recreation (2 years after surgery)	PROM	HSS
Total hip replacement	Pain reduction following total hip replacement (2 years after surgery)	PROM	HSS
Total knee replacement	Total replacement of both knees during same surgery	Volume	BIDMC
Total knee replacement	Overall hip & knee replacement quality rating (composite)	Outcome	California Healthcare Compare
Total knee replacement	Avoiding knee surgical site infections	Outcome	California Dept. of Public Health
Total knee replacement	30-day morbidity	Outcome	ACS NSQIP

Condition	Measure Name	Type	Steward/Number
Total knee replacement	30-day readmission	Outcome	ACS NSQIP
Total knee replacement	Unilateral total knee arthroplasty: yearly volume	Volume	Cleveland Clinic
Total knee replacement	Unilateral total knee arthroplasty: length of stay, days	Outcome	Cleveland Clinic
Total knee replacement	Unilateral total knee arthroplasty: discharged home	Outcome	Cleveland Clinic
Total knee replacement	Unilateral total knee arthroplasty: in-hospital mortality	Outcome	Cleveland Clinic
Total knee replacement	Unilateral total knee arthroplasty: 30-day readmission rate	Outcome	Cleveland Clinic
Total knee replacement	Unilateral total knee arthroplasty: 30-day reoperation rate	Outcome	Cleveland Clinic
Total knee replacement	Unilateral total knee arthroplasty: 90-day infection rate	Outcome	Cleveland Clinic
Total knee replacement	Pre-op function	PROM	Cleveland Clinic
Total knee replacement	90-day post-op function	PROM	Cleveland Clinic
Total knee replacement	Knee-related pain and function 1 year after surgery	PROM	KOOS questionnaire
Total knee replacement	Leg-related physical function 1 year after surgery	PROM	ROMS questionnaire
Total knee replacement	Whole-body physical function 1 year after surgery	PROM	Veterans RAND 12-Item Health Survey
Total knee replacement	Recovery following total knee replacement sports and recreation (2 years after surgery)	PROM	HSS
Total knee replacement	Recovery following total knee replacement activities of daily living (2 years after surgery)	PROM	HSS
Total knee replacement	Pain reduction following total knee replacement (2 years after surgery)	PROM	HSS

Appendix Table 5 lists quality measures found in our gap analysis that might also be useful for consumers.

Appendix Table 5. Quality Measures from the Gap Analysis

Condition	Measure	Type	Steward
Breast cancer	Ambulatory breast procedure surgical site infection	Outcome	CDC (NQF #3025)
Breast cancer	Shared decision-making process	PROM	Informed Medical Decisions Foundation (NQF #2962)
Cataract surgery	Complications within 30 days following cataract surgery requiring additional surgical procedures	Outcome	AMA-PCPI (NQF #0564)
Cataract surgery	Intra-operative complications	Outcome	AAO
Cataract surgery	Patient satisfaction within 90 days following surgery	PROM	AAO
COPD	Health-related quality of life before and after pulmonary rehabilitation	Outcome	AACVPR (NQF #0700)
CHF	Functional status assessment	PROM	CMS
Diabetes	Lower-extremity amputation rate	Outcome	AHRQ (NQF #0285)
Prostate Cancer	Shared decision-making process	PROM	Informed Medical Decisions Foundation (NQF #2962)
Total hip replacement	Shared decision-making process	PROM	Informed Medical Decisions Foundation (NQF #2962)
Total hip replacement	Functional status assessment	PROM	CMS
Total hip replacement	Informed, patient centered hip and knee replacement surgery	PROM	MGH (NQF #2958)
Total hip replacement	Fellowship in joint replacement	Structure	ICHOM
Total knee replacement	Informed, patient centered hip and knee replacement surgery	PROM	MGH (NQF #2958)
Total knee replacement	Fellowship in joint replacement	Structure	ICHOM
Total knee replacement	Shared decision-making: trial of conservative (non-surgical) therapy	Process	AAHKS
Total knee replacement	Shared decision-making process	PROM	Informed Medical Decisions Foundation (NQF #2962)
Total knee replacement	Functional status assessment	PROM	CMS