



**Measuring Affordable Care
White Paper Outline and In-Person Meeting Discussion Guide**

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Meeting Objectives:

- To explore the concept of affordability from the patient’s perspective
- To identify the types of measures that is most relevant to consumer’s decision making
- Determine the type of data needed to support this type of measurement
- Determine how this information should be distributed to support consumer decision-making

I. Consumer Experience

Session Goal: To better understand the current consumer experience and the impact of healthcare costs on consumers.

Consumers are increasingly being asked to make health care decisions based on price but the information they need to do so may not be available to them.ⁱ Consumers lack comparative price information to support decision making and have difficulty acting on priceⁱⁱ. To better understand what consumers are experiencing when they need to purchase healthcare and the information they need to make a decision about whether care is affordable, NQF has convened this expert panel, including individual consumer representatives, to provide real world examples of what patients experience due to health care costs, the decisions they need to make, and if/how cost measurement can support these decisions.

Questions for Consumer Panel Consideration:

- What has been your experience with healthcare costs?
- How have your healthcare decisions been influenced by cost?

All expert panel members are welcome to share their experiences as well.

II. Definition of Affordability

Session Goal: To determine what affordable care means to consumers and how it relates to concepts such as quality, patient preference, value, and efficiency.

Affordability is a broad concept that can be interpreted in many ways depending on the individual stakeholder’s vantage point. For example, purchasers (who purchase healthcare on behalf of employers) prioritize achieving the highest quality care at the lowest cost, while patients tend to be concerned more about out-of-pocket costs and often equate higher costs with better quality. Additionally, information on the various components of what may constitute affordable healthcare varies by stakeholder.ⁱⁱⁱ During this meeting, the Panel will explore what affordability means from the consumer perspective and how cost and resource use measurement can promote the affordability of health care to consumers.

Relationship to Other Concepts

This work will build on established consensus-based definitions:

Quality of Care

Quality of care is a measure of performance based on the Institute of Medicine’s (IOM) six aims for healthcare: safety, timeliness, effectiveness, efficiency, equity, and patient centeredness.^{iv}

Cost

Cost of care is a measure of total healthcare spending, including total resource use and unit price(s), by payor or consumer, for a healthcare service or group of healthcare services, associated with a specified patient population, time period, and unit(s) of clinical accountability.^v

Efficiency

“Efficiency of care” is a measure of the relationship of the cost of care associated with a specific level of performance measured with respect to the other five IOM aims of quality (safety, timeliness, effectiveness, equity, and patient centeredness).

Value

Value of care is a measure of a specified stakeholder’s (such as an individual patient’s, consumer organization’s, payor’s, provider’s, government’s, or society’s) preference-weighted assessment of a particular combination of quality and cost of care.^{vi}

Resource Use:

Resource use measures are defined as broadly applicable and comparable measures of health services counts (in terms of units or dollars) that are applied to a population or event (broadly defined to include diagnoses, procedures, or encounters).

Price:

The amount paid for a service or product, typically determined via market mechanisms that take into account the supply of and demand for the service or product.^{vii} Price can be greatly influenced by the effectiveness of the market in question.

Charge:

The maximum amount of money a provider would seek to be paid. This amount often is charged to patients who do not have health insurance; health plans typically negotiate the charge down to the allowable amount on behalf of their members.^{viii}

NQF’s Previous Work in Cost and Resource Use Measurement

The National Quality Forum (NQF) uses its formal consensus development process (CDP) to review, endorse, and recommend the use of standardized healthcare performance measures. Through [recent projects](#) to endorse cost and resource use measures several principles emerged. Measures of cost and quality must be aligned in order to truly understand efficiency and value. As a starting place in understanding efficiency and value, NQF supports using and reporting of resource use measures in the context of quality performance, preferably outcome measures. Using resource use measures independent of quality measures does not provide an accurate assessment of efficiency or value and may lead to adverse unintended consequences in the healthcare system.^{ix}

Appropriateness and Patient Preference

Many factors weigh into a consumer’s health care decisions. When determining if the costs of a service are worth the benefit, it is important to consider whether a patient truly needs a

service, has a choices between services, and has had his or her preferences (such as needs, desires, and lifestyle) established.

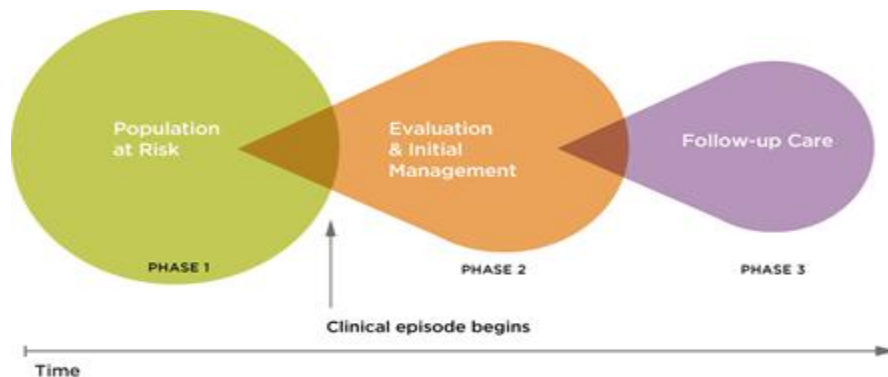
Questions for Panel Consideration:

- What does affordable care mean to consumers?
- What information is needed to determine if care is affordable?
- How can measurement help inform consumers to make better health care decisions?
- From the consumer perspective, how does affordability relate to cost, efficiency and value?
 - How is affordability different from cost, efficiency and value?
 - What is the relationship between quality and affordability?

III. How Can Cost and Resource Use Measurement Support Consumer Decision Making and Improve Affordability of Care for Consumers?

Session Goal: To explore the types of cost and quality information consumers need and how the episode of care conceptual model can be used to understand consumer decision making.

NQF’s *Measurement Framework: Evaluating Efficiency Across Patient-Focused Episodes of Care* identifies three components—population at risk, evaluation and initial management, and follow-up care—that must be measured and evaluated longitudinally over the course of an episode of care. Additionally, the framework notes that performance measurement should shift towards assessments of value: considering the appropriateness of the service, whether there are options, interpreting measures of quality, cost of care, and outcomes in accordance with patients’ preferences.^x An episode of care is defined as “a series of temporally contiguous healthcare services related to the treatment of a given spell of illness or provided in response to a specific request by the patient or other relevant entity”. This work will use the Patient-Focused Episode of Care framework to identify when patients need information on cost and quality and how this information can support them in their healthcare decisions.



An episode of care may be acute, such as a fractured arm, or more chronic such as diabetes. A single episode may also include both acute and chronic care. The patient-focused episode of care model includes three phases: population at risk, evaluation and initial management, and follow-up care. The population at risk phase covers activities that can help promote wellness and prevent the onset of an illness. The evaluation and initial management phase begins when a person is diagnosed with a disease /illness or is injured. This phase addresses the care a person receives to acutely treat their illness or injury. The follow-up care addresses on-going care a patient may need after an acute episode such as a stay in a nursing home, rehabilitation, or medication management. The episode of care is a continuum on which patients may alternate between phases; for example, depending on the condition a patient may stay in the follow-up care phase (medication management of hypertension) or return to the evaluation and management phase (admission to the emergency room for a stroke).

Consumer Attributes

Consumers weigh a number of factors when making decisions about healthcare spending including health status, insurance status, socioeconomic factors, and other competing non-health demands influence what is affordable to a consumer. This discussion will examine the factors that influence a consumer's ability to purchase health care.

Questions for Panel Consideration:

- What factors are consumers weighing when making decisions about costs related to health and healthcare?
- How do these attributes affect consumer's decisions?

Questions for Consumer Panel Consideration:

- Can you give an example of when another factor has outweighed health and healthcare?

Needed Information in the Cost and Quality Domains

Consumers need information on both cost and quality to help them make healthcare decisions. Additionally, consumers need this information to be transparent and easily accessible to them. While the specific information needed may vary by the decision to be made, there are some general types of cost and quality information that may be needed to make healthcare decisions:

Cost Domains:

Consumers want information to understand how much they will need to spend out-of-pocket for healthcare services, including prices for services and, if they are insured, contributions towards premiums and/or cost sharing.^{xi} Examples of cost domains may include:

- Premiums
- Deductibles
- Out of pocket costs
- Price for a specific service
- Co-Pays

- Costs not covered by insurance
- Insurance plan “allowable” amount/”approved pricing”

Quality Domains:

The quality issues in healthcare are well established. Like most products, consumers do not want to make healthcare decisions on price alone; they want to know if a service will be safe, it will improve their health, and they will be treated with respect during the process. Quality measurement can help to provide consumers with this information. Quality domains that consumers may want information on include:

- Appropriateness (including adherence to guidelines/evidence based medicine)
- Patient and family experience or satisfaction
 - Is treatment in accordance with patient preferences?
 - Was the billing information correct and easy to understand?
- Access to care
- Safety
 - Risks associated with a healthcare service
- Outcomes
 - Does a service improve health status (clinical and functional status)?
 - What is the expected recovery experience?

Questions for Panel Consideration:

- What cost and price information do consumers need to support their healthcare decisions?
- How can cost and price information be more transparent to consumers?
 - At the beginning of care?
 - When a consumer receives a bill?
- What quality information do consumers need to support their decisions healthcare decisions?
- How can quality information be more transparent to consumers?

Decisions about Affordable Care across the Patient-Focused Episode of Care

Population at Risk

The population at risk includes the population of patients other than those who have started in the clinical phase of the episode of care. Patients in this phase may be at risk for a condition but they have not yet been diagnosed with one. Patients in this phase may make health and healthcare decisions that promote wellness as well as prevent disease.

Decisions in the Population at Risk Phase

Consumers face a number of choices in this phase, and may include making choices about whether a behavior that may keep them healthy will be worthwhile, whether they can afford health insurance and if so, what plan to enroll in, which primary care provider to see, and what screening, preventive, and wellness services to receive.

Examples of decisions consumers may face in the population at risk phase include:

Selecting a health plan

In the current payment system, consumers must first decide if they want to purchase health insurance coverage and, if so, select an insurance plan. Consumers may receive coverage through an employer-sponsored plan, purchase a plan on the newly established health insurance exchanges, or be eligible for care through Medicare or Medicaid. Consumers need information on health plan cost and quality to make a decision on affordable coverage.

Selecting Primary Care Providers

Patients who have regular access to primary care are more likely to receive preventative services and timely care for medical conditions before they become more costly to treat. Access to primary care is associated with fewer hospitalizations and emergency department visits, better management of chronic conditions, increased adherence to treatment recommendations and reduced mortality^{xii}.

Preventing Disease

Selected prevention strategies are the most efficient approach to care.^{xiii} With 60 percent of American deaths attributable to behavioral factors, social circumstances, and physical environmental exposures, it is crucial to ensure the optimal use of preventive services and superior clinical preventive care, provide support for healthy lifestyle behaviors, and address social and environmental issues that lead to poorer health outcomes.^{xiv} However, a healthy lifestyle is not without costs. For example, one study found that a healthy diet costs about \$1.50 more per day than an unhealthy one, about \$550 more per year per person^{xv}. This can be a significant barrier to healthy eating to low-income families.

Screening

Consumers are frequently subjected to unnecessary tests with no evidence of benefit and possible risk of harm.^{xvi} Unwarranted tests, based on U.S. Preventive Services Task Force recommendations, have been estimated to be ordered more than 40 percent of the time during annual health exams.^{xvii} Consumers may have choices when it comes to having a screening, and what type of test may be most affordable for them. For example, if a consumer chooses to have a screening for colon cancer may have a range of options with varying prices including colonoscopy, flexible sigmoidoscopy, or a fecal occult blood test.

Question(s) for Panel Consideration:

- When and what are the decisions consumers make during the population at risk phase?

Information needed by consumers:

Consumers need access to information about the appropriateness of a given service for someone with their risk factors as well as cost and quality information to help them make healthcare decisions in the population at risk phase. Consumers may need both population level information to help them see cost or quality information broadly, as well as information that is individualized to help them understand their own possible costs.

Questions for Panel Consideration:

- Is it possible to currently get the cost and quality information consumers need to make decisions before being diagnosed with an illness?
 - If so, where do consumers currently get cost and quality information to support their decisions in this phase?
- Where would consumers like to get information about cost and quality from? Who is the authoritative source?
- How might the decisions consumers make vary by consumer attributes?
- How can clinicians help consumers make affordable choices? Can clinicians incorporate cost information into a shared decision making process? Would you change providers based solely on price if this information was share?
- What is the role of other stakeholders (providers such as hospitals, payors, purchasers) in supporting these decisions?
- How might the willingness of these entities to be transparent (or to not be transparent) impact a consumer’s decision? For example would it impact your decision in choosing between two hospitals, if one hospital had no pricing/cost information available and another shared it on their website or provided it to information ahead of time?
- Considering the cost and quality domains discussed above, what are the specific pieces of information consumers would need to make a decision?
 - Examples may include the amount of time a primary care provider spent with you, the experience of similar consumers with an insurance plan, or the amount a consumer might have to pay for a preventive service such as a mammogram.
- Given all of the factors (information, players, consumer attributes, etc.) that are weighed during decision-making, what/who is it that “clenches” the decision?

Evaluation and Initial Management

This phase begins at the onset or diagnosis of a clinical illness or an acute event. It should include an initial assessment of an informed patient’s preferences regarding the available treatment options.

Decisions in the Evaluation and Initial Management Phase

The decision to seek treatment for an urgent or emergent medical condition may need to occur without time for reviewing alternative providers or treatment options. When a person is sick, cost becomes just one factor in determining where and when treatment is obtained.^{xviii} However, many conditions are less urgent and allow for consumers to have a choice about when and how they seek treatment. For treatment of such conditions, consumers increasingly need to make decisions based on price.

Examples of decisions consumers may face in the evaluation and initial management phase include:

Selection of a physician

A patient may face a number of choices about selecting a physician. A condition may require care from a specialist or it may be handled by a primary care physician.

Selection of a hospital

Conditions that are not immediately urgent may allow a consumer a choice about where to seek treatment. While prices can vary widely from one hospital to another, there is limited information available to help consumers choose the most affordable option.

Alternative Approaches

Some conditions can be effectively treated with less intense, less invasive options that can be more affordable for the consumer. For example, low back pain may be successfully treated with physical therapy and a patient may not necessarily need surgery to address the problem. Clinicians are more commonly engaging patients in shared-decision making to help them make choices when a number of treatment options may have similar effectiveness but have different risks and timelines. Clinicians may not always address cost in this discussion. Additionally, there may be limited cost data available to support the conversation between clinicians and consumers.

Question(s) for Panel Consideration:

- When and what are the decisions consumers make during the evaluation and initial management phase?
- How can consumers get access to important information about appropriateness and choice of treatment options?

Information needed by consumers:

Non-emergent conditions may allow consumers to have a choice of which provider to see or which treatment to receive. However, the limited available data can make it challenging for consumers to find relevant cost and quality information. For consumers with insurance, some information on cost and quality is available from their health plan. Some states have started providing pricing information based on databases of insurance claims. Additionally some non-profits are also offering state level pricing information. Websites allow consumers to search and compare the prices of providers in their areas. Information on quality can be found on websites operated by the Department of Health and Human Services as well some non-profit groups.

Questions for Panel Consideration:

- Is it possible to currently get the cost and quality information consumers need to make decisions about treating a disease?
 - If so, where do consumers currently get cost and quality information to support their decisions in this phase?
- Where would consumers like to get information about cost and quality from? Who is the authoritative source?

- How might the decisions consumers make vary by consumer attributes?
- How can clinicians help consumers make affordable choices? Can clinicians incorporate cost information into a shared decision making process? Would you change providers based solely on price if this information was share?
- What is the role of other stakeholders (providers such as hospitals, payors, and purchasers) in supporting these decisions?
- Considering the cost and quality domains discussed above, what are the specific pieces of information consumers would need to make a decision?
 - Examples may include the outcome of a certain procedure, what the chance of a complication might be, and what portion of the cost a consumer would be expected to pay.

Follow up Care:

This phase addresses a patient’s on-going care needs that may exist after the evaluation and initial management phase. This phase should focus on seamless care coordination, targeting care transitions and medication reconciliation, particularly during hand-offs between providers and across different settings. This phase may involve post-acute or long-term care. Post-acute care (PAC) refers to healthcare provided following an acute hospitalization and typically delivered in skilled nursing facilities (SNF), inpatient rehabilitation facilities, long-term care hospitals, home health care, and outpatient rehabilitation.^{xix} Long-term care (LTC) includes both medical and non-medical care rendered to people with chronic illnesses or disabilities and can be provided in the home, nursing home, or in assisted living facilities.^{xx}

Decisions in the Follow up Care Phase

Consumers face a number of healthcare decisions in the follow up care phase. Consumers may need time in a nursing home to fully recover from a condition or may require medications to help manage a condition long-term.

Examples of decisions consumers may face in the follow-up care phase include:

Selection of PAC/LTC Providers

After a hospitalization a consumer may require continuing care, either in a specialized facility or at home to help improve the transition back to the community. Consumers need cost data to help support their choice of a post-acute care or long term care provider.

Chronic Disease Management

A patient may require on-going medication therapy and follow up visits to a clinician to help manage chronic conditions. Consumers need information about whether a medication is on their plan’s formulary, about the availability of lower cost alternatives and if there is variation in the price of a medication from one pharmacy to another as well as information on the quality of their clinician and what they will need to pay for follow-up visits.

Family Support and Caregiving

Patients with chronic conditions may need ongoing caregiving support. Informal caregiving is a vital part of the long-term care system and family caregivers can face financial insecurity and financial burdens^{xxi}. Out-of-pocket medical expenses for a family caring for someone who needs help with activities of daily living such as bathing or dressing are more than 2.5 times greater than for a non-caregiving family (11.2% of income vs. 4.1%).^{xxii} Additionally, caregivers face workplace issues and caregiving can be costly to both employers and employees in terms of lost wages and job productivity.^{xxiii} Additionally, not all patients may have family support available. Consumers also need information about eligibility for home and community based services to help provide caregiving support.

Question(s) for Panel Consideration:

- When and what are the decisions consumers make during the follow up care phase?
- How can consumers get access to important information about appropriateness and choice of treatment options?

Information needed by consumers:

The care a patient needs in the follow-up care phase can vary greatly. The choices a consumer faces in the phase can be particularly challenging and costly as they may involve a long stay in a facility such as a SNF or long term care hospital (LTCH) or a difficult decision about the affordability of a certain medication required to manage a chronic condition. Consumers may need information about the post-acute and long-term care that their insurance plan will cover or which facilities are included in their plan's network. In this phase, more information about what to expect from the costs and duration of treatments may be available. Consumers may have to carefully monitor changing costs for managing a chronic condition or may have to consider limits in their benefits, such as the number of SNF days covered by Medicare or reaching coverage gaps such as the Medicare Part D "donut hole".

Questions for Panel Consideration:

- Is it possible to currently get the cost and quality information consumers need to make decisions about follow up care?
 - If so, where do consumers currently get cost and quality information to support their decisions in this phase?
- Where would consumers like to get information about cost and quality from? Who is the authoritative source?
- How might the decision consumers make vary by consumer attributes?
- How can clinicians help consumers make affordable choices? Can clinicians incorporate cost information into a shared decision making process?
- What is the role of other stakeholders (providers such as hospitals, payors, purchasers) in supporting these decisions?
- Considering the cost and quality domains discussed above, what are the specific pieces of information consumers would need to make a decision?
 - Examples may include the price of a certain medication or the rate of adverse events such as pressure ulcers or infections at a certain nursing facility

IV. Case Studies

Session Goal: To use case studies to understand the application of the episode of care framework for determining consumer decisions and information needs.

The expert panel will break into small groups and work through a case study of how a consumer could use cost and quality measurement information across their episode of care. Cases have been developed to represent a number of conditions and consumer types to demonstrate the ways cost and resource use measurement can support a consumer in determining if care will be affordable for them.

Questions for Panel Consideration:

- What are the decisions this patient with these conditions would need to make at the various different phases across the episode of care?
- What information (cost and quality) would this patient need to support their decisions?
- What are the factors (insurance status, income, health literacy, etc.) that may impact the patient's decisions?

V. Current Challenges and the Path Forward

Session Goal: To explore the challenges consumers face when trying to make healthcare decisions, as well as possible solutions.

A number of challenges exist that can prevent consumers from using cost and quality data to support their healthcare decisions. Information is not always available to consumers or if it is available may not be accessible or available to them in a timely manner. Additionally, consumers may not feel empowered to bargain or to make decisions based on cost or quality data.

Availability of Information

Price and cost information are not always available to consumers at the time they need it and in a way that supports decision-making and negotiation. Additionally, clinicians may not have information about cost or price to assist in consumer decision making. Increased availability of information to consumers and clinicians, including more transparent prices, could allow consumers to make choices that are affordable for them.

Question(s) for Panel Consideration:

- Who do consumers expect to have information about how much a service will cost?
- How can we fill gaps in the availability of cost and quality information to consumers?
- How should cost and quality data be reported?
- How can cost and quality data be meaningful to consumers?

Timing and Customization of Information

Consumers need information on healthcare costs at the right time. Additionally, information that is customized to the individual and what he/she can expect the actual costs to be may be preferred over population level measures in some cases. However, different consumers may prefer to receive information in different ways. More research, both theoretical and applied is needed in this area.

Question(s) for Panel Consideration:

- How can consumers get the necessary information at the right time?
- What different modes of information distribution may be needed?

Consumers Associate Higher Cost with Higher Quality

A current challenge in publicly reporting information on affordability is that consumers often associate higher costs with higher clinical quality^{xxiv} underscoring the need to show cost data in the context of meaningful health outcomes data. Studies show that presenting cost data alongside easy-to-interpret quality information and highlighting high-value options improved the likelihood that consumers would choose those options.^{xxv} Showing consumers that in some instances all the alternatives are equal in quality—such as in many drug and device situations enables them to pursue the lowest priced option for them.

Trust

Consumers need to trust that quality and cost information is non-biased and allows them to act in their best interest. Studies have shown that consumers do not trust drug companies, insurers, and government but do trust doctors, nurses, pharmacists and consumer groups.

Questions for Panel Consideration:

- What are the implications of consumer trust on the use of cost and quality information?
- What sources of information on cost and quality would consumers trust the most?

Consumer Empowerment

Some consumers may not feel empowered to seek out cost and price data when making healthcare decisions. Incorporating a consideration of cost into conversations about shared-decision making may be one way to empower consumers to make affordable healthcare choices. Decision aids or tools may help lay out a consumer's options to give them information on choices and appropriateness to help inform their preferences.

Question(s) for Panel Consideration:

- How can we encourage consumers to use cost and quality information to support their decisions?
- How can cost data be more accessible and useful to consumers?
- How can consumers be empowered to seek and use cost and quality data?
- How can we encourage consumers to use cost and quality information to support their decisions?

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