Measuring Affordability from the Patient's Perspective

Review Draft for Comment

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NATIONAL QUALITY FORUM

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DRAFT PAPER FOR REVIEW

Executive Summary

Rising healthcare costs burdening the nation's economy and impacting the competitiveness of U.S. businesses, the sustainability of federal and state government finances, and family's budgets. To understand the impacts healthcare costs are having on patients and consumers, the National Quality Forum (NQF), with support from the Robert Wood Johnson Foundation, organized a two-day meeting that brought together key stakeholders including patients, consumers, health plans, researchers, clinicians, and community health experts. The goal of the meeting was to explore what healthcare affordability means from the consumer and patient perspective and to understand what information patients and consumers need to find affordable care.

Given significant concerns about people's ability to pay for healthcare, a primary focus of the meeting was defining affordability from a patient and consumer point of view. During the meeting discussions, consumer and patient representatives emphasized that they first judged whether care was affordable based on what their out of pocket costs for healthcare were relative to their family's overall budget, taking into consideration tradeoffs that may need to be made in order to afford healthcare and make ends meet. However, cost alone was not the only factor considered, as consumer and patient representatives also emphasized that they were interested in high quality care at the best possible cost, not low quality care at low cost. Adding additional complexity to understanding affordability, the consumer and patient representatives highlighted that different groups of patients will be making different healthcare decisions based on their health status, with those who minimally interact with the healthcare system operating differently from those who engage the healthcare system frequently.

Context is critical, as consumers and patients view affordability differently based on the particular situation, such as buying insurance, selecting preventive screenings to stay healthy, seeking treatment for an urgent ailment, managing chronic illness, or dealing with end-of-life issues. Each of these situations introduces different complexities, has different challenges in navigating the health care system, and requires different information for decisionmaking. Lack of availability to needed information can often present a barrier in making informed choices, and consumers and patients are often unsure of what questions to ask to get the answers they need.

While this meeting focused on the patient and consumer perspective, it is clear that patients alone cannot accomplish the needed changes; rather, sustainable change will require effort from all stakeholders—health plans, purchasers and employers, providers, suppliers and industry, and communities. Each group has different actions they can take to improve the affordability of healthcare, and each group has different resources that can be brought to bear. Yet, there is promise that coordinated action should help ensure health care is affordable for patients and the nation.

Urgent need to act on healthcare cost and affordability

Rising healthcare costs have become a significant burden to the nation, with healthcare now comprising approximately 18 percent of the nation's economy.[1] Beyond national figures, healthcare costs are having real impacts on the competitiveness of U.S. businesses, on the sustainability of federal and state government finances, and on family's budgets. Families have seen their health insurance premiums increase by almost 130 percent in the past decade while their out-of-pocket spending has risen by almost 80 percent.[2] Because of these increases, families' real income has been essentially flat for the past decade as all increases in people's wages and income have been consumed by growing healthcare costs.[3]

As patients and consumers shoulder greater healthcare costs, they are increasingly shopping around for high quality healthcare they can afford. Yet, people rarely are able to find the information they need, and, even when they can, the information may not be understandable, or they encounter barriers in using it to reduce their bills. At the same time, people often do not know that there are options—although not always good options—and that the final decision is theirs to make.

NQF action on understanding healthcare cost and affordability

To understand the impacts healthcare costs are having on patients and consumers, the National Quality Forum (NQF), with support from the Robert Wood Johnson Foundation, organized a two-day meeting that brought together key stakeholders including patients and families (some who interact with the health system regularly because of serious health conditions), consumers, health plans, researchers, clinicians, and community health experts. The goal of the meeting was to explore what healthcare affordability means from the consumer and patient perspective and to understand what information patients and consumers need to find affordable care.

This project is part of a portfolio at NQF aimed at improving healthcare affordability, with other projects including:

- *Linking Cost and Quality*: Exploring approaches to combine cost and quality information and identifying best practices in producing and communicating this information.
- *Cost and Resource* Use: Recognizing and endorsing new cost and resource use measures.
- *Episode Grouper Evaluation Criteria*: Understanding the best approaches for collecting costs information for episodes of care.
- *MAP Affordability Task Force*: Selecting a suite of measures for value-based purchasing and public programs that can help promote affordability.

This portfolio of projects is intended to work together to provide tools and guidance to multiple stakeholders in controlling costs while improving quality and people's health. The current project undergirds these efforts by centering attention on the patient and their needs.

Patient perspectives on affordability

Given significant concerns about people's ability to pay for healthcare, a primary focus of the meeting was defining affordability from a patient and consumer point of view. Understanding people's views is critical to providing useful information to consumers, and allows for assessment of whether different initiatives affect the affordability of care. The committee recognized that individuals will have different perspectives depending on whether they are currently receiving healthcare services (patients), are shopping around and considering different healthcare options (consumers), or are part of the broader community (all people). This report largely focuses on the consumer and patient perspective, but does include other terms where appropriate.

Affordability centers on out of pocket costs

During the meeting discussions, consumer and patient representatives emphasized that they first judged whether care was affordable based on how much of their budget they spent on healthcare. Summarizing this from a financial perspective, patient affordability can be viewed as:

$$Patient\ Affordability = {}^{Out\ of\ pocket\ costs}/_{Household\ budget}$$

In this equation, out-of-pocket costs include the multiple ways that patients spend on healthcare: health insurance premiums, deductibles, co-pays or co-insurance, and paying for healthcare services not covered by insurance. The denominator captures a person's total earnings from their work and other sources. The meeting participants highlighted this must be adjusted for other obligations on their income, such as debt from prior medical bills and family responsibilities.

Multiple sources support this definition of affordability. First, this equation fits with an intuitive understanding of affordability—the more that a household budget goes toward healthcare, the more that people have to make trade-offs with other expenses. Second, it is currently used in public policies and is being used to determine whether health insurance options are affordable under state and federal health reform efforts.[4] Furthermore, it is consistent with prior research, with multiple focus group and consumer testing studies finding that people are concerned about their total out of pocket costs, and find this information meaningful and useful.[5,6,7,8]

Affordability does not exist in a vacuum

While appearing simple, there are several complexities in applying the model in practice. Most notably, this model assumes high quality care at all settings, including health outcomes, patient experience and patient engagement, and safety. Patient and consumer representatives at the meeting stressed that they were interested in high quality care at the best possible cost, not low quality care at low cost.

While patients and consumers were mainly interested in their out of pocket costs when calculating affordability, they did account for other factors in their decisions. For example, patients consider indirect costs, like inconvenience, missing work or other commitments, managing childcare and eldercare

responsibilities, and overall effort in navigating their care. Furthermore, several patients noted that they were interested in the total costs paid (by the health plan and themselves) for a given treatment, clinician, or hospital because higher total costs would eventually affect their insurance premiums.

An important consideration was whether care was needed or appropriate. Consumers felt that spending money on care that is not needed or inappropriate negatively impacted healthcare's affordability, as those costs did not help them get better. Yet, there was uncertainty in identifying unnecessary or inappropriate care. For instance, consumers reported that they were often unsure whether they should go to the emergency room for a concern or visit their doctor, and they were unsure how to get information to help make that decision. This example has to be viewed based on people's overall perceptions of risk and benefit, as some people are more comfortable waiting to see if they got better while others preferred the certainty of a medical examination.

Affordability differs for different types of health decisions

Different groups of consumers and patients will be making different healthcare decisions based on their health status. For example, some people are not using many healthcare services, such as younger, healthy adults or "young invincibles," while other people have significant health needs, such "frequent flyers" to hospitals or emergency rooms.[9] As an example of the differences in decision making, behavioral economics research shows that people facing repeated decisions, like those with a chronic disease, will have different decision making processes than those dealing with acute conditions.[10]

There are a variety of healthcare decisions—for physical or behavioral health—that a patient might face, including:[11]

- Buying insurance (whether on exchanges, through employer, or with public program)
- Staying healthy (prevention and wellness)
- Getting better (acute care, emergency and urgent care, scheduled and unscheduled care)
- Managing ongoing condition/living with disease (chronic care)
- Dealing with serious illness (ex. care at the end of life)

Figure 1 illustrates these different decisions and highlights that they take place in the context of a person's overall life, underscoring that affordability decisions do not take place in a vacuum. The remainder of this section describes the considerations for each decision.

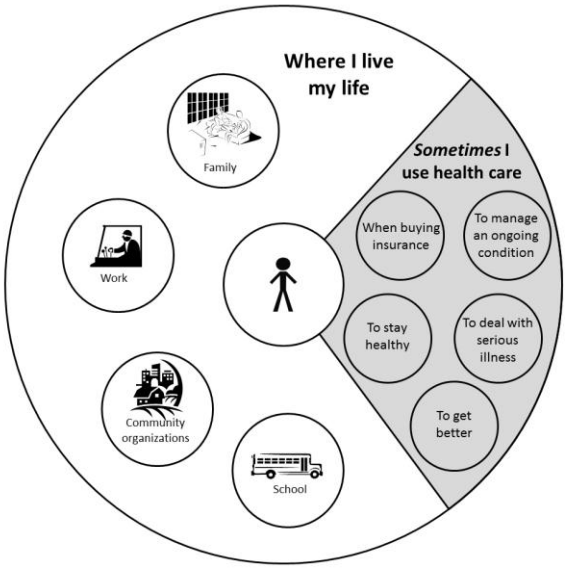

Figure 1. Conceptual model of consumer decision making, outlining the key decisions people face and their context.

Buying insurance

Currently, consumers may buy coverage through their employer; purchase a plan on the newly established health insurance exchanges; or be eligible for care through Medicare, Medicaid, Veterans Health Administration, or other public programs. When there are multiple options for consumers to choose between, people need information on the plan's cost (premiums and cost-sharing), covered services and benefits, and overall quality. This information has changed in recent years with the introduction of coverage facts labels, which were established by the Affordable Care Act. Yet, further information is still needed to understand exactly how an insurance plan affects an individual consumer, with their specific health conditions, medications, and regular healthcare services.

Staying healthy

There are several ways that clinical care can help people stay healthy or avoid specific conditions, but consumers may not have the information they need to decide what tests, screenings, scans, or services are appropriate for them. As a result, consumers and patients can be subjected to unnecessary tests with no evidence of benefit and possible risk of harm; alternatively, consumers and patients may not be getting the tests they need, leading to future costs or harm. Addressing this situation requires patients and providers to engage in a shared-decision making process, with communication of more information on what is appropriate and where options exist to prevent a given condition.

Getting better

When seeking unscheduled treatment for an urgent or emergent medical condition, patients may not have time to consider different options for providers or treatments. This is compounded for extremely serious or life-threatening conditions, as noted in the serious illness section. In the middle of these situations, cost becomes a small factor in determining where and when treatment is obtained.[12] However, many conditions are less urgent and allow for consumers and patients to have a choice about

when and how they seek treatment. For treatment of such conditions, consumers and patients increasingly are making decisions based on cost and quality, including the choice of clinician or hospital.

There is limited data available when selecting clinicians, hospitals, or post-acute care. For consumers with insurance, some information on cost and quality may be available from their health plan. Other information on cost and quality may also be provided by states, federal agencies, non-profits, and commercial websites. These sources vary in their scientific accuracy, comprehensiveness of information, and usability. However, their proliferation suggests that there is untapped demand in using this information.

Beyond the choice of clinicians or hospitals, consumers and patients may also have the opportunity to consider different treatment options. When there is no clear best option, clinicians are increasingly engaging patients in shared-decision making process to discuss the different risks and benefits of each treatment possibility. For example, low back pain may be treated with physical therapy or surgery, and shared decision making could help consumers decide which option is right for them. Clinicians may not always address cost in the conversation, but evidence suggests that involved patients often choose less invasive options.[13]

Managing ongoing conditions or living with disease

Patients diagnosed with chronic conditions will have an ongoing relationship with the health system in order to manage their condition and treatment. For example, such patients may require regular medication therapy or regular visits to check their current status. Individuals with more extensive healthcare needs will be more focused on healthcare costs because their out of pocket expenses will be significantly larger. To help ensure their care is affordable, individuals with chronic disease will need information about their treatments—whether their medications are on their plan's formulary, whether options are available, and how to do their part to manage the disease. As they often see multiple providers, they also will need assistance coordinating their care and ensuring that necessary clinical information is shared to all of their providers.

Dealing with serious illness

As noted earlier, patients dealing with life-threatening conditions or extremely serious illnesses will view affordability in a different light, as healthcare costs may be only a small part of a patient's decisionmaking process. Beyond costs, patients managing life-limiting illnesses have additional issues to navigate. Under these difficult circumstances, people have to make decisions about what clinical treatments to pursue or not, how to take advantage of palliative care options to manage their pain or symptoms, and how to ensure that care is respectful of their preferences. Despite progress, there is still evidence that care at the end of life does not align with people's goals, such as passing away at home versus in the hospital.[14] Furthermore, patients with serious illness may require ongoing caregiving support, either through family and friends or through home and community-based services. These can be costly to obtain (either directly or indirectly through burdens on informal caregivers), and there is little information to help patients and their families make these decisions under stressful circumstances.

Common challenges facing patients

Regardless of the type of decision, the meeting participants highlighted similar challenges in accessing affordable care.

Difficulty navigating the health system

An overarching theme throughout the meeting was that healthcare is complex and difficult to navigate. There are many causes for this—care is fragmented among many providers, clinicians may not communicate about a patient's care, and it is not clear what options people have for their clinician or treatment. These problems are compounded when patients are struggling with an illness and its associated stresses.

However, unless patients and consumers can navigate the system, they will be unable to be active participants in improving the affordability of their care. Technology can provide an opportunity for improving the situation, with new web tools for providing information on options for clinicians and healthcare organizations, connecting consumers and patients to each other, or considering options for healthcare decisions. However, consumers need to be involved in the development of these tools in order to ensure that they are accessible, understandable, and actionable when making healthcare decisions.

Understanding what questions to ask

Consumers noted the need for resources to help them understand what information they need to determine if care is affordable. As one panel member noted, "I don't know what I don't know." The panel was clear that many people don't even know the questions to ask, what resources are available to them, that there are tools that could be useful to them as they navigate healthcare decisions, or how to use available tools. In one survey, when consumers and patients were asked about their confidence in finding more qualified doctors by using quality data and quality information, about 60 percent of participants believed that they could do so. When asked about their confidence in getting lower cost healthcare by comparing cost information and shopping for better prices, only about one-third believed that they could actually reduce the cost of healthcare.[15] Furthermore, studies suggest that patients need basic information about their condition first, which can then serve as context when comparing treatment options, providers, or hospitals.[16]

Confusing and uncoordinated healthcare billing

Consumers need information to help them understand billing and what to expect. Consumers expressed frustration with the current way they are billed for healthcare services and the difficulty they experience when trying to understand their bills. There is a need for consumer-friendly language for billing—the terms are not clearly explained and have different meanings that those used in other parts of everyday life. This is compounded by the fact that people receive multiple bills for each treatment, such as different bills for radiology or anesthesia or an overall hospital stay. For patients with complex diseases that see multiple clinicians, each of them will likely send their own bill. These patients may set up monthly payment plans to manage the bills, but may juggle multiple bills from different providers, each

with a separate minimum monthly payment. Adding to the complexity, some clinicians may allow patients to set up a monthly payment plan, while others may not. Confusing billing makes care seem less affordable, as well as making the healthcare system harder to navigate.

Finding out prices and costs in advance

The current lack of price transparency makes it difficult for consumers to know what care will cost ahead of time.[17] Since healthcare prices for private health insurance are generally negotiated, they are often not disclosed to the public. For example, most healthcare facilities, imaging centers, and clinician practices do not have price information publicly available for frequently performed procedures. [18] Patients are not alone in not knowing this information—their clinician also often does not know the negotiated price of a given treatment or service. The panel noted that the development of tools such as total estimated price of the service, the provider's network status, and the patient's estimated out-of-pocket responsibility would help patients to make informed decisions and better understand if their decisions are affordable.[19] Some price and cost resources are available—such as through employers, insurance plans, or state efforts—and more work is needed to make these tools consumer-friendly and provide cost and quality in an easy to use format.[20,21]

Difficulty obtaining meaningful, usable information about quality

Similar to other aspects of people's lives, consumers and patients do not want to make healthcare decisions on price alone; they want to know if a service will be safe, if it will improve their health, and if they will be treated with respect during the process. Yet, currently available tools do not support this goal—few patients and consumers are aware of publicly reported information of healthcare quality, and fewer still are able to apply it to their particular healthcare decision.[22,23] Prior research has uncovered the multiple factors for effectively presenting quality information—the information must be easy to use, meaningful to a patient's situation, understandable, and from a trusted source of information—and more work is needed to address these specific concerns.[24] The patient participants at the meeting consistently highlighted that they were interested in more information on quality and would like to know where to access that data.

Tailoring information to people's circumstances and needs

Different consumers and patients have different capabilities for understanding healthcare information, with different levels of healthy literacy, overall literacy, numeracy, and health benefits literacy varying widely across the patients. [25] This is partially due to the complexity of modern medicine, as well as the intricacies of the benefit structure of health plans. Tools will need to be customized based on people's health literacy in order to have the greatest impact, and clinicians and other professionals working with the patient should consider customized communication based on health literacy.

However, the panel noted that consumers will differ in what information they would like, and the same consumer may seek different information depending on both the reasons for which he or she is seeking healthcare and his or her personal circumstances (ex. available support network, current financial status, current medical conditions, and other factors). [26,27] As well, patients are at different levels of

engagement with their healthcare, and more engaged or empowered patients may be more willing to seek out information and apply it to their care.[28] Furthermore, insured and uninsured patients will have different concerns and need for information.

As consumers obtain and analyze cost and quality information, each individual will consider it differently as an input into making a healthcare decision. One decisionmaking framework discussed at the meeting was the health belief model (see Table 1), which describes the multiple factors people weigh in any health or healthcare decision.[29] The model is useful for identifying specific factors patients and consumers consider, recognizing how perspectives differ for those factors, and outlining potential strategies for assisting people as they weigh each factor.

Table 1. Summary of health belief model, which describes the factors individuals weigh in making a health decision.

Factors	Strategies for affecting that factor
Perceptions about possibility of getting a disease or condition (susceptibility)	Help people understand their real susceptibility if it differs from perception
Perceptions on severity of conditions and its consequences	Communications about the consequences of the condition
Perceptions of the benefits of treatments	Help people understand what action to take and how to do so, communicate the potential positive effects and risks
Perceived barriers to care and costs (direct and indirect)	Identify and reduce the perceived costs and barriers to care
Communication strategies, reminders, and other cues that could encourage action	Increase awareness through information, providing how-to information
Confidence in ability to take action	Provide training and supports for self care

Adapted from National Institute of Health. [30]

Moving forward: Everyone has a role to play

While this meeting focused on the patient and consumer perspective, it is clear that patients alone cannot accomplish the needed changes. Rather, sustainable change will require effort from all stakeholders—health plans, purchasers and employers, providers, suppliers and industry, and communities. Each group has different actions they can take to improve the affordability of healthcare, and each group has different resources that can be brought to bear. Examples where further action could occur include:

- Clinicians can provide information and help patients understand how it affects their particular situation, perhaps through a shared-decision making model. Patients at the meeting reiterated that their clinician is their preferred and trusted source of information. However, the panel noted that clinicians may not have the tools or training they need to provide patients with necessary price information.[31] The panel noted that clinicians may struggle with the concept of having a conversation about the cost of care and may not know what the total cost of care will be, a patient's insurance status, or where a patient is in regards to deductible or out of pocket maximum.

- Health insurance companies could share estimates of expected expenses and provide resources to help consumers understand what care is covered and what expenses they might be responsible for.
- Federal and state agencies, non-profits, health plans, healthcare organizations, and others can increase the amount of cost and quality information available online. Patients are increasingly turning to the internet for health information, with almost three-quarters reporting they used the internet to find information in the past year. [32]
- Hospitals and clinicians can provide more transparent pricing and provide consumers with "good faith estimates" about the cost of care before they agree to a service.
- Other patients in similar situations are critical for helping people understand what options mean for their life and can help connect people to healthcare and community resources.[33,34]
- The educational system can integrate health concepts and health benefits concepts into the curriculum in secondary education and beyond to increase understanding across society.
- Independent non-profit organizations, free from conflict of interest or financial incentives, can assist in advancing cultural change and transparency in how purchasers, payers, the federal government, providers, and other stakeholders share cost and quality information.

The actions of all stakeholders can help to ensure healthcare remains affordable for patients and their families.

Appendix A: Measuring Affordability Panel and NQF Staff

PANEL MEMBERS

Elizabeth Mort, MD, MPH (Co-Chair)
Massachusetts General Hospital, Massachusetts General Physician Organization
Boston, MA

Melissa Thomason (Co-Chair)
Vidant Health
Greenville, NC

Deborah Dahl, BSE, MBA
Banner Health
Phoenix, AZ

Maureen Ediger
Children's Hospital of Colorado
Denver, CO

Tina Frontera, RN, MHA
MN Community Measurement
Minneapolis, MN

Jessica Greene, PhD
George Washington University
Washington, DC

Alyssa Keefe, MPP
California Hospital Association
Washington, DC

Lisa Latts, MD, MSPH, MBA, FACP
LML Health Solutions
Denver, CO

Tayler Lofquist
Beekeeper Group
Washington, DC

Marci Nielsen, PhD, MPH
Patient Centered Primary Care Collaborative
Washington, DC

Carrie Nelson, MD, MS, FAAFP
Advocate Physician Partners
Rolling Meadows, IL

Cynthia Rolfe
Blue Cross and Blue Shield Association
Chicago, IL

Paul Sierzenski, MD, RDMS, FACEP
Christiana Care Health System
Wilmington, DE

Alison Shippy, MPH
National Partnership for Women & Families
Washington, DC

Joseph Singer, MD
HealthCore, Inc.
Wilmington, DE

Kris Soegaard
Minnesota Health Action Group
Bloomington, MN

Adam Thompson
Charlottesville, VA

Lina Walker, PhD
AARP
Washington, DC

Ronald Walters, MD, MBA, MHA, MS
The University of Texas M. D. Anderson Cancer Center
Houston, TX

Corey Wilborn
Jacksonville, FL

NQF STAFF

Helen Burstin, MD, MPH
Senior Vice President
Performance Measures

Robert Saunders, PhD
Senior Director
Strategic Partnerships

Taroon Amin, MA, MPH
Senior Director
Performance Measures

Ashlie Wilbon, RN, MPH
Managing Director
Performance Measures

Lindsey Tighe, MS
Senior Project Manager
Performance Measures

Erin O'Rourke
Project Manager
Strategic Partnerships

Vy Luong
Project Analyst
Performance Measures

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