

June 22, 2012

The Honorable Kathleen Sebelius  
Secretary  
Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201

***Subject: Immediate Steps to Improve Support for Consumers' Health Decision-Making***

Dear Madam Secretary:

This letter contains observations and recommendations from the National Committee on Vital and Health Statistics (NCVHS) on the improvements needed to provide meaningful quality information to consumers, patients, and family caregivers to support their health care choices. NCVHS is the statutory public advisory body on health data, statistics, and health information policy for the Department of Health and Human Services (HHS). One of its focus areas is helping to identify strategies for better aligning the nation's quality measurement strategy with the goals of health care reform and with our national investment in health information technology. In this letter, we propose actions the Department can take to enhance the usefulness of consumer-oriented cost and quality information, regardless of the consumers' coverage. Health insurance exchanges present an immediate opportunity to apply these recommendations.<sup>1</sup>

Over the past ten years, the interest in and supply of quality measures for the nation's health system have expanded, as can be seen in a host of public policy and measure endorsement activities. In addition, the Department has produced two annual progress reports to Congress on the *National Strategy for Quality Improvement in Health Care*.<sup>2</sup> These reports support the three aims of improving health, improving quality of care, and lowering the cost of care for all Americans. One of the six priorities in the National Quality Strategy is "Ensuring Person- and Family-Centered Care," with strategies that include building patients' perspectives into all performance assessments and establishing the Patient Centered Outcomes Research Institute (PCORI) to assist patients, clinicians and policymakers in making informed health decisions.

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<sup>1</sup> This letter addresses cost from the consumer's perspective, defining it as *the insurance premium plus out-of-pocket costs to the consumer*.

<sup>2</sup> These reports, which are mandated by the Patient Protection and Affordable Care Act of 2010 (P. L. 111-148), were released in March 2011 and April 2012.

NCVHS saw an important intersection between the priorities of the National Quality Strategy and the Department's near-term obligation to support the decision-making needs of the consumers accessing federally-supported health insurance exchanges, as outlined in the Affordable Care Act (ACA).<sup>3</sup> The Committee held a hearing on "Measures that Matter to Consumers" on February 28-29, 2012, and heard from a wide array of experts and stakeholder groups including AARP, Consumers Union, patient advocates, researchers, large employers, communities, providers, and standards and technology firms. The panelists focused on three fundamental consumer decisions: 1) selecting a health plan, 2) choosing appropriate providers of care, and 3) evaluating treatment options offered by their providers.

Two overriding themes stood out in the hearing. The first is that today, health care consumers are often "flying blind" as they select a health insurance plan, choose a health care provider or care team, and try to participate in decisions about their health. They struggle to use existing publicly reported quality measures because neither the measures nor quality improvement approaches were designed to help consumers make health-related decisions. The second hearing theme underscores the paramount importance of building patients' perspectives into all performance assessments by listening to consumers and patients and engaging them in the design and testing of consumer-oriented quality measures and information retrieval tools.

The Committee recognizes that there is an urgent need to provide consumers with data to help them make informed decisions when selecting their health insurance through the health insurance exchanges. As the Department proposes and finalizes rules regarding the insurance exchanges, we seek to enhance the relevance and informative nature of the resources presented through the exchanges. We believe that some of the recommendations in this letter can be applied immediately to the insurance exchanges as they are being established, and all of the recommendations also can be applied to health insurance markets to help consumers make health-related choices. Another opportunity available to the federal government where these recommendations could be implemented is the Federal Employee Health Benefits Program. Of course, the majority of the recommendations apply to all health-related measures, whether or not they are administered by the federal government.

### ***Major Findings from the February Hearing***

The findings from the February, 2012, NCVHS hearing on measures that matter to consumers can be briefly summarized as follows:

1. The cost and quality information now available to consumers is insufficient and inadequate for enabling consumers to make decisions about health care coverage, providers, and treatment.

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<sup>3</sup>ACA Section 1311, Part 2 (Consumer Choices and Insurance Competition through Health Benefit Exchanges).

- a. Although coverage and cost are threshold issues for health care consumers, available information makes it difficult to answer the simple question, *What will it cost me?* Ideally, consumers would like to be able to understand the expected costs for their personal health situation.
  - b. There is a lack of quality information (for example, local, provider-level measures on performance, patient experience, and outcomes) that consumers can easily understand and use to make informed decisions about providers or insurers.
  - c. The absence of standards is a major barrier to useful comparative cost and quality information for consumers and patients. In addition, the existence of proprietary measures, especially related to functional status, may limit their use due to the costs involved.
2. To enable consumers to make value-based health care decisions, cost and quality information must be understandable and relevant to the individual and be derived from both quantitative measures and qualitative comments. In addition, consumer-oriented quality information and decision support must accommodate the diverse needs, preferences, and capacities of American consumers and allow for variations in language, general literacy, health literacy, numeracy, and the ability to access and use computer and online technologies.
3. As a source of quality and cost information, providers and health systems need to be more proactive in providing consumers with the data and tools they need to make informed, value-based health care decisions. Providers need to enhance their skills to effectively discuss care decisions and personal health management with patients. In addition, providers need to incorporate routine functional status assessments into their practice.
4. Aggregate information on the health of local communities is a critical and underdeveloped dimension of health care quality information. Few U.S. communities have access to local information that integrates population health data with data on the performance and outcomes of local health care providers. Community-wide health assessments are necessary to inform local decisions about prevention and interventions targeting local health priorities, as discussed in the December 2011 NCVHS report, *The Community as a Learning System: Using Local Data to Improve Local Health*.
5. The U.S. can improve health care consumer decision-making now by providing the best data and tools available, in accordance with what is already known about how consumers make decisions. Over time, more meaningful and usable information can be developed by involving consumers and patients in user-centered design and conducting further research on consumer decision-making and information use.

Based on these findings, the National Committee on Vital and Health Statistics offers the following recommendations to the Department:

## ***NCVHS Recommendations***

- 1. HHS should provide technical guidance to support development and implementation of measures and consumer decision-making tools that are relevant, usable, and accessible (i.e., “consumer-helpful”).**
  - a. Guidance should ensure that the measures and tools used in federal health insurance exchanges are relevant to and usable by consumers. HHS-supported consumer information presentations should include formal usability/validation testing prior to release and an ongoing feedback mechanism for assessing usability, accessibility, and usefulness to their intended audiences.
  - b. Additional research is needed to understand how consumers choose health plans and providers and how to support those decisions with appropriate information.
  - c. Additional research is needed to develop measures of patient-centered care, including patients' evaluations of communications with clinicians, assistants, and others who interact with patients. Research is also needed on measures of patient activation.
  - d. Training materials and software should be developed to support consumer assessment of the suitability of prospective health plans and providers for the specific needs of individuals.
  
- 2. In order to address the immediate need to support consumer decision-making in selecting health insurance, HHS should develop model report formats for use by federally-supported state health insurance exchanges to present information on coverage, cost, and quality for insurance products listed in the exchange.**
  - a. Exchanges should display information and provide tools for decision-making on health insurance coverage options in a way that allows user-friendly comparisons among available options. Displays should include a way for consumers to compare both cost and quality for the 30 most common services, procedures, and prescription drugs along the lines of nutrition-style labeling. Consumers should be able to customize the visual display based on personal preferences and health concerns so the information is of maximum value to them. Information on costs should be linked to (or organized in terms of) information on quality.<sup>4</sup>
  - b. Because choosing a provider and a plan are inextricably linked for many consumers (for example, for consumers who will base coverage choices on

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<sup>4</sup>We recognize that starting in September 2012, additional information will be available to consumers in the required Summary of Benefits and Coverage. Another promising emerging resource is the Insurance Finder on [healthcare.gov](http://healthcare.gov).

whether their physicians are in a plan's network), health insurance exchanges should provide geographically specific information on the health care provider networks available through each insurance/plan option. Descriptive information and quality measures about providers should be made available to consumers and patients in standardized form and should contain the following information content, at a minimum:

- Provider demographics, location, office hours, and language;
- Quality measures in domains including functional status, longitudinal measures of quality, and patient-reported outcomes; and
- Patient experience of care.

- c. HHS should develop a consolidated set of existing federal and federally mandated reports (e.g., Meaningful Use-qualified, Physician Quality Reporting System, and the various Consumer Assessments of Healthcare Providers and Systems—HCAHPS and CG-CAHPS), with software to help consumers visualize the data in meaningful ways. This set should appear on all federally supported insurance exchange web sites.

**3. HHS should encourage collaboration among the entities that develop and endorse consumer-oriented measures of health and health care to ensure that these measures are relevant, well-specified, and publicly available and that they leverage consistent value sets.<sup>5</sup>**

- a. HHS should promote the public availability and use of consumer-helpful and patient-centered measures and instruments.
- b. Specifications for consumer-helpful/patient-centered measures should have clear details regarding terminology, numerator and denominator construction, value sets, and metadata so that measures can be understood and implemented consistently.
- c. NQF and other measure endorsement bodies should incorporate these specifications into endorsement criteria for measures for consumers.
- d. Additional standards development is needed related to representing consumer-oriented quality measures.
- e. All consumer-oriented measures should be developed and tested according to the principles of user-centered design.

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<sup>5</sup>The scope of work defined for the Patient-Centered Outcomes Research Institute (PCORI) by the Affordable Care Act would support work in this area.

***Final Comments***

In conclusion, the lack of relevant and usable cost and quality information for consumers impedes attempts to reform our current health delivery system. We believe the establishment of health insurance exchanges provides a unique opportunity to stimulate the development and presentation of information that consumers find usable, meaningful, and actionable. Our recommendations leverage the near-term opportunity to influence the information available on health insurance plans and health care providers, to help consumers make informed choices. Helping consumers make meaningful decisions about their health is essential to improving the health system.

As always, NCVHS stands ready to assist the Department in implementing these recommendations.

Sincerely,

/s/

Justine M. Carr, M.D.

Chairperson,

National Committee on Vital and Health Statistics

Cc: Data Council Co-Chairs