

# CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS  
ADDRESSING PUBLIC POLICY ISSUES IN CANCER

October 31, 2011

Donald M. Berwick, M.D., M.P.P.  
Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
Room 445-G  
Hubert H. Humphrey Building  
200 Independence Avenue, SW  
Washington, DC 20201

RE: CMS-9989-P, Proposed Rule on Establishment of Exchanges and Qualified Health Plans

Dear Dr. Berwick:

The Cancer Leadership Council, including cancer patient, provider, and research organizations, appreciates the opportunity to comment on the proposed rule setting standards for the establishment of health insurance exchanges and qualified health plans. Our comments focus on revisions to the proposed rule that will ensure that the exchanges are responsive to the needs of patients with serious and life-threatening illnesses, including the 12 million Americans living with cancer and the 1.5 million newly diagnosed each year. Our recommendations relate to governance of the exchanges, availability of assistance to consumers to obtain accurate information about the exchanges and insurance coverage options in order to make informed insurance decisions, and network adequacy standards.

## *Entities Eligible to Carry Out Exchange Functions (§155.110)*

We strongly recommend that the proposed rule be amended to include patient and consumer advocates among the categories of individuals identified for service on the governing boards of exchanges. The proposed standards specify that: 1) the governing board not include a majority of members with conflicts of interest, and 2) the board include a majority of members with relevant experience in health benefits administration, public health, or health policy issues related to the small group and individual markets and the uninsured. The list of potential governing board members should include patient and consumer advocates, as their role as voting members of the boards will help to guarantee that the experience of patients is fully understood and reflected in decisions about the operation of the exchanges. The perspective of patients will be valuable in

deliberations and decision-making on such matters as design and content of plan information, the enrollment process, the benefit package, and special enrollment periods.

We believe that individuals with direct experience in the health care system as patients would be appropriate nominees as members of governing boards. In addition, those who have served as volunteers or employees of patient advocacy, patient service, or research organizations – assisting patients in understanding health insurance coverage options, the benefits and cost-sharing requirements of plans, and other important issues related to plan access and affordability -- will also have the depth of experience and expertise to serve as governing board members. Whether their work is professional or volunteer, those individuals who have direct experience interacting with and counseling consumers would bring valuable assets to exchange governing boards.

Through appointment of high quality governing board members with direct understanding of consumers' health insurance needs and deep experience in consumer and patient education, the exchanges will be able to capitalize on the other positive attributes of proposed exchange governance to the benefit of their consumers. These standards include the operation of the exchanges under publicly adopted charters and the advance scheduling of public exchange meetings.

#### *Stakeholder Consultation (§155.130)*

Cancer patients – currently 12 million strong with their number projected to increase rapidly with the aging of the American population—typically have significant health care needs at the time of diagnosis and substantial ongoing health care needs during the period of long-term survivorship. Because of their significant numbers and health care needs, cancer patients should be among those stakeholders consulted by exchanges on topics related to the operation of the exchanges and the insurance coverage options offered through the exchanges.

We commend the general language related to stakeholder consultation and the language identifying among those stakeholders to be consulted, “Advocates for enrolling hard to reach populations, which include individuals with mental health or substance abuse disorder.” We propose that the regulation be amended to add “advocates for those diagnosed with, treated for, and living with cancer” as a specific group to be consulted by exchanges. Cancer patient representatives will be in a solid position to provide advice to the exchanges about the information, insurance, and health care needs of a sizable population of Americans with significant and complex insurance and health care needs.

Consultation with cancer patient advocate stakeholders should be undertaken in addition to, rather than as a substitute for, inclusion of consumer and patient advocates on the governing boards of the exchanges.

### *Navigator Program Standards (§155.210)*

Many of the undersigned organizations have extensive experience in providing counseling, patient services, and navigation assistance to individuals with cancer. Although in many cases the patient assistance programs have not focused primarily on health insurance matters, these organizations have the ability to reach cancer patients and their families through diverse means and strategies, systems for ensuring high quality of information and individual counseling, and strategies for training counselors and patient service representatives to ensure that information and services are up-to-date and delivered timely and professionally.

We are pleased that the Affordable Care Act authorizes navigation services for consumers and that the proposed rule establishes reasonable standards for the navigators who will assist consumers with regard to insurance options and enrollment. We recommend that officials consider the successful models and standards for navigation services in clinical settings, including those in community-based settings, in refining the standards for navigation services in the Exchanges. We are concerned, however, that the promise of navigation services may not be realized because of the prohibition against the use of federal funds for exchange operation to support navigation services. The restriction on the use of federal funds for navigation and state budget challenges combine to create a situation in which the promise of navigation in the exchanges may not be realized.

Although organizations with navigation services or comparable programs can provide significant assistance to consumers seeking insurance coverage through the exchanges, an expansion of their services and appropriate training of navigators with regard to health insurance coverage will require some commitment of resources. We urge the Centers for Medicare & Medicaid Services (CMS) to offer advice and resources to those administering exchanges to enable them to utilize the network of organizations already serving consumers and patients for the purpose of providing navigation services to those relying on the exchanges for purchase of insurance.

### *Establishment of Exchange Network Adequacy Standards (§155.1050)*

Cancer patients often have complex health care needs and depend on access to multi-disciplinary teams of cancer care specialists for their care. Cancer patients may require access to surgery, radiation, and chemotherapy, along with management of the side effects of cancer and cancer treatment. That care can often be provided in the community, at practices or clinics that are close to the patient's home and that provide advantages for the patient undergoing treatment that may administered daily for a period of weeks, or weekly for a matter of months. For some patients, in contrast, the only appropriate care may be in the academic health center or cancer center.

We recommend that exchanges be required to set standards for qualified health plans (QHPs) that will protect the access of cancer patients to appropriate and high quality care. We are concerned that the access of cancer patients to quality care may not be protected

by the proposed rule, which provides that an exchange “must ensure that the provider network of each QHP offers a sufficient choice of providers for enrollees.” This standard is not adequate to ensure cancer patients access to care in reasonable proximity to home or care in a cancer center or other academic health center, if such care is necessary for appropriate management of the patient’s disease. We urge that CMS establish more detailed standards for network adequacy, including: 1) a requirement that QHPs retain sufficient numbers of cancer care specialists and sub-specialists, located in reasonable proximity to patients enrolled in their plans, and 2) a standard that cancer patients be assured access to care provided by out-of-network providers, at no additional cost compared to in-network care, when adequate care cannot be provided by in-network providers.

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The undersigned cancer organizations appreciate the opportunity to offer recommendations that would strengthen the involvement of consumers and patients in exchange governance and that would ensure the adequacy of the provider network of the exchanges for quality cancer care. We look forward to the completion of this rulemaking process and additional rulemaking to address other issues related to the functioning of the exchanges.

Sincerely,

**Cancer Leadership Council**

American Society for Radiation Oncology  
Bladder Cancer Advocacy Network  
Cancer Support Community  
The Children's Cause for Cancer Advocacy  
International Myeloma Foundation  
The Leukemia & Lymphoma Society  
LIVESTRONG  
Lymphoma Research Foundation  
Multiple Myeloma Research Foundation  
National Coalition for Cancer Survivorship  
National Lung Cancer Partnership  
Prevent Cancer Foundation  
Sarcoma Foundation of America  
Susan G. Komen for the Cure Advocacy Alliance  
Us TOO International Prostate Cancer Education and Support Network

