

# CANCER LEADERSHIP COUNCIL

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

October 4, 2010

The Honorable Kathleen Sebelius  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: OCIO-9989-NC

Dear Secretary Sebelius:

The undersigned cancer patient, provider, and research organizations are pleased to submit comments on the establishment of the American Health Benefits Exchanges (Exchanges) authorized by the Patient Protection and Affordable Care Act. Our comments focus on the development of Exchange standards that would ensure cancer patients access to meaningful health insurance coverage and the implementation of mechanisms and structures for providing cancer survivors comprehensive information to compare health insurance options.

## *Exchange Governance or Advisory Groups*

We recommend that the Secretary develop standards that would require the Exchanges to have patient advocates as part of the governance structure of the Exchanges or as members of advisory groups that would be routinely consulted by the Exchange management. The advice of patient advocates, including those with serious health care needs and significant experience in the health insurance system, would be beneficial on topics such as the optimal utilization of Navigators, the development of a standardized format for comparison of health plans, and monitoring of the status of Qualified Health Plans (QHPs).

## *Qualified Health Plans*

Cancer survivors have serious health care needs, including the need for comprehensive and well-coordinated specialty care upon diagnosis and survivorship monitoring and follow-up care after active treatment. We encourage the Secretary to exercise her authority for certification of QHPs to define standards that will guarantee those with cancer and other serious and life-threatening illnesses access to the specialty care that is necessary for good outcomes. We urge the Secretary, in developing such standards, to consult with professional societies, patient advocacy, and consumer organizations

regarding the scope and number of providers, including cancer centers and academic health centers, that should be included in QHPs.

We are pleased that the Affordable Care Act includes a requirement for coverage of the routine patient care costs for those enrolled in cancer clinical trials. This provision will ensure that the QHPs that are offered through the Exchanges will include this coverage and will eliminate the serious concern regarding reimbursement for those cancer patients receiving care in a clinical trial.

### *Survivorship*

The undersigned organizations embrace the designation of an individual as a “cancer survivor” from the time of diagnosis, through active treatment to survivorship monitoring and follow-up care. We would like to direct special attention to the health care needs of cancer patients after active treatment, as this group of survivors may experience a wide range of late and long-term effects of cancer and its treatment, including second cancers. These cancer survivors, numbering 12 million, require access to survivorship monitoring and care. We encourage the Secretary to consider standards for QHPs that would enhance the access of cancer survivors to the specialized survivorship care that can contribute to early detection and appropriate treatment of the side effects of cancer and treatment.

We also encourage strong standards for the coordination by the Exchanges of Medicaid, Children’s Health Insurance Program (CHIP), and Exchange plan enrollment, a matter of special importance to survivors of childhood cancer. Two-thirds of childhood cancer survivors experience at least one late and long-term effect, and as many as one-fourth experience a life-threatening side effect. For these patients, interruptions in care because of lack of coordination of Medicaid, CHIP, and Exchange enrollment are unacceptable.

### *Health Plan Ratings*

We encourage the development of a plan rating system that would be adopted across all Exchanges, including those administered by the states and those administered by the federal government. Consumer utilization of such a rating system would be facilitated by a web portal developed by the federal government and adopted by all Exchanges. We acknowledge that the state-based structure of the Exchanges may create hurdles to adoption of a single plan rating system but urge its development and utilization despite these obstacles. The utilization of such a system will provide important consumer education and protections.

### *Navigators*

The Affordable Care Act authorizes the Exchanges to make grants to Navigators to be involved in the insurance enrollment process and to provide referrals for grievances, complaints, or questions. We enthusiastically endorse this provision of the Act, which will allow states to utilize the abilities of community-based organizations, disease

foundations, patient advocacy organizations, and consumer groups to reach diverse communities to share information about the Exchanges and to assist individuals in the insurance choice and enrollment process. We also believe the Navigators may play a key role in ensuring that Exchange information is made available in a manner that is culturally and linguistically appropriate to the needs of consumers.

We recommend that the Exchanges aggressively exercise their authority to make grants to Navigators, including by considering grants to multiple Navigators per Exchange and by giving the Navigators significant authority for the enrollment process. There may be special value in awarding Navigator grants to organizations that have deep roots in a single disease community, as they may have strong connections and skills for reaching out to their community.

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We appreciate the opportunity to offer comments on the Exchanges in advance of the rulemaking process and look forward to additional opportunities for comment.

Sincerely,

**Cancer Leadership Council**

American Society for Radiation Oncology  
American Society of Clinical Oncology  
Bladder Cancer Advocacy Network  
C3: Colorectal Cancer Coalition  
Cancer Support Community  
The Children's Cause for Cancer Advocacy  
Education Network to Advance Cancer Clinical Trials (ENACCT)  
International Myeloma Foundation  
Lance Armstrong Foundation  
The Leukemia & Lymphoma Society  
Lymphoma Research Foundation  
Multiple Myeloma Research Foundation  
National Coalition for Cancer Survivorship  
National Lung Cancer Partnership  
Ovarian Cancer National Alliance  
Pancreatic Cancer Action Network  
Prevent Cancer Foundation  
Sarcoma Foundation of America  
Us TOO International Prostate Cancer Education and Support Network