

# CANCER LEADERSHIP COUNCIL

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

February 21, 2013

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

Re: CMS-2334-P, Proposed Rule on Medicaid, Children's Health Insurance Programs, and Exchanges: Essential Health Benefits in Alternative Benefit Plans, Eligibility Notices, Fair Hearing and Appeal Processes for Medicaid and Exchange Eligibility Appeals and Other Provisions Related to Eligibility and Enrollment for Exchanges, Medicaid and CHIP, and Medicaid Premiums and Cost Sharing

Dear Secretary Sebelius:

The undersigned organizations, representing cancer patients, physicians, and researchers, appreciate the opportunity to comment on the proposed rule on Medicaid, Children's Health Insurance Programs, and Exchanges. Our organizations are committed to the implementation of the Affordable Care Act in a manner that permits informed consumer decision-making with regard to insurance options and also encourages the delivery of quality care. We appreciate the considerable challenge that the Centers for Medicare & Medicaid Services (CMS) faces in implementing new health insurance options in a way that balances cost and access. In the agency's decisions to grant states considerable flexibility in imposing cost-sharing requirements for the expanded Medicaid program, it has tilted toward cost containment in a way that puts cancer patient access to care at risk. Our comments address that issue and additional concerns of cancer patients and physicians.

## ***Cost-Sharing Requirements***

The expanded Medicaid program holds great promise for providing cancer survivors access to care that many have not received at all and others have received too late. We anticipate that many who are living with cancer as a chronic disease and who may have suffered interruptions in employment may find Medicaid to be a life-saving insurance

option. These individuals may need complex multi-disciplinary care for the management of their cancer and the late and long-term effects of cancer and its treatment.

The cost-sharing flexibility that CMS has provided the states may undermine the effectiveness of the Medicaid expansion as a viable option for those with cancer by increasing cost-sharing responsibilities and putting quality care out of the reach of enrollees. The proposed rule would permit states to boost cost-sharing for non-preferred drugs to \$8 for those with family income at or below 150 percent of poverty and 20 percent of the cost the agency pays for non-preferred drugs for those with incomes above 150 percent of the federal poverty level. The cost-sharing requirements for inpatient stays would be 50% of the cost the agency pays for the first day of care (for those at or below 100 percent of poverty), 50% of the cost of the first day or 10% of the total cost the agency pays for the entire stay (for those with incomes at 101-150% of poverty), and 50% of the cost the agency pays for the first day of care or 20% of the total cost the agency pays for the stay (for those with incomes at or above 150% of poverty).

The preferred drug list might not include the drugs that are necessary for treatment of a Medicaid patient's cancer, and the patient who is living paycheck to paycheck might not be able to afford the cost-sharing for the non-preferred drug (or in the case of cancer patients, cost sharing for multiple drugs, all considered non-preferred). A similar situation might exist for inpatient care. Cancer patients have repeatedly expressed their interest in receiving their cancer care in outpatient settings, but inpatient care is required for administration of certain chemotherapy agents and in some situations for management of serious side-effects. Inpatient care is also necessary for those patients whose cancer care includes surgery. The cost-sharing requirements for this treatment option may be crippling, and as a result the patient will seek other options in the place of inpatient care – options that may not be appropriate or adequate for treatment of their cancer.

The proposed rule contains two provisions that might offer the patient some protection if the state imposes the most aggressive cost-sharing requirements, but the protections are inadequate. The overall out-of-pocket cap on spending will offer protection too late in the care process, and patients will make decisions about specific episodes of care without consideration of their ultimate out-of-pocket protection. States are required to define a process whereby a physician would recommend that a non-preferred drug is the best treatment option and that no preferred drug is an acceptable alternative, but the proposed rule does not set appropriate standards for this process and as a result it is not clear that such process would offer protections in many states.

The balance between cost and access must be adjusted with regard to state flexibility on patient cost-sharing in order to protect patient access to appropriate and high quality care.

### ***Essential Health Benefits***

According to the proposed rule, the alternative health plan would be designed by the choice of one of four benchmark plans, with coverage of the chosen plan supplemented if necessary to ensure that all essential health benefit categories are included. In addition, whereas the preamble to the rule says that all drugs of the companies that participate in the drug rebate program should be included in the alternative benefit plan, that language is not included in the language of the proposed regulation. We recommend that the regulatory language be amended to correct that omission.

The agency also says that the states have the flexibility to “adopt prior authorization and other utilization control measures, as well as policies that promote use of generic drugs.” There is the potential for conflict between the prescription drug coverage of an alternative health plan supplemented by the state’s essential health benefit standard and a drug benefit that is consistent with the state’s Medicaid program. We urge clarification of the coverage standard, accompanied by protections to ensure that patients can appeal utilization controls that might prevent them from receiving necessary medications.

### ***The Medically Frail***

We commend CMS for the definition of medically frail and the inclusion in this definition of “individuals with serious and complex medical conditions.” Cancer survivors managing complex treatment or a complicated set of late and long-term effects would fit this definition and would be exempt from mandatory enrollment in an Alternative Benefit Plan. We support this definition, which would permit those with serious and complex medical conditions the choice of the most appropriate benefit plan for their special and complex health care needs.

### ***Coordination of Eligibility and Appeals Processes***

We commend CMS for seeking advice about the eligibility and appeals processes from many stakeholders, including states, consumer advocates, and plain language experts. The advice is reflected in the solid progress toward a coordinated system for determination of eligibility for health coverage and appeals of eligibility decisions. We regret that the consolidated eligibility process will not be in place until 2015. We urge that every effort be made to honor the date of January 1, 2015; we do not support the extension of the deadline until October 15, 2015, for a consolidated system. Until the implementation date of January 1, 2015, it is our hope that the use of coordinated content about eligibility will help individuals and families through an eligibility and enrollment process in which they may receive notices from Medicaid, the Children’s Health Insurance Program, and the Exchange.

### *Certified Application Counselors*

We support establishment of the “Certified Application Counselor” program and the requirement that every exchange have such a program. We also approve of the proposed standards for training and performance for Certified Application Counselors, which will help to ensure that these counselors provide effective assistance to individuals and families evaluating health insurance options. We urge CMS to address the relationship among Navigators, Assisters, and Certified Application Counselors. In addition, although it is outside the scope of this regulation, we urge the agency to offer guidance about possible funding streams or mechanisms to support the Certified Application Counselor programs.

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We appreciate the opportunity to comment on the proposed rule including many core standards to guide the operation of the exchanges and the expanded Medicaid program.

Sincerely,

### **Cancer Leadership Council**

American Society for Radiation Oncology  
Bladder Cancer Advocacy Network  
Cancer Support Community  
The Children's Cause for Cancer Advocacy  
Fight Colorectal Cancer  
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  
Susan G. Komen for the Cure Advocacy Alliance