

# CANCER LEADERSHIP COUNCIL

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

June 5, 2019

The Honorable Lamar Alexander  
Chairman  
Senate Committee on Health, Education, Labor and Pensions  
United States Senate  
Washington, DC 20510

The Honorable Patty Murray  
Ranking Member  
Senate Committee on Health, Education, Labor and Pensions  
United States Senate  
Washington, DC 20510

Dear Chairman Alexander and Ranking Member Murray:

The undersigned organizations representing cancer patients, health care professionals, and researchers appreciate the opportunity to comment on bipartisan discussion draft legislation to reduce health care costs. We commend your leadership in developing this discussion draft, which you have indicated will likely be part of a larger health care package.

## ***Surprise Medical Bills***

Cancer patients regrettably find themselves all too often managing surprise medical bills. Important cancer care delivery reforms and care coordination efforts have reduced cancer patient utilization of the emergency department for management of treatment side effects. Nonetheless, patients sometimes find that the emergency department is the best or only option for treatment of serious treatment side effects. Unfortunately, those visits are sometimes followed by surprise medical bills.

The legislative option that you have offered is a patient-centered one that seems to offer meaningful protections. We do not have strong advice about the three options you have outlined for payment of providers who generate surprise out-of-network bills. We generally support the concept that “choosing an in-network hospital means receiving in-network care,” which would require providers to join an insurance network or send a bill through the hospital. We offer the caution that in the case of emergency care, the patient may not be able to make a choice of in-network care.

### ***Lower Prescription Drug Costs***

Financial toxicity has been added to the list of serious side effects of cancer treatment, with patients all too often struggling to manage the cost-sharing for all elements of complex multi-disciplinary care. Among those responsibilities are cost-sharing amounts for expensive medicines that can improve quality of life, extend survival, and even prove life-saving. We are pleased that the bipartisan package that you have offered would take steps to encourage competition in drug markets.

The discussion draft would also require the Food and Drug Administration (FDA) to establish an internet website to provide educational materials for health care professionals, providers, and caregivers on biological products, including biosimilar and interchangeable biological products. In the past, we have offered advice to the agency regarding the potential for agency collaboration with patient advocacy organizations and professional societies on educational efforts related to biosimilars. The websites and educational materials maintained and disseminated by these organizations are trusted sources of information for patients and providers, and they could be of critical importance in biosimilar educational efforts. FDA has a strong record of engaging in patient-focused drug development and other patient-focused efforts, both initiated before and subsequent to the enactment of the 21<sup>st</sup> Century Cures Act. Biosimilar education could be another important area for collaboration.

We encourage you to revise the draft bill to include collaborative educational efforts related to biosimilars as an option for FDA.

We understand the draft bill that you have offered will likely be combined with other provisions related to drug pricing. We look forward to reviewing those additional measures when they are offered.

### ***Transparency in the Health Care Market***

We support the provisions of the legislation that are aimed at providing more transparency in the health care market. These include the requirements for transparency in the costs, fees, and rebate information in the contracts between plan sponsors and pharmacy benefit managers (PBMs), standards for supplying bills to patients after hospital discharge, bans of gag clauses that prevent employers and patients from knowing the price and quality of health care services, and requiring insurance companies to supply up-to-date provider directories to patients.

There is also included in the bill a requirement that providers and insurers provide patients with price quotes on out-of-pocket costs for care, to empower patients to shop for care.

Perhaps the most aggressive transparency requirement is the designation of a nongovernmental, nonprofit entity to improve the transparency of healthcare costs. This entity, to be advised by a public-private advisory board regarding uses of health claims data from public and private health plans, would use de-identified data to help patients, providers, academic researchers, and plan sponsors understand cost and quality of care.

Transparency in health care is an important goal, as the free flow of information is generally a good thing for consumers. However, raw data are not always actionable by consumers, and providing actionable cost and quality information can be challenging. There is an ongoing experiment in supplying patients out-of-pocket cost information through the Oncology Care Model, a Medicare payment and delivery demonstration project. Accomplishing the goal of out-of-pocket cost communication has presented challenges and required hard work and adaptation by the OCM participating practices. We urge that the lessons of the OCM be considered as proposals for transparency in health care focusing on cost communication are advanced.

In the case of the nongovernmental, nonprofit entity to receive and analyze health care claims data, we also urge consideration of current and ongoing efforts using health care claims data and coordination with those efforts. In addition, cancer organizations are working to develop common cancer care data elements to improve medical records. These efforts may also inform the transparency aims of the draft discussion bill.

### ***Leading Healthier Lives***

In our initial comments to you regarding development of this package, we urged a stronger federal emphasis on obesity prevention, and we are pleased to see such efforts included in your package. Our interest in obesity prevention is motivated by research that links obesity and the risk of developing certain cancers. We see efforts to prevent obesity as part of an overarching cancer risk reduction initiative.

We are also pleased by the emphasis on technology-based health care models for patients in rural and underserved areas. Cancer care providers are engaged in innovative efforts to use technology to strengthen cancer care delivery; some see special promise in the use of technology for long-term survivorship care.

We appreciate the opportunity to comment on the discussion draft and look forward to continued discussions regarding strategies to improve health care quality and reduce costs.

Sincerely,

### **Cancer Leadership Council**

Academy of Oncology Nurse & Patient Navigators  
CancerCare  
Cancer Support Community  
The Children's Cause for Cancer Advocacy  
Fight Colorectal Cancer  
International Myeloma Foundation  
LUNgevity Foundation  
Lymphoma Research Foundation  
National Coalition for Cancer Survivorship  
Ovarian Cancer Research Alliance  
Prevent Cancer Foundation  
Susan G. Komen