CANCER LEADERSHIP COUNCIL

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

March 1, 2019

The Honorable Lamar Alexander
Chairman
Senate HELP Committee
United States Senate
Washington, DC 20510

Submitted electronically at LowerHealthCareCosts@help.senate.gov

Dear Chairman Alexander:

The undersigned cancer organizations represent cancer survivors, health care professionals, and researchers. We appreciate the opportunity to share our ideas about improving the delivery of cancer care so that quality is boosted, health care resources are protected, and care is truly patient-centered.

Improving Treatment Decision-Making from Diagnosis Across the Care Continuum

We agree that health care resources should be used as efficiently as possible and that patients should receive all care that is necessary but should also be able to avoid unnecessary care. For cancer patients, informed decision-making accompanied by the coordination of all elements of cancer care can improve access to patient-centered care.

We have two recommendations for Congressional action to foster cancer care planning and coordination and to ensure the efficient use of cancer care resources: 1) enactment of the Cancer Care Planning and Communications Act (HR 5160 in the 115th Congress and soon to be reintroduced in the 116th Congress) and 2) continuation of the Oncology Care Model demonstration model for its full five-year test. These efforts – one aimed at improving payment and delivery in the fee-for-service Medicare program and the other a test of an episode-of-care pilot that includes treatment planning services and core navigation services – hold promise of ensuring the delivery of high-quality to cancer patients.

We recommend a strong focus on improving the Medicare program as a cancer care payer because one-half of all cancer diagnoses occur among seniors.[1] A reform effort aimed at Medicare will provide benefits to a large proportion of cancer patients and will also set a standard for other third-party payers.

[1] National Cancer Institute website. Retrieved on February 27, 2019, from https://www.cancer.gov/about-cancer/causes-prevention/risk/age.

The Institute of Medicine (now the National Academy of Medicine) has recommended that a cancer care plan be provided to all cancer patients.[2] This planning process should consider the patient's preferences for treatment, provide information about all treatment options and side effects, supply information about symptom management, and supply data about cost of care to the patient, among other elements. The Cancer Care Planning and Communication Act would reimburse providers for developing and sharing a cancer care plan (meeting the standards above) with patients at the beginning of treatment, when there is a change in prognosis or treatment, and at the transition from active treatment to survivorship. A plan of this sort holds promise of ensuring that patients receive the care that they need and that their multi-disciplinary care will be coordinated.

The Oncology Care Model (OCM) incorporates the cancer care planning process outlined by the Institute of Medicine and includes additional efforts that are aimed at ensuring access to patient-centered care.[3] The Oncology Care Model is about halfway through its five-year term, and we urge Congress to support its continuation through the planned five years and through additional evaluations. We recommend that Congress express its support for the Oncology Care Model, to prevent the disruption of the model that might occur if there is a challenge to the work of the Center for Medicare & Medicaid Innovation, or CMMI.

We support the continuation of the OCM to learn all possible lessons from an episode-of-care payment model that emphasizes treatment planning, navigation, and 24/7 access to medical professionals with health records access. Early evaluations of the OCM indicate that key goals of the patient-centered model are being realized.[4] After the full term and final evaluation of the OCM, changes to Medicare cancer care payment and delivery may be warranted on the basis of the demonstration.

The establishment of a cancer care planning service in fee-for-service Medicare and the continuation of the OCM will foster a better treatment decision-making process for many cancer patients. We urge Congressional support for these efforts.

Improve the Delivery of Survivorship Care

While efforts are underway among professional societies to improve the development of survivorship care plans, we recommend that Congress consider ways to define and finance episodes of survivorship care. The survivorship care plan may serve as the roadmap for long-term survivorship care after active treatment. However, even with a written plan, cancer survivors may be lost in transition from active treatment to survivorship care. [5]

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[22] National Academy of Medicine, Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis, 2013.

[3] Centers for Medicare & Medicaid Services website. Description of the Oncology Care Model and key milestones, retrieved on February 27, 2019: https://innovation.cms.gov/initiatives/oncology-care/.

[4] Abt Associates, Evaluation of the Oncology Care Model: Performance Period One, December 2018.

[5] National Academy of Medicine, From Cancer Patient to Cancer Survivor: Lost in Transition, 2005. The NAM report on cancer survivors detailed the problems faced by patients as they transition from active treatment to long-term survivorship during which health care monitoring and follow-up care are critical.

For some survivors, monitoring of late and long-term effects of treatment and follow-up care may be provided by the cancer center at which they received cancer treatment. Others are left to find survivorship care from oncologists or primary care physicians, sometimes finding a high-quality system of care and sometimes not. Survivors need an assurance that they can find an appropriate survivorship system of care, after a risk assessment that identifies the intensity of survivorship services that they may require.

We recommend that Congress consider two actions to improve survivorship care:

- Authorize a collaboration among federal agencies that might contribute to the design of new models of cancer survivorship care. The federal agencies or offices to engage in this effort might include the Centers for Disease Control and Prevention, the Office of Cancer Survivorship at the National Cancer Institute, and the Health Resources and Services Administration.
- Encourage CMMI to design a Survivorship Care Model that would test an episode of care model for survivorship care. The Oncology Care Model is a demonstration project that pays for episodes of care that center on delivery of chemotherapy. The Survivorship Care Model would provide for an episode of care beginning after active treatment. Congress might encourage CMMI to develop and test a survivorship care model.

Cancer survivorship is a public health problem, and Congress should consider the two actions above as part of a public health strategy to address the challenge of cancer survivorship.

Transparency Regarding the Cost of Cancer Care

Financial toxicity is a serious side effect of cancer treatment.[6] Cancer patients need the assurance of affordable and adequate insurance coverage to protect their access to care. Only with adequate insurance can a cancer patient be assured of coverage and payment for essential elements of cancer care with cost-sharing responsibilities that do not bankrupt them. However, patients will also benefit from reliable information about the cost of their care, so that they can consider that information as part of their treatment decision-making process.

The Oncology Care Model discussed above imposes a requirement on participating practices that they provide information on the cost of care to their patients. This has proven to be a difficult requirement for providers to meet, as providers struggle to understand the insurance coverage of their patients and the cost burden that patients will bear for various treatment options. However, this is the cost information that is useful to patients making treatment decisions.

The Trump Administration has proposed requiring that list prices be included in direct-to-consumer drug ads, a proposal that is of limited use to patients in their treatment decision-making. The recently implemented requirement that hospitals publish certain price data is also of limited use to consumers. The information that is most useful to patients – their own cost-

[6] Zafar SY and Abernethy AP, Financial Toxicity, Part I: A New Name for a Growing Problem. Oncology, 2015. Zafar SY and Abernethy AP, Financial Toxicity, Part II: How Can We Help With the Burden of Treatment-Related Costs?" Oncology, 2015.

sharing responsibilities for specific elements of care – is most difficult to obtain. We urge Congress to consider strategies for enhancing health care cost transparency in a manner that is meaningful to patients, at the time of treatment decision-making and throughout the management of their care.

The Trump Administration has proposed, in one of its drug pricing proposals, to support the development of a real-time drug pricing comparison tool. This sort of tool, although details are not yet known, would seem to be the sort of tool that would be useful to patients. Tools and information related to other elements of care are also important to patients, and we urge Congress to consider options for achieving greater price and cost-sharing transparency, in ways meaningful to patients.

Cancer Risk Reduction

Our recommendations focus on strategies to improve the delivery and payment of cancer care, to boost the overall quality of cancer care and to foster the efficient utilization of health care resources. We also wish to stress the importance of access to primary care and preventive services for cancer patients. Investing in preventive services is a wise financial choice for the nation.[7] If Americans have access to quality primary care, they will also be more likely to have access to cancer screening tests, including cervical cancer screening, colorectal cancer screening, and mammography, at the appropriate time and according to current recommendations. These screening tests are critical to cancer detection efforts.

Preventive care also holds the potential for improving quality of care and life for cancer patients. At the transition from active treatment to survivorship, cancer patients may require access to quality primary care. Smoking cessation services and counseling about alcohol use and weight control are important services for reducing cancer risk for all Americans and improving treatment outcomes for cancer patients.

Smoking accounts for about 30% of all cancer deaths in the United States. Although the link between smoking and lung cancer is well-understood, tobacco use is a risk factor for a number of cancers in addition to lung cancer.[8] Reduction in tobacco use is critical to reducing the incidence of a number of cancers. Fortunately, access to smoking cessation products and/or counseling is ensured to some extent in all insurance plans except grandfathered plans. Tobacco cessation services are also important to people with cancer, whose treatment outcomes may be adversely affected by their tobacco use. Ending tobacco use is of critical importance for those undergoing cancer treatment.

Recently published research studies and analyses have established that alcohol use is a risk factor for a number of malignancies.[9] Researchers are engaged in work to identify more precisely the risks of alcohol use. Even as research continues, some public health interventions

[7] Surgeon General's National Prevention Strategy, retrieved on February 27, 2019, at https://surgeongeneral.gov/priorities/prevention/strategy.appendix1.pdf.
[8] Centers for Disease Control and Prevention website, retrieved on February 27, 2019, at https://www.cdc.gov/tobacco/campaign/tips/diseases/cancer.html.
[9] National Cancer Institute website, retrieved on February 27, 2019, at https://www.cancer.gov/about-cancer/causes-prevention/risk/alcohol/alcohol-fact-sheet.

are possible. Public education about the links between alcohol use and cancer should be undertaken, and Congress could ensure that federal agencies have the resources to encourage such public education efforts. Congress should also consider whether counseling about the risks associated with alcohol use should be a preventive service that is subject to an insurance coverage requirement.

Cancers associated with overweight and obesity account for about 40% of all cancer diagnosed in the United States. The National Comprehensive Cancer Control Program and the state programs that are part of this effort have been the locus for education about the cancer risks associated with obesity. Congress should ensure that this program has appropriate resources to support federal and state cancer control efforts that include a focus on obesity and its links to cancer.

We appreciate the opportunity to comment on strategies to improve the delivery of patient-centered care and to ensure the efficient utilization of health care resources. We would be pleased to meet with you to share the experiences of our organizations related to the issues confronting cancer survivors that we have address above and to provide more detail on the policy proposals that we have identified in brief.

Sincerely,

Cancer Leadership Council

American Society of Clinical Oncology
Cancer*Care*
The Children's Cause for Cancer Advocacy
International Myeloma Foundation
LUNGevity Foundation
Lymphoma Research Foundation
National Coalition for Cancer Survivorship
Ovarian Cancer Research Alliance
Prevent Cancer Foundation
Sarcoma Foundation of America
Susan G. Komen