

# CANCER LEADERSHIP COUNCIL

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

November 20, 2017

Seema Verma  
Administrator  
Centers for Medicare & Medicaid Services  
Hubert H. Humphrey Building  
200 Independence Avenue, SW  
Washington, DC 20201

Dear Administrator Verma:

The undersigned organizations represent cancer patients and health professionals. We appreciate the opportunity to comment on the informal Request for Information (RFI) regarding the Innovation Center at the Centers for Medicare & Medicaid Services.

Our organizations, both cancer patient and cancer care professional, have a significant, productive, and ongoing relationship with the Innovation Center. Many of us have been engaged with the Innovation Center regarding the design and implementation of the Oncology Care Model (OCM), and some of the professional organizations in our membership are currently involved in the design of alternative payment models in addition to the OCM.

This letter will focus on strategies for testing new models of patient-centered patient care, which we will describe as models of relatively small scope that might be complementary to the OCM and other alternative payment models designed by cancer care professionals.

## ***Engagement of Patients and Patient Advocates in Design and Evaluation of New Models for Care and Payment***

The cancer patient community had a positive working relationship with the Innovation Center during the period of design and implementation of the OCM. Innovation Center staff made multiple presentations on the OCM to patient advocacy coalitions during the design phase, receiving and responding to input from patient advocates regarding suggested design refinements. In addition, Innovation Center staff accepted meetings with individual advocacy organizations to discuss OCM design issues.

Patient organizations have been among the stakeholders that have been briefed on the OCM as it has been implemented and have received information regarding the experience of participating practices and their patients. In addition, we have offered advice on certain written materials utilized in the OCM.

Not all of the recommendations of patient advocates have been accepted. For example, we have suggested that patient advocates be formally engaged in the evaluation of OCM, a recommendation that has not been accepted.

We offer this history to recommend it as a general model for engaging patients and patient advocates in design and evaluation of alternative payment models. We encourage transparency in the process of design and review of alternative payment models comparable to that we enjoyed during the OCM process, and we recommend that formal processes and structures be established for receiving patient and consumer advice about alternative payment models.

We also recommend that the membership of the Physician-Focused Payment Model Technical Advisory Committee (PTAC) be more diverse and include patient representatives. We understand that the PTAC membership is defined in statute and that the statute does not designate patient representative members. Neither does the statute suggest that patient representatives should not be included. We will strongly encourage the Comptroller General to appoint patient representatives in the future.

### ***Models to Encourage Patient-Centered Care***

We recommend to the Innovation Center several care and payment models that would respond to cancer care shortcomings or gaps in care that patients have identified. These models share fundamental goals of achieving better coordination of care and ensuring that symptom management is incorporated into active treatment at the earliest possible opportunity. We believe that these models have the potential for improving the quality of care and at the same time addressing the growth in cancer care costs.<sup>1</sup> We understand that these will, of course, be among the effects of the demonstration models that will be evaluated. However, there is strong experience related to these models to recommend them for further evaluation.

- Care coordination model

One of the objectives of the OCM is to encourage better coordination of care, beginning with the preparation of a treatment plan. Early feedback from OCM practices suggests some difficulty in completing the cancer care planning process, consistent with the standards of the care plan identified in the OCM. We recommend a model that would evaluate strategies for care coordination outside the OCM, a model that might also inform the process of care coordination within the OCM.<sup>2</sup>

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<sup>1</sup> Temel JS, Greer JA, Muzilansky A, et al: Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *New England Journal of Medicine* 368;8, 2010.

<sup>2</sup> Press MJ. Instant Replay –A Quarterback’s View of Care Coordination. *New England Journal of Medicine* 317;6, 2014.

We propose a payment model in which each patient would be assigned a professional navigator from the time of diagnosis through treatment, and this navigator would be engaged in the treatment planning process and coordination of care as well as assisting the physician in providing information about care – treatment options, cost of care, insurance coverage and payment issues – to the patient.

We anticipate that this model would be a complement to the OCM and other potential cancer care models. This model could test the impact of a navigator on the treatment planning and shared decision-making process, coordination of care, and quality of care. We also suggest that the impact of navigation on total cost of care should be evaluated in this model.

- Patient empowerment through technology

Although the request for information cautions against models that rely on technology, we recommend a model that would provide cancer patients an app, accessed by computer, tablet, or other electronic device, for communicating information to them about their treatment options and supportive care.<sup>3</sup> This information would include a completed and detailed treatment plan. The app would also be used by patients to communicate with their cancer care team regarding the side effects of treatment and any complications of care.

We also recommend that the app be utilized to help patients prepare for their visits with their cancer care team by identifying information that will be discussed with the team and prompting the patient to review health status and side effects of treatment prior to the face-to-face visit.

We anticipate that this model would encourage coordination of care, prevent emergency department visits for treatment complications, and ensure better communication between patients and their cancer care teams.

- Survivorship care model

The Institute of Medicine recommended that every cancer survivor be provided a care plan for survivorship care after active treatment, and patient advocates have embraced that recommendation. Survivorship issues confront virtually all cancer patients, and availability of a plan is seen as a first step toward better health care and better health after active treatment. Survivors of childhood cancer, many of whom experience multiple late and long-term effects of their cancer treatment, might see especially important benefits from planning for a lifetime of survivorship monitoring and care. The Commission on Cancer has identified provision of a survivorship care plan as an accreditation standard, and increasing numbers of patients receive such plans. Despite the strong support for survivorship care planning, to date evaluations do not find a strong benefit from survivorship care planning.<sup>4</sup>

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<sup>3</sup> Morgan ER, Laing K, McCarthy J, et al. Using tablet-based technology in patient education about systemic therapy options for early-stage breast cancer: a pilot study. *Current Oncology* 22;5, 2015.

<sup>4</sup> Grunfeld G, Julian JA, Pond G, et al. Evaluating survivorship care plans: results of a randomized, clinical trial of patients with breast cancer. *J Clin Oncol* 20;29, 2011.

We recommend a care and payment model that would define an episode of care for survivorship care, with requirements that during the episode of care a survivorship plan will be developed, with detailed advice for patients regarding the appropriate schedule for monitoring and follow-up care. The episode should also be appropriately reimbursed to permit coordination of care among the oncologist who provides the survivorship care plan and other specialists and primary care physicians who may be engaged in providing survivorship care.

We believe that defining a survivorship episode of care might be the best strategy for overcoming the difficulties associated with preparation of the survivorship care plan and also realizing the benefits of the plan through follow-up monitoring and care.<sup>5</sup>

For the three models we describe above, we recommend that these models be of limited geographic scope, or of limited scope in a number of geographic areas. There is potential for these three models to be collaborations between providers in cancer centers or academic centers and community oncologists, with patient organizations engaged as advisors on the design and implementation of each. A number of patient-focused groups that support research, provide patient service, or engage in advocacy have experience in collaborating with cancer care providers in patient programs. That experience will provide patient organizations important background for participating in new payment and delivery models.

### ***Cautions about Consumer-Directed Care***

The request for information states that, “CMS believes beneficiaries should be empowered as consumers to drive change in the health system through their choices. Consumer-directed care models could empower Medicare, Medicaid, and CHIP beneficiaries to make choices from among competitors in a market-driven healthcare system.” As we have made clear from the care models we have recommended above, we believe in the ability of cancer patients to manage their care, make choices about their care, and engage in long-term survivorship care management.

However, we do not believe that the current health care system has adequate price and quality transparency or availability of fundamental information about health care provider options to empower cancer care consumers to make truly informed choices among providers and especially to make choices about bundles of care. We look forward to a system that would have that level of information and transparency about quality and price. We recommend that great care be taken in the design of any consumer choice models to guarantee a high quality of information about provider or system choices and to ensure that the payment streams are aligned appropriately with the wide range of possible consumer choices.

We would highlight one issue that has arisen in the OCM to underscore our misgivings about consumer choice models at the current time. One of the most difficult requirements of the OCM is the requirement that participating practices inform patients regarding their cost of care. That has proven to be very difficult, because information about the coverage and payment

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<sup>5</sup> Daudt HML, van Mossel C, Dennis DL: Survivorship Care Plans: A Work in Progress. *Current Oncology* 21;3, 2014.

standards for each patient's insurance plan may not be clear, and the provider encounters substantial difficulty in ascertaining the costs of care and the adequacy of insurance to pay for that care. We want to ensure that in a consumer choice model the patient has the financial wherewithal, through third-party payment, to obtain their choice of care.

We appreciate the opportunity to respond to the RFI regarding the Innovation Center. We look forward to ongoing discussion and interaction with the Center.

Sincerely,

Cancer Leadership Council

*CancerCare*

Cancer Support Community

The Children's Cause for Cancer Advocacy

Fight Colorectal Cancer

International Myeloma Foundation

Kidney Cancer Association

The Leukemia & Lymphoma Society

**LIVESTRONG**

Lymphoma Research Foundation

National Coalition for Cancer Survivorship

Ovarian Cancer Research Fund Alliance

Prevent Cancer Foundation

Susan G. Komen