

December 17, 2018

Seema Verma  
Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: CMS-4187-P -- Medicare and Medicaid Programs; Regulation to Require Drug Pricing Transparency

Dear Administrator Verma:

The National Coalition for Cancer Survivorship (NCCS) represents survivors of all forms of cancer in efforts to improve the quality of cancer care. The public policy work of NCCS focuses significantly on payment and delivery reforms that are aimed at creating a system that empowers patients to participate in shared decision-making with their care team, make informed decisions about their care, and participate in the coordination of their care. A quality cancer care system depends on access to comprehensive information about care and its cost.

We agree with one of the central aims of the proposal, which is to provide patients with information that will assist them in making decisions about care. We also support the suggestion that a new payment code be created to encourage discussions between patients and their providers about their treatments, although we would refine the terms of the service described by the Centers for Medicare & Medicaid Services (CMS).

However, we are not persuaded that requiring the inclusion of list price in direct-to-consumer (DTC) ads is necessary to improve provider-patient communication and enhance treatment decision-making. We believe that the information to be required is incomplete, and we are concerned that list price information may create confusion among patients.

To improve patients' ability to participate in informed shared decision-making, patients should have access to comprehensive information about treatment options and treatment costs. The proposal at hand fails to advance that goal in the following ways.

- The cost information that is most important to patients is information about the actual out-of-pocket costs that they would have to pay. Simply providing patients list price will not inform them about their own personal costs of care. Informing patients about the costs that they will bear requires knowledge about their insurance coverage and how their treatments will be covered and reimbursed by third-party payers. We support initiatives that would provide this sort of information to patients, but the requirement to provide list prices in DTC ads falls short of that effort.

- Cancer patients typically undergo multi-disciplinary care, including but not limited to, drug therapy. In addition, their drug therapy may involve multiple agents. The proposal at hand will fail to provide patients the information they need in two ways. First, the proposal does not include a provision requiring publication of non-drug costs, such as radiation therapy, surgery, hospitalization, and other costs. Second, it only requires list prices for those drugs that are the subject of DTC ads, which does not allow for comparison of all drug costs, as many cancer drugs are not the subject of DTC advertising. As a result of these factors, requiring list prices in DTC ads provides patients a limited scope of information.

We are also concerned that the requirement to include list prices in DTC ads will be perceived inaccurately as a significant solution to the cost communication problem and may discourage other efforts to improve patient access to cost of care information. We are closely monitoring the Oncology Care Model pilot project, which includes a requirement that providers discuss cost of care with patients. We look forward to additional evaluation of the Oncology Care Model and the replication of positive practices related to cost communication.

We also wish to direct attention again to a suggestion included in this proposal rule, which is the establishment of a separate code “for doctors to dialogue with patients on the benefits of drugs and drug alternatives.” Creating a new service, and accompanying payment for it, is a critically important way of encouraging communication between providers and patients. NCCS and its colleagues in the cancer community have long supported the establishment of a Medicare service for cancer care payment and coordination. We believe this is a key to the provision of quality cancer care. We recommend that the code that CMS references be expanded to support consideration of all treatment planning issues and not just cost of care.

Fostering dialogue between providers and patients about all elements of care will also ensure that there is a serious discussion about the cost of care to the patient. In fact, this is a more effective way of encouraging communication than assuming that publication of list price will prompt patients to have a cost of care discussion with their providers. Discussion between providers and patients can also ensure that patients are part of a serious treatment planning process and that they can participate in care coordination that will also boost quality of care.

We support the aims of the agency to provide patients more information about their care. However, we do not think that supplying list price via DTC ads is adequate, accurate, or complete. Instead, we encourage CMS to focus on provider-patient communication that would include, but not be limited to, cost of care discussions.

We appreciate the opportunity to comment on this proposal and look forward to working with the agency to foster better provider-patient communication.

Sincerely,



Shelley Fuld Nasso, MPP  
Chief Executive Officer