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January 29, 2020

Alex M. Azar II
Secretary
Department of Health and Human Services
Room 445-G
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, D.C. 20201

Seema Verma
Administrator
Centers for Medicare & Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244-1850

Sunita Lough
Deputy Commissioner for Services and Enforcement
Internal Revenue Service
P.O. Box 7604
Ben Franklin Station
Washington, D.C. 20044

Preston Rutledge
Assistant Secretary
Employee Benefits Security Administration
Department of Labor
200 Constitution Avenue, NW
Washington D.C. 20210

Re: CMS-9915-P: Transparency in Coverage
84 Fed. Reg. 65464 (November 27, 2019)

Dear Secretary Azar, Administrator Verma, Deputy Commissioner Lough, and Assistant Secretary Rutledge:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to comment on the Transparency in Coverage proposed rule. ACS CAN is making cancer a top priority for public officials and candidates at the federal, state, and local levels. ACS CAN empowers advocates across the country to make their voices heard and influence evidence-based public policy change, as well as legislative and regulatory solutions that will reduce the cancer burden. As the American Cancer Society's nonprofit, nonpartisan advocacy affiliate, ACS CAN is critical to the fight for a world without cancer.

Having adequate and affordable health insurance coverage is a key determinant in surviving cancer. Research from the American Cancer Society shows that uninsured Americans are less likely to get screened for cancer and thus are more likely to have their cancer diagnosed at an advanced stage when survival is less likely and the cost of care more expensive.[1] This not only impacts the 1.8 million Americans who will be diagnosed with cancer this year, but also the 16.9 million Americans living today who have a history of cancer.[2]

[1] E Ward et al, "Association of Insurance with Cancer Care Utilization and Outcomes," *CA: A Cancer Journal for Clinicians* 58:1 (Jan./Feb. 2008), http://www.cancer.org/cancer/news/report-links-health-insurance-status-with-cancer-care.

[2] American Cancer Society. *Cancer Facts & Figures 2020.* Atlanta: American Cancer Society; 2020.

ACS CAN applauds the intent of the proposed rule, which is to provide consumers with information regarding their expected out-of-pocket health care costs for items and services before they receive care. As noted, having access to this information will help consumers make more informed decisions about their health care services.

This disclosure is a significant step in the right direction, but we caution that disclosure of cost information alone fails to provide sufficient consumer protection. Cost information disclosure will not shield consumers against high out-of-pocket health care costs. In order to truly protect consumers from unanticipated high out-of-pocket costs for health care services, consumers need affordable, comprehensive health care coverage. In addition, disclosure of cost information is one factor consumers will consider when choosing health care products and services. The quality of care provided is equally important. We caution that consumers should not simply look for the lowest-cost provider if the quality of care is poor.

II. Overview of the Proposed Rules Regarding Transparency – the Departments of the Treasury, Labor, and Health and Human Services

A. Proposed Requirements for Disclosing Cost-Sharing Information to Participants, Beneficiaries, or Enrollees

1. Information required to be disclosed to participants, beneficiaries, or enrollees

The Departments propose to require group health plans and health insurance issuers to disclose estimated out-of-pocket cost information for a particular service upon the request of the patient (or his or her authorized representative) in "plain language." Items or services included in the disclosure requirement are encounters, procedures, medical tests, supplies, drugs, durable medical equipment, and fees (including facility fees). The goal of this requirement is to enable patients to obtain an estimate of their anticipated out-of-pocket expenses in advance and then shop for covered health care items and services. The proposed requirements are modeled after explanation of benefits (EOB) documents.

ACS CAN strongly supports the Departments' efforts to make this estimated cost-sharing information available to patients. Cancer patients and their families deal with an overwhelming amount of information during treatment – much of which is confusing and scary. This situation is compounded by the high costs that patients and their families must pay for cancer care. Requiring the advance disclosure of cost-sharing estimates will benefit cancer patients by: (1) allowing them to anticipate costs and plan for them; (2) allowing patients who are able and interested to "shop" for care based on cost estimates; and (3) understand the cost implications of choosing out-of-network care, as applicable.

As the Departments acknowledge, in some cases providers and plans cannot anticipate all the services the patient will receive due to many factors including the severity of the patient's illness or injury, provider treatment decisions, or other unforeseen events. The Departments makes it clear that providers are not required to provide estimates for these unanticipated services/costs. While it is unfortunate that patients who receive such unanticipated services will have not received a fully accurate cost estimate, ACS CAN recognizes that this is an unavoidable reality of medical practice, and we are encouraged that plans are required to include a disclaimer in content element 7 (addressed below) that actual cost-sharing may differ from the estimate.

The Departments require cost estimate information be provided in "plain language," defined as "written and presented in a manner calculated to be understood by the average participant, beneficiary, or enrollee." While the definition of this plain language standard is very helpful, it is unclear in the proposal

who will be enforcing this standard. ACS CAN encourages the Departments in the final rule to clarify that they will be carefully enforcing this standard. Furthermore, we encourage the Departments to establish a system that regularly monitors these cost estimates and disclosures, and tests common examples with patients to determine whether the plan implementation of this standard accomplishes the agency's goals for this policy.

The proposed rule outlines seven content elements that a plan or insurer must disclose, upon request, to an individual. ACS CAN's comments on each element as applicable are below:

a. Content Element: Estimated Cost-Sharing Liability

The Departments propose to require plans to disclose the estimated cost-sharing liability – an estimate of the amount that the individual would be responsible for paying under the plan's specific deductible, coinsurance, and copay structure. It should reflect any cost-sharing reductions that the individual would receive if eligible and enrolled in a silver marketplace plan. This estimate would not include premiums, balance billing amounts for out-of-network providers, or the cost of non-covered items or services.

ACS CAN strongly supports the requirements in this content element, as they are foundational to the purposes of this proposal and will provide patients with important information. In particular, providing advance information about coinsurance amounts will be very helpful for patients. ACS CAN has long advocated for more transparency in this area, as a patient's actual cost-sharing responsibility is difficult to determine when they pay a percentage of an unknown number.

b. Content Element: Accumulated Amounts

The Departments propose to require plans to disclose accumulated amounts -- the amount of cost-sharing that the individual (or, in the case of family coverage, the individual and family) has already paid towards the plan's deductible or out-of-pocket maximum. The accumulated amount would also reflect any progress towards reaching a treatment limit on certain items or services (such as showing the number of physical therapy visits already used if the plan caps the number of visits for physical therapy).

ACS CAN strongly supports this content element being included. Many cancer patients spend through their deductibles – and even their maximum out-of-pocket limits – in 1-3 months after their diagnosis and treatment for cancer.[3] The status of their progress towards such amounts is very important for a cancer patient to know, allowing them to plan for expenses. ACS CAN also supports the inclusion of information about treatment limits. Cancer patients often use services that are commonly limited in such ways, like physical and occupational therapy and mental health services, and would benefit from this information.

c. Content Element: Negotiated Rate

The Departments propose to require plans to disclose the amount paid to an in-network provider (including a pharmacy or mail order service) for covered items or services. This amount would be expressed in a dollar amount. Plans would not have to disclose the negotiated rate if it does not impact the individual's cost-sharing obligations (e.g., if the individual is charged a fixed co-payment and not co-insurance).

[3] See American Cancer Society Cancer Action Network. Costs of Cancer: Addressing Patient Costs. April 2017. www.fightcancer.org/costsofcancer.

ACS CAN supports the Departments' proposal to require the disclosure of the negotiated rate, particularly with respect to prescription drugs. Currently, plans use co-insurance for certain products and services, and in so doing will disclose the cost of the co-insurance amount, but not the amount of the negotiated rate. As a result, plan designs using coinsurance are not transparent to the consumer. Coinsurance makes it impossible for an individual to determine her expected out-of-pocket costs because the cost of the drug is not provided to the individual. The ability to predict and plan for costs is very important for individuals with cancer and those with chronic conditions, particularly patients who are low-income and very price-sensitive.

d. Content Element: Out-of-Network Allowed Amount

The Departments propose to require plans to disclose out-of-network allowed amounts when an enrollee requests cost-sharing information for a covered item or service furnished by an out-of-network provider – the maximum amount that a plan or insurer would pay for services furnished by an out-of-network provider. The Departments note that this content element works with the first content element (estimated cost-sharing liability) to provide as much information as possible to a patient considering out-of-network care.

ACS CAN recognizes that plans will not have all the information necessary to provide a true cost estimate to patients in a situation where the provider is out-of-network and therefore does not have a contract established with the insurer to determine costs. We agree with the Departments that providing the out-of-network allowed amount, along with information about patient cost-sharing liability, is the best the agencies can require in a healthcare system that continues to allow balance billing. Knowing the out-of-network allowed amount will also help a patient that is able and willing to do so to shop for care.

Out-of-network care is common for cancer patients – and in some cases patients do not have much choice in the matter. Some patients with advanced or rare cancer are very limited in their choices because of the scarcity of specialists who are able to treat their specific cancer. For patients who do not have an appropriate specialist to treat them in-network, they can appeal to their plan to have their out-of-network specialist treated as in-network in respect to cost-sharing liability. ACS CAN encourages the Departments to require that a patient's appeals rights be included in the seventh content element below (disclosure notices) so that patients know upon receiving this cost estimate that they can appeal these policies.

e. Content Element: Notice of Prerequisites of Coverage

The Departments propose to require plans to provide a notice informing the individual that a specific covered item or service may be subject to a prerequisite for coverage. The term "prerequisite" would include medical management tools such as concurrent review, prior authorization, and step-therapy/fail-first protocols. However, the proposed definition does not include medical necessity determinations generally or other forms of medical management that do not require action by the participant, beneficiary, or enrollee.

ACS CAN supports this disclosure element. Consumers should have easy access to information regarding which products and services are subject to medical management tools. This information can be helpful to consumers as a way to steer them towards lower-cost products and services, where medically appropriate. In cases where it may not be appropriate, providing the consumer with information regarding the use of medical management tools can allow the consumer the opportunity to inform

his/her health care provider of the use of medical management on a particular product/service to facilitate a discussion on whether an appeal or exception may be warranted.

f. Content Element: Disclosures Notice

The Departments propose the final content element to include a notice that communicates certain information in plain language and includes several specific disclosures: (1) a statement that out-of-network providers may balance bill enrollees and that the estimates included in the disclosure notice do not account for these amounts; (2) notice that the actual charges for the enrollee's covered items and services may be different than those described in the estimate, depending on the actual item or services received at the point of care; (3) a statement that the estimated cost-sharing liability for a covered item or service is not a guarantee that coverage will be provided for those items and services; and (4) plans would be permitted to include any additional information, provided it does not conflict with the required disclosure notices.

Out-of-network provider notice: ACS CAN appreciates the intent to provide the individual with notice that plan disclosures of anticipated costs do not include products and services provided by out-of-network providers. At the same time, we are concerned of potential confusion by consumers who are not provided with advance information regarding anticipated out-of-pocket costs for out-of-network providers and thus are unable to prepare accordingly. At the very least, plans should provide information to consumers on in-network providers who are able to perform the out-of-network service or product. If an in-network provider or product is not available, consumers should be informed of how to file an appeal or exception to attempt to gain coverage.

Notice of actual charges: We appreciate that plans will inform consumers that the actual charges may differ from the estimate provided by the plan. We agree that there are instances where an individual may need additional products and services at the point of care that were not anticipated in advance (for example, surgical complications necessitating additional services). However, we would urge the Departments to clarify that to the extent that the actual services provided were consistent with those provided under the estimate, plans would not be permitted to charge an enrollee more than what was provided under the estimate.

Guarantee of coverage: We support the intent of the proposed rule which "is to support a market-driven health care system by giving consumers the information they need to make informed decisions about their health care and health care purposes."[4] However, we are concerned that allowing plans to include a statement that the estimated cost-sharing liability is not a guarantee of coverage negates the intent of the proposed rule. Consumers who receive a notice from their health plan regarding estimated out-of-pocket costs would naturally assume coverage of those services. If the point of the notice is to provide consumers with information they need to make informed decisions about their health care, consumers should be able to act on the notice they receive from their health plan.

2. Required methods for disclosing information to participants, beneficiaries, or enrollees

The Departments propose that the cost-sharing information would be made available two ways: (1) through a self-service tool that meets certain standards and is available on an internet website and (2) in paper form. The proposed rule would require that the paper form be mailed to the individual within two business days of the request.

[4] 84 Fed. Reg. at 65465.

We support the Departments' proposal to allow individuals the ability to access their information through electronic means or via paper form. We recognize that approximately half of individuals nationwide have been offered online access to their medical information by a health care provider, and of those who were offered access, only half chose to do so.[5] In addition, many Americans lack access to high-speed internet services. Thus, we appreciate the Department's requirement that consumers be given the option to obtain this information in either paper or electronic means.

Conclusion

On behalf of the American Cancer Society Cancer Action Network we thank you for the opportunity to comment on the proposed rule. If you have any questions, please feel free to contact me or have your staff contact Anna Schwamlein Howard, Policy Principal, Access and Quality of Care at Anna.Howard@cancer.org or 202-585-3261.

Sincerely,

Lisa A. Lacasse, MBA
President
American Cancer Society Cancer Action Network

[5] Department of Health and Human Services. The Office of the National Coordinator for Health Information Technology. 2018 Report to Congress: Annual update on the adoption of a nationwide system for the electronic use and exchange of health information. Available at https://www.healthit.gov/sites/default/files/page/2018-12/2018-HITECH-report-to-congress.pdf.