December 24, 2018

The Honorable Alex M. Azar II
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, SE
Washington, DC 20201

The Honorable David J. Kautter
Assistant Secretary for Tax Policy
U.S. Department of Treasury
1500 Pennsylvania Avenue, NW
Washington, D.C. 20220

Re: State Relief and Empowerment Waivers (CMS 9936-C)

Dear Secretary Azar and Assistant Secretary Kautter:

On behalf of the Cancer Support Community (CSC), an international nonprofit organization that provides support, education, and hope to cancer patients, survivors, and their loved ones, we appreciate the opportunity to provide comments on the State Relief and Empowerment Waivers guidance relating to section 1332 of the Patient Protection and Affordable Care Act (PPACA). Our comments address our concerns that the guidance will undermine key protections, particularly for the most vulnerable populations including those that are older, with low incomes, or with pre-existing conditions including cancer, and because of this we ask that the Department of Health and Human Services and the Department of the Treasury withdraw the guidance.

As the largest direct provider of social and emotional support services for people impacted by cancer, and the largest nonprofit employer of psychosocial oncology professionals in the United States, CSC has a unique understanding of the cancer patient experience. Overall, we deliver more than $50 million in free, personalized services each year to individuals and families affected by cancer nationwide and internationally. Additionally, CSC is home to the Research and Training Institute—the only entity of its kind focused solely on the experiences of cancer patients and their loved ones. The Research and Training Institute has contributed to the evidence base regarding the cancer patient experience through its Cancer Experience Registry, various publications and peer-reviewed studies on distress screening, and the psychosocial impact of cancer and cancer survivorship. This combination of direct services and research uniquely positions CSC to provide valuable patient and evidence-informed feedback on this guidance.
Section 1332 of the Affordable Care Act (ACA) was designed to provide states with the flexibility to improve coverage, affordability, and comprehensiveness of benefits offered through the marketplace. This section includes four essential “guardrails” outlined in the 2015 guidance to ensure that programs implemented through waivers continue to provide comprehensive coverage and protect consumers at risk including those with pre-existing conditions, older populations, or those with low incomes. These guardrails included that:

1. The proposal must provide coverage that is at least as comprehensive as the coverage defined by the ACA, including coverage for essential health benefits.
2. The proposal must provide coverage and cost-sharing protections against excessive out-of-pocket spending that are at least as affordable.
3. The proposal must provide coverage to at least a comparable number of the states residents.
4. The proposal must not increase the federal deficit.

The guidance released on October 22, 2018 supersedes the original 2015 guidance, and encourages waiver design that erodes at the consumer protections currently in place and will harm individuals living with cancer.

The guidance alters the measure of coverage that is “at least as comprehensive” by creating broader flexibility for states to choose the benchmark plan by which they must base the benefit design of their plans. In the past, a state looked to job-based plans within that state as well as other factors to set its essential health benefits, the benchmark level of coverage which all plans offered must at least meet if not exceed. Under the new guidance, states can pick and choose their benchmark standards, further reducing covered services and widening the disparity between expensive, comprehensive plans and the low-cost options that meet the “benchmark.”

This broader definition of coverage also encourages the growth of other insurance products like short-term limited-duration (STLDs) health plans and association health plans (AHPs). STLDs and AHPs are not held to the patient protections implemented by the ACA including protections for consumers with preexisting conditions, coverage of essential health benefits without annual or lifetime dollar limits, preventative care, maternity and prescription drug coverage, and more. Individuals with preexisting conditions, such as cancer patients and survivors, depend on access to comprehensive and affordable coverage. Beneficiaries who enroll in these plans before receiving a diagnosis during the plan year may find themselves facing insurmountable health care costs or the loss of coverage all together. In CSC’s Access to Care study (2016), we found that patients were most concerned with high-out-of-pocket costs, high deductibles, high premiums, and high co-pay costs for medications. This guidance could put cancer patients, survivors, and all those with chronic illness at significant risk of financial toxicity if they are unable to access or retain affordable coverage.

The waiver concepts discussion paper, released on November 29, 2018 also includes suggested options for states to implement risk stabilization strategies. In the past, states have used this to implement state-based reinsurance programs to reduce premiums and help insurers cover enrollees with high health care costs. This guidance, however, also suggests that states use this flexibility to establish high risk pools. The ACA sought to calibrate the greater risk pool amongst both health individuals who often cost less to insurers and individuals living with illnesses like
cancer that may be more expensive to insurers. High risk pools leave the sickest and most vulnerable patients without access to affordable, comprehensive health care options as it would place those with the greatest health care needs in a pool with the highest cost. We are concerned that the guidance will encourage states to develop these high risk pools to segment consumers, leaving cancer patients without access to affordable care.

The recent guidance will also undermine protections against excessive out of pocket health costs for beneficiaries by allowing states to make changes to the ACA’s subsidy structure, which provides financial assistance for beneficiaries with incomes below 400 percent of the federal poverty level (FPL). One option within the waiver concepts discussion paper suggests that states could change their subsidy structure to a fixed per-member-per-month contribution to a health care account. This structure does not provide any financial protection to beneficiaries if healthcare premiums go up, and could dramatically limit access for low-income populations. Furthermore, the guidance suggests that a state could use its premium tax credit dollars, provided by the federal government, to provide sparse coverage to people with incomes below 100 percent FPL, instead of expanding Medicaid to provide comprehensive coverage to low income adults. Low income cancer patients and survivors depend on Medicaid for access to essential services like primary care visits, prescription drugs, preventative screenings and other treatments and services that help them manage their illness and stay healthy. Hundreds of thousands of people across the country have benefited from the expansion of Medicaid eligibility and this guidance puts patient’s current and future stability on the Medicaid program at risk.

Finally, the guidance would allow a state to evaluate the adequacy of its coverage options based on the aggregate impact on all state residents rather than the coverage offered to various sub-populations. Under the 2015 guidance, states were required to prove in their waiver plans that at least as many residents would have coverage that is at least as comprehensive as the states essential health benefits package was before the waiver. Now, the state must only prove that comprehensive coverage that meets the state’s benchmark plans is available to the same number of consumers as would be covered without the waiver, regardless of how many are actually enrolled in coverage. With the other changes suggested by the guidance that will increase barriers in access to coverage, many to whom coverage may be available are unlikely to be able to purchase it.

Ultimately, the 1332 waiver process was created to allow states the flexibility to make changes to their marketplace, while still ensuring that all beneficiaries would have access to comprehensive and affordable health coverage. The new guidance regarding “State Relief and Empowerment Waivers” will do the opposite by allowing states to use federal pass-through funding to expand access to inconsistent and insufficient health insurance plans that will ultimately harm those living with preexisting conditions, those with limited incomes, and those living with chronic or serious illness like cancer.
We appreciate the opportunity to provide comments on the 2018 guidance relating to State Relief and Empowerment Waivers. For the reasons above, we urge the withdrawal of this guidance, to ensure that cancer patients retain access to necessary and affordable healthcare. Please reach out to me at efranklin@cancersupportcommunity.org if you would like to discuss any of the above in more detail.

Respectfully Submitted,

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Executive Director, Cancer Policy Institute  
Cancer Support Community

References

Washington, DC: Author.