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February 5, 2019

The Honorable Alex Azar
Secretary
Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, D.C. 20201

Re: TennCare II Demonstration (No. 11-W-00151/4), Amendment 38

Dear Secretary Azar:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to comment on Tennessee's TennCare II Section 1115 research and demonstration waiver amendment request. 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.

ACS CAN supports Tennessee's goal to improve health outcomes for individuals enrolled in TennCare, but we believe the proposed Amendment 38 to the TennCare II Demonstration could negatively impact the adult Medicaid population, particularly cancer patients, survivors, and those who will be diagnosed with cancer in their lifetime. Over 37,300 Tennesseans are expected to be diagnosed with cancer this year[1] and there are nearly 300,000 cancer survivors in the state[2] – many of whom are receiving health care coverage through the TennCare Medicaid program. ACS CAN wants to ensure that cancer patients and survivors in Tennessee will have adequate access and coverage under the Medicaid program, and that specific requirements do not create barriers to care for low-income cancer patients, survivors, and those who will be diagnosed with cancer.

The proposed Medicaid workforce participation and community engagement requirement could limit eligibility and access to care for some of the most vulnerable Tennesseans, including those with cancer, cancer survivors, and those who will be diagnosed with the disease. We strongly urge the Centers for Medicare and Medicaid Services (CMS) address the concerns that we and other stakeholders have or reject this waiver in its current form.

The following are our specific comments on the TennCare 1115 waiver application:

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[1] American Cancer Society. *Cancer Facts & Figures 2019*. Atlanta, GA: American Cancer Society; 2019.
[2] American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta, GA: American Cancer Society; 2018.

Encouraging Workforce Participation and Community Engagement

Tennessee seeks to require that all non-pregnant, non-disabled, non-elderly adults enrolled in TennCare's parent/caretaker relative eligibility category and aged 19-64 be employed 20 hours per week (averaged monthly) in order to maintain eligibility or enrollment in the Medicaid program. This policy could unintentionally disadvantage patients with complex chronic conditions, including cancer patients and recent survivors. We understand the intent of the proposal is to incentivize employment, but cancer patients in active treatment are often unable to work or require significant work modifications due to their treatment.[3,4,5]

ACS CAN opposes tying access to affordable health care for lower income persons to work or participate in community engagement requirements because cancer patients, survivors, and those who will be diagnosed with the disease - as well as those with other complex chronic conditions - could be seriously disadvantaged and find themselves without Medicaid coverage because they are physically unable to comply. Research suggests that between 40 and 85 percent of cancer patients stop working while receiving cancer treatment, with absences from work ranging from 45 days to six months depending on the treatment.[6] Recent cancer survivors often require frequent follow-up visits and maintenance medications to prevent recurrence,[7] and suffer from multiple comorbidities linked to their cancer treatments.[8,9] Cancer survivors are often unable to work or are limited in the amount or kind of work they can participate in because of health problems related to their cancer diagnosis.[10,11,12,13] If work and community engagement is required as a condition of eligibility, many cancer patients, recent survivors, and those with other chronic illnesses could find that they are ineligible for the lifesaving care and treatment services provided through the State's Medicaid program. We also note that imposing work or community engagement requirements on lower income individuals as a condition of coverage could impede individuals' access to preventive care, including cancer screenings.

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[3] Whitney RL, Bell JF, Reed SC, Lash R, Bold RJ, Kim KK, et al. Predictors of financial difficulties and work modifications among cancer survivors in the United States. *J Cancer Surviv.* 2016; 10:241. doi: 10.1007/s11764-015-0470-y.

[4] de Boer AG, Taskila T, Tamminga SJ, et al. Interventions to enhance return to work for cancer patients. *Cochrane Database Syst Rev.* 2011; 16(2): CD007569. doi: 10.1002/14651858.CD007569.pub2.

[5] Stergiou-Kita M, Pritlove C, van Eerd D, Holness LD, Kirsh B, Duncan A, Jones J. The provision of workplace accommodations following cancer: survivor, provider, and employer perspectives. *J Cancer Surviv*. 2016; 10:480. doi:10.1007/s11764-015-0492-5.

[6] Ramsey SD, Blough DK, Kirchhoff AC, et al. Washington State Cancer Patients Found to be at Greater Risk for Bankruptcy then People Without a Cancer Diagnosis," Health Affairs, 32, no. 6, (2013): 1143-1152.

[7] National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care*. Accessed September 2018. https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care.

[8] Mehta LS, Watson KE, Barac A, Beckie TM, Bittner V, Cruz-Flores S, et al. Cardiovascular disease and breast cancer: Where these entities intersect: A scientific statement from the American Heart Association. *Circulation*. 2018; 137(7): CIR.0000000000000556.

[9] Dowling E, Yabroff R, Mariotto A, et al. Burden of illness in adult survivors of childhood cancers: Findings from a population-based national sample. *Cancer.* 2010; 116:3712-21.

[10] Ibid.

[11] Guy GP Jr, Berkowitz Z, Ekwueme DU, Rim SH, Yabroff R. Annual economic burden of productivity losses among adult survivors of childhood cancers. *Pediatrics*. 2016; 138(s1):e20154268.

[12] Zheng Z, Yabroff KR, Guy GP Jr, et al. Annual medical expenditures and productivity loss among colorectal, female breast, and prostate cancer survivors in the United States. *JNCI J Natl Cancer Inst.* 2016; 108(5):djv382.

[13] Kent EE, Davidoff A, de Moor JS, et al. Impact of sociodemographic characteristics on underemployment in a longitudinal, nationally representative study of cancer survivors: Evidence for the importance of gender and marital status. *J Psychosoc Oncol*. 2018; 36(3):287-303.

We appreciate the State's acknowledgement that not all people are able to work and the decision to include several exemption categories and good cause exemptions from the community engagement requirement and associated lock-out period. However, the waiver does not go far enough to protect vulnerable individuals, including recent cancer survivors, those with conditions that put them at risk for cancer, and other serious chronic diseases often linked to cancer treatments.[14,15] The increase in administrative requirements for enrollees to attest to their working status and exemptions on a monthly basis would likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt.[16]

As an example, in the sixth month of implementation of the *Arkansas Works* work requirement (November 2018) only 14 percent of the over 9,800 Medicaid enrollees, who did not declare an exemption, were able to navigate the complex reporting system and satisfy the state's reporting requirement.[17] As of January 7, 2019 (the seventh month of implementation), an additional 1,232 *Arkansas Works* enrollees were locked out of coverage due to noncompliance with the work requirement.[18] This number is in addition to the 16,932 individuals the state removed from the program in the last four months, totaling 18,164 Arkansans losing coverage since September 2018. Some of these individuals may have been eligible for an exemption but did not realize they were exempt or were unable to successfully navigate Arkansas' reporting system. Given the experience with Arkansas' work requirement, CMS should consider the number of Tennesseans whose health could be negatively impacted and the coverage losses that could occur due to this proposal.

Suspension of Coverage
We are deeply concerned about the proposed Medicaid coverage suspension period if they do not comply with the work requirement. The Department specifies that Medicaid coverage can be reinstated if the individual demonstrates compliance with work and community engagement requirements for one month. The Department also suggests that they may offer additional opportunities for beneficiaries to regain full coverage through participating in an activity that "supports the goals of the community engagement program (e.g., taking a state-approved health or financial literacy course)." Additionally, the State offers "good cause" exemptions for enrollees who have failed to meet the work requirements. However, it is unclear how long the appeals process would take for good cause exemptions and whether the beneficiary would lose health coverage during the process.

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[14] Mehta LS, Watson KE, Barac A, Beckie TM, Bittner V, Cruz-Flores S, et al. Cardiovascular disease and breast cancer: Where these entities intersect: A scientific statement from the American Heart Association. *Circulation*. 2018; 137(7): CIR.0000000000000556.
[15] Dowling E, Yabroff R, Mariotto A, et al. Burden of illness in adult survivors of childhood cancers: Findings from a population-based national sample. *Cancer.* 2010; 116:3712-21.
[16] Garfield R, Rudowitz R, Musumeci M. Implications of a Medicaid work requirements: National estimates of potential coverage losses. Kaiser Family Foundation. Published June 2018. Accessed September 2018. http://files.kff.org/attachment/Issue-Brief-Implications-of-a-Medicaid-Work-Requirement-National-Estimates-of-Potential-Coverage-Losses.
[17] Arkansas Department of Human Services. Arkansas Works Program: November 2018 Report. Accessed December 2018. https://humanservices.arkansas.gov/images/uploads/newsroom/181217_AWreport.pdf.
[18] Arkansas Department of Human Services. Arkansas Works Program: December 2018 Report. Accessed January 2019. https://humanservices.arkansas.gov/images/uploads/011519_AWReport.pdf.

Those with acute health care conditions who apply for an exemption to avoid the suspension period will still have to verify their exemption and undertake a burdensome documentation process. This could lead to instances where those who should be able to maintain coverage are disenrolled, jeopardizing access to life-saving treatment. If individuals are locked out of coverage for a month they will likely have no access to affordable health care coverage, making it difficult or impossible for a cancer patient or recent survivor to continue treatment or pay for their maintenance medication until they come into compliance with the requirement or they are determined to be exempt. This is particularly problematic for cancer survivors who require frequent follow-up visits and maintenance medications as part of their survivorship care plan to prevent recurrence[19] and who suffer from multiple comorbidities linked to their cancer treatments.[20] For those cancer patients who are mid-treatment, a loss of health care coverage could seriously jeopardize their chance of survival. Being denied access to one's cancer care team could be a matter of life or death for a cancer patient or survivor and the financial toll that the lock-out would have on individuals and their families could be devastating.

Workforce and Community Engagement Requirement Does Not Meet CMS Criteria

We note that Tennessee's proposed waiver does not appear to meet the criteria established by the CMS for approval of work and community engagement proposals under the guidance that CMS sent to state Medicaid Directors on January 11, 2018. The guidance specifically states that "…states will need to link these community engagement requirements to those outcomes and ultimately *assess the effectiveness of the demonstration in furthering the health and wellness objectives* of the Medicaid program [emphasis added]."[21] Although the Department states the goal of the proposal is to improve health outcomes for the impacted adult population, the hypotheses that the work and community engagement requirement will decrease hospitals stays and emergency room (ER) visits for the impacted adult population are not appropriate indicators of health and wellness. There are occasions when individuals appropriately use the ER or require hospitals stays. For example, cancer patients undergoing chemotherapy and/or radiation often have adverse drug reactions or other related health problems that require immediate care during evenings or weekends.[22,23] If primary care settings and other facilities are not available, these patients are often directed to the ER. At times, these emergency visits may require the patient to stay overnight for observation. Neither of these scenarios would indicate that work or community engagement requirement would decrease these types of visits. In fact, it is possible that the state may see an increase in ER visits, as some people who are working may have more difficulties making health care appointments during or after work hours. Therefore, we believe that the use of an ER or an inpatient hospital stay are not appropriate indicators of Medicaid recipients health or wellness outcomes.

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[19] National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care*. Accessed December 2018. https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care.

[20] Mehta LS, Watson KE, Barac A, Beckie TM, Bittner V, Cruz-Flores S, et al. Cardiovascular disease and breast cancer: Where these entities intersect: A scientific statement from the American Heart Association. *Circulation*. 2018; 137(7): CIR.0000000000000556.

[21] Centers for Medicare & Medicaid Services. Opportunities to promote work and community engagement among Medicaid beneficiaries. Baltimore, MD. Department of Health and Human Services. SMD: 18-002. Published January 11, 2018. Accessed January 2019.

[22] Numico G, Cristofano A, Mozzicafreddo A, et al. Hospital Admission of Cancer Patients: Avoidable Practice or Necessary Care? Santini D, ed. *PLoS ONE*. 2015;10(3):e0120827. doi:10.1371/journal.pone.0120827.

[23] Hjermstad M, Kolfaath J, Løkken A, et al. Are emergency admissions in palliative care always necessary? *BMJ Open*. 2013; 3 e002515 doi:10.1136/bmjopen-2012-002515.

Additionally, the state failed to provide coverage loss estimates in the waiver. The waiver only states that "it is not possible to reliably project the magnitude of this decrease in enrollment at this time." Federal rules for the state public notice process for 1115 waivers require states to include, "an estimate of the estimated increase or decrease in annual enrollment" and expenditures for the demonstration requested by the state.[24] This allows stakeholders and CMS to adequately assess the impact the demonstration waiver may have on state residents. Therefore, we strongly urge CMS to require the state to include these projections, as required by federal law, so that the public has an opportunity to comment on the impact of the proposed waiver demonstration with adequate information.

Conclusion

We appreciate the opportunity to provide comments on Tennessee's TennCare Section 1115 demonstration waiver application. The preservation of eligibility and coverage through Medicaid remains critically important for many low-income Tennesseans who depend on the program for cancer prevention, early detection, diagnostic, and treatment services. We ask CMS to weigh the impact that this policy proposal may have on access to lifesaving health care coverage, particularly for those individuals with cancer, cancer survivors, and those who will be diagnosed with cancer during their lifetime.

Our comments include numerous citations to supporting research, including direct links to the research for the benefit of CMS in reviewing our comments. We direct CMS to each of the studies cited (please see attached addendum) and we request that the full text of each of the studies cited, along with the full text of our comments be considered part of the administrative record in this matter for purposes of the Administrative Procedure Act.

Maintaining access to quality, affordable, accessible, and comprehensive health care coverage and services is a matter of life and survivorship for thousands of low-income cancer patients and survivors, and we look forward to working with the Administration to ensure that all Americans are positioned to win the fight against cancer. If you have any questions, please feel free to contact me or have your staff contact Michelle DelFavero of our policy team at Michelle.DelFavero@cancer.org or 202-585-3266.

Sincerely,

Lisa Lacasse
President

[24] 42 CFR 431.408 (a)(1)(i)(C).