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December 4, 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: Utah Section 1115 Demonstration Application: "Fallback Plan"

Dear Secretary Azar:

The American Cancer Society Cancer Action Network (ACS CAN) appreciates the opportunity to comment on Utah's 1115 Demonstration "Fallback Plan" Application. 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.

Over 11,600 people in Utah are expected to be diagnosed with cancer this year[1] and there are nearly 116,000 cancer survivors in the state[2] – many of whom rely on Medicaid or would greatly benefit from receiving their health care through a full expansion of the program. To that end, we are pleased to see that Utah is expanding coverage to 138 percent of the federal poverty level (FPL) to ensure that all low-income Utah residents have access to critical health insurance coverage. Research has demonstrated that individuals who lack health insurance coverage are more likely to be diagnosed with advanced-stage cancer, which is costly and often leads to worse outcomes.[3,4] Research has also shown that individuals in expansion states are more frequently diagnosed with cancer at earlier stages than those in

[1] American Cancer Society. Cancer Facts & Figures: 2019. Atlanta: American Cancer Society, 2019.
[2] American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2019-2021*. Atlanta, GA: American Cancer Society; 2019.
[3] Ward E, Halpern M, Schrag N, et al. Association of insurance with cancer care utilization and outcomes. *CA Cancer J Clin*. 2008; 58(1):9-31.
[4] American Cancer Society. *Cancer Prevention & Early Detection Facts & Figures 2019-2020*. Atlanta: American Cancer Society; 2019.

non-expansion states.[5,6,7] Additionally, individuals enrolled in Medicaid prior to their diagnosis have better survival rates than those who enroll after their diagnosis.[8]

While we support Utah's proposed expanded coverage, ACS CAN wants to ensure that cancer patients have adequate access and coverage and that any requirements included in the waiver do not create unintentional barriers to care for low-income cancer patients. There are several proposals included in the current waiver – as well as the previous waivers – that cause us serious concern.

We reiterate our concern with recently adopted proposals, including the enrollment limits and community engagement requirements highlighted below, particularly how these proposals will impact the policy proposals at issue under the current proposed waiver. And we strongly urge the Centers for Medicare and Medicaid Services (CMS or "the Department") reconsider moving forward with the previous accepted and currently proposed waivers until stakeholder concerns are addressed.

Following are our specific comments:

<u>Community Engagement through a Self Sufficiency Requirement</u>
ACS CAN remains concerned with the community engagement requirement for the expansion population. 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 find themselves without Medicaid coverage. 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.[9] 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 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, and those with other serious chronic diseases

[5] Jemal A, Lin CC, Davidoff AJ, Han X. Changes in insurance coverage and stage at diagnosis among non-elderly patients with cancer after the Affordable Care Act. *J Clin Oncol*. 2017; 35:2906-15.
[6] Soni A, Simon K, Cawley J, Sabik L. Effect of Medicaid Expansion of 2014 on overall and early-stage cancer diagnoses. *Am J Public Health*. 2018; 108:216-18.
[7] Fedewa SA, Yabroff R, Smith RA, et al. Changes in breast and colorectal cancer screening after Medicaid expansion under the Affordable Care Act. *Am J Prev Med.* 2019;57(1):3-12.
[8] Adams E, Chien LN, Florence CS, et al. The Breast and Cervical Cancer Prevention and Treatment Act in Georgia: effects on time to Medicaid enrollment. *Cancer.* (2009); 115(6):1300-9.
[9] 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.

linked to cancer treatments.[10] Additionally, the increase in administrative requirements for enrollees to attest to their working status would likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not, as seen in the first year of implementation of Arkansas' work requirement.[11]

Given the recent experience with Arkansas' work requirement, where uninsured rates were driven up and employment actually declined in the state since the work requirement went into effect,[12] we urge the Department to consider the number of Utahns whose health could be negatively impacted, and coverage lost due to this proposal – which the state already estimates to be between 20-25 percent of eligible individuals.[13] Additionally, it is clear from the preliminary data from Arkansas that the work requirements are not meeting the state's goal of incentivizing employment and increasing the number of employed Arkansas Works beneficiaries. Given that Utah shares the same stated goal, we urge the state to adopt a different tactic -- beyond work requirements – to accomplish this laudable goal.

We are also concerned about the proposed lock-out period for non-compliance with the work or community engagement requirement. The state offers individuals who have failed to participate in the work/community engagement requirement the opportunity to use "good cause" exemptions, but it is unclear how long the appeal process would take and whether the beneficiary would lose health coverage during the process. If individuals are locked out of coverage during the appeal process, they will likely have no access to health care coverage, making it difficult or impossible to continue treatment or pay for their maintenance medication until it is determined that they have "good cause" or meet one of the exemptions. 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.

<u>Enrollment Limits for the Limited Expansion Group</u>

We remain troubled by the establishment of an enrollment limit on the Adult Expansion demonstration group. An arbitrary enrollment limit could prevent eligible individuals, such as cancer patients and survivors, from receiving critical health care and treatment services. In particular, it is unclear how an enrollment limit would work with retroactive eligibility, which allows hospitals and providers to retroactively enroll eligible low-income, uninsured individuals into the Medicaid program. For example, fifteen uninsured individuals eligible under the expansion group are either retroactively enrolled in the program or presumed to be eligible for coverage through multiple hospital/provider systems throughout Utah in one day. Unbeknownst to those hospitals/providers, the enrollment limit is reached at five. What will happen to the 10 individuals who were informed they would initially be eligible for coverage but are not, due to the enrollment limit? Instead of being cost effective for the state, enrollment limits

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[10] 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.

[11] Sommers BD, Goldman AL, Blendon RJ, Orav EJ, Epstein AM. Medicaid work requirements – Results from the first year in Arkansas. *NEJM*. 2019; DOI: 10.1056/NEJMsr1901772.

[12] Ibid.

[13] See Waiver Application at Pg. 6.

could instead increase uncompensated care, as individuals think they are now eligible for Medicaid, but are not given coverage.

The state also assumes the enrollment limits, which were originally approved by CMS in March 2019 only for the Adult Expansion group up to 100 percent of FPL, would also apply to the full expansion population (up to 138 percent FPL). We believe this assumption is premature and that Utah's application should be considered incomplete until an enrollment limit proposal for the full expansion population is included in a 1115 waiver application for public comment. Either way, ACS CAN opposes any form of enrollment caps on Medicaid beneficiaries as they would result in either an individual facing significant out-of-pocket expenses for care that they believed would be covered by their presumed eligibility or a provider being responsible for the cost of the provided services – should the patient be unable to pay for them. Therefore, we urge CMS to consider the patients who rely on Medicaid for health care coverage, as well as the providers and their contribution to Utah's safety net and deny the state from establishing an enrollment limit on the Adult Expansion demonstration group.

Current Proposals
We are extremely concerned with the proposals included in the current 1115 waiver application and how they will interact with the previously non-approved proposals from the per-capita-cap waiver and with the proposals previously approved by CMS in March 2019.

Lock-out for Adult Expansion Population for Intentional Program Violation
The state is requesting authority to apply a six-month lockout on individuals determined by the Utah Department of Health Medicaid to have committed an intentional program violation (IPV) to become or remain eligible for Medicaid. While we appreciate the state's attempt to prevent fraud and abuse in the Medicaid program, it is critical that CMS require the state to provide an effective and swift appeals process to ensure the 750 individuals per year the state anticipates[14] will lose eligibility for six months do not lose access to critical health care coverage due to an administrative error by the state.

Waiving Presumptive Eligibility for Low-Income Adults
Patients rely on presumptive eligibility to receive affordable health care, particularly if they did not realize they were eligible for affordable coverage through Medicaid. Safety net hospitals and providers also rely on presumptive eligibility for reimbursement of provided services, allowing these facilities to keep the doors open.[15,16] Waiving presumptive eligibility, along with the already approved enrollment limit, could result in either an individual facing significant out-of-pocket expenses for care that they believed would be covered by their presumed eligibility or a provider being responsible for the cost of the provided services should the patient be unable to pay for them. The state anticipates that approximately 500-750 individuals per month[17] will no longer receive eligibility through presumptive eligibility, solidifying our concern that fewer individuals will receive health insurance coverage.

[14] See Waiver Application at Pg. 11.
[15] Centers for Medicare & Medicaid Services. Emergency medical treatment & labor act (EMTALA). Updated March 2012. Accessed October 2019. https://www.cms.gov/regulations-and-guidance/legislation/emtala/.
[16] National Association of Community Health Centers. Maine health center fact sheet. Published March 2017. Accessed October 2019. http://www.nachc.org/wp-content/uploads/2016/03/ME_17.pdf.
[17] See Waiver Application at Pg. 18.

Therefore, we urge deny the state's request to waiver presumptive eligibility, as it could negatively impact patients, hospitals, and providers in the state.

Flexibility to Make Changes through the State Administrative Rulemaking Process

The state requests to begin enrollment the first of the month after application for Adult Expansion beneficiaries with income over 100 percent FPL (prospective enrollment). The state estimates that this proposal would result in the removal of one month out of twelve from a beneficiary's eligibility span, reducing total beneficiary months by 8.3 percent for the group. We are concerned this proposal could cause a gap in coverage for beneficiaries. For those cancer patients who are mid-treatment, a gap in their health care coverage could seriously jeopardize their chance of survival. Similarly, a gap in coverage for a cancer survivor could jeopardize their health, as cancer survivors often require frequent follow-up visits and maintenance medications as part of their survivorship care plan to prevent recurrence.[18] 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. Therefore, we urge CMS to deny the state's request to maintain continuity of care.

Change the benefit package for Adult Expansion and Targeted Adult demonstration groups (excluding medically frail) to the State's non-traditional benefit package

The state requests to provide a "non-traditional" benefit package to the Adult Expansion and Targeted Adult demonstration groups. ACS CAN believes it is important that beneficiaries have access to all basic services provided under Medicaid to ensure the greatest health outcomes for Utahns and are therefore concerned with the non-traditional package. While it appears that cancer patients could be included under the "medically frail" definition provided in this waiver, and therefore able to choose between the traditional and non-traditional benefit packages, we are concerned the definition may not include recent cancer survivors. Access to comprehensive benefits are critical for recent cancer survivors. Recent cancer survivors often require frequent follow-up visits and maintenance medications as part of their survivorship care plan to prevent recurrence,[19] and suffer from multiple comorbidities linked to their cancer treatments.[20] Ensuring both cancer patients and recent survivors receive the care they need is critical to positive health outcomes. Therefore, we urge CMS to require the state to more clearly define who would be included under the "serious and complex medical condition" category and ensure both cancer patients and recent survivors are included in that definition before CMS allows the state to move forward with this proposal.

Flexibility for Providing Managed Care

In general, we are supportive of Utah's decision to provide health care coverage to the expansion population through managed care. However, we are concerned with the state's proposal to implement

[18] National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care*. Accessed October 2018. https://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care.
[19] National Cancer Institute. *Coping with cancer: Survivorship, follow-up medical care*. Accessed October 2019. 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.

managed care rates and draw down federal funds prior to CMS review and final approval of the proposed rates. In addition, we are concerned about the extent to which the state will provide needed education and notice to individuals whose care will be provided through managed care. We urge CMS to require the state to provide additional information on the education and awareness processes it intends to implement to notify current enrollees of the change to managed care, as well as those who will become eligible for the program through the partial expansion.

We also urge CMS to require the state to consider continuity of care provisions that would ensure that individuals in active treatment for life-threatening illnesses, such as cancer, not face significant care disruptions. For an individual undergoing cancer treatment, timely and uninterrupted access to services is critical. When cancer treatment is delayed or disrupted, the effectiveness of the treatment could be jeopardized, and the individual's chance of survival can be significantly reduced. Failure to consider the care delivery and/or treatment regimen of patients, especially those managing a complex, chronic condition like cancer, could have devastating effects on patients, their families, and providers. Additionally, we recommend that the Department establish a clearly defined process through which a Medicaid enrollee can inform the state that they are in active treatment. These actions will allow cancer patients to maintain their cancer care treatment regimen and continue to see their providers in the same health care systems through the end of their treatment.

ACS CAN also urges CMS to require the state provide clarification on how it intends to ensure that managed care plan networks include an adequate number of specialists to guarantee that enrollees have access to the specialists necessary to treat their medical conditions, especially oncologists, cancer surgeons, and radiologists.

<u>Premiums for Adult Expansion Beneficiaries</u>

ACS CAN opposes the proposed mandated monthly premiums for individuals with incomes at or above 100 percent of the Federal Poverty Level (FPL) in the Adult Expansion group. We are concerned the cost sharing and related penalties for non-payment for the expansion population could create administrative burdens for enrollees, deter enrollment or result in a high number of disenrollment, and potentially cause significant disruptions in care, especially for cancer survivors and those newly diagnosed. Studies have shown that imposing even modest premiums on low-income individuals is likely to deter enrollment in the Medicaid program.[21,22,23] Imposing cost sharing on low-income populations has been shown to decrease the likelihood that they will seek health care services, including preventive

[21] Hendryx M, Onizuka R, Wilson V, Ahern M. Effects of a Cost-Sharing Policy on Disenrollment from a State Health Insurance Program. *Soc Work Public Health*. 2012; 27(7): 671-86.
[22] Wright BJ, Carlson MJ, Allen H, Holmgren AL, Rustvold DL. Raising Premiums and Other Costs for Oregon Health Plan Enrollees Drove Many to Drop Out. *Health Affairs*. 2010; 29(12):2311-16.
[23] Office of the Assistant Secretary for Planning and Evaluation. Financial Condition and Health Care Burdens of People in Deep Poverty. Published July 16, 2015. Accessed October 2019. http://aspe.hhs.gov/basic-report/financial-condition-and-health-care-burdens-people-deep-poverty.

screenings.[24,25,26] Cancers that are found at an early stage through screening are less expensive to treat and lead to greater survival.[27] Uninsured and underinsured individuals already have lower screening rates resulting in a greater risk of being diagnosed at a later, more advanced stage of disease.[28] Proposals that place greater financial burden on low-income residents create barriers to care and could negatively impact enrollees – particularly those individuals who are high service utilizers with complex medical conditions.

Loss of Eligibility for Non-Payment

We are deeply concerned about the loss of eligibility for Adult Expansion Medicaid for non-payment of premiums until past due premiums are paid. Denying individuals health coverage for non-payment of a premium could place a substantial financial burden on enrollees and cause significant disruptions in care, particularly for cancer survivors (who require frequent follow-up visits) and individuals in active cancer treatment. While we appreciate that beneficiary's coverage can be reinstated after six months from when coverage was ended, low-income cancer patients or survivors will likely have no access to health care coverage during those six months, making it difficult or impossible to continue treatment or pay for their maintenance medication until they can pay all outstanding premiums. 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 for six months could have a significant impact on an individual's cancer prognosis and the financial toll that the lock-out would have on individuals and their families could be devastating.

ACS CAN urges CMS to require the state to implement a medical or hardship exemption that would exclude individuals managing complex medical conditions, like cancer, from any lock-outs or other penalties. Additionally, we encourage CMS to require the state to allow enrollees and/or their health care providers to proactively attest to any change in their health status that could qualify them for the medical or hardship exemption, preventing any unnecessary gaps in coverage.

<u>Surcharge for Non-emergent Use of the Emergency Department</u>

The Department's request to impose a $10 surcharge (up to $30 per quarter, per individual) directly to the individual's premium for each "non-emergent" or "inappropriate" use of the emergency department (ED) for those with incomes at and above 100 percent of FPL could increase premium costs for cancer patients. Imposing this surcharge, even with the added educational piece after an initial "inappropriate use", may dissuade an individual from seeking care from an ED setting – even if the case is medically warranted. 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. If

[24] Solanki G, Schauffler HH, Miller LS. The direct and indirect effects of cost-sharing on the use of preventive services. *Health Services Research.* 2000; 34: 1331-50.
[25] Wharam JF, Graves AJ, Landon BE, Zhang F, Soumerai SB, Ross-Degnan D. Two-year trends in colorectal cancer screening after switch to a high-deductible health plan. *Med Care.* 2011; 49: 865-71.
[26] Trivedi AN, Rakowsi W, Ayanian JA. Effect of cost sharing on screening mammography in Medicare health plans. *N Eng J Med.* 2008; 358: 375-83.
[27] American Cancer Society. *Cancer Prevention & Early Detection Facts & Figures 2019-2020.* Atlanta: American Cancer Society; 2019.
[28] Ibid.

primary care settings and other facilities are not available, these patients are often directed to the ED. Penalizing enrollees, such as cancer patients, by requiring a surcharge for non-emergent use of the ED could become a significant financial hardship for these low-income patients.

We urge CMS to require the state to define the term "non-emergent" use of the ED, as a definition is not included in the waiver. Additionally, when evaluating ED cost sharing requirements, we urge CMS to require the state evaluate the impact it has on patients with complex chronic conditions, such as cancer, not just evaluate the financial impact of this type of requirement.

Conclusion

We appreciate the opportunity to provide comments on Utah's 1115 waiver amendment. Expanding eligibility and coverage through the Medicaid program is critically important for many low-income Utahns who could greatly benefit from the program for cancer prevention, early detection, diagnostic, and treatment services. However, the proposed changes in this 1115 waiver could negatively impact Utah residents. We ask CMS to weigh the potential impact the previously accepted waiver proposals (community engagement requirements, lock-out periods, and limited enrollment) along with the current 1115 proposed changes could have on low-income Utahns access to lifesaving health care coverage, particularly those individuals with cancer, cancer survivors, and those who will be diagnosed with cancer during their lifetime.

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 CMS to ensure that all people 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 A. Lacasse, MBA
President