Harold P. Wimmer
National President and
CEO

August 16, 2018

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

Re: Kentucky HEALTH - Application and CMS STCs

Dear Secretary Azar:

The American Lung Association appreciates the opportunity to submit comments on the Kentucky HEALTH Section 1115(a) Demonstration Waiver and the Centers for Medicare and Medicaid Services (CMS) Special Terms and Conditions (STC).

The American Lung Association is the oldest voluntary public health association in the United States, currently representing the 33 million Americans living with lung diseases including asthma, lung cancer and COPD, including over 700,000 Kentuckians. The Lung Association is the leading organization working to save lives by improving lung health and preventing lung disease through research, education and advocacy.

The American Lung Association believes everyone, including Medicaid enrollees, should have access to quality and affordable health coverage. Unfortunately, this waiver will jeopardize patients' access to quality and affordable health coverage, and the Lung Association therefore urges CMS to reject this waiver.

Premiums and Cost-Sharing

One of the key features of the Kentucky HEALTH program, as originally approved by CMS, is to charge premiums to both Medicaid expansion enrollees and extremely low-income parents and caregivers. Premiums will be no less than $1 and can be up to 4 percent of household income.[1] This would allow Kentucky to increase premiums for enrollees who are on Medicaid for over a year, as the state proposed. Kentucky only needs to give enrollees a 60-day notice of a premium increase.

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Premiums both increase the number of enrollees who lose Medicaid coverage and discourage eligible people from enrolling in the program.[2] When Oregon implemented a premium in its Medicaid program, with a maximum premium of $20 per month, almost half of enrollees lost coverage.[3] For individuals with lung disease, maintaining access to comprehensive coverage is vital. Patients with lung diseases such as COPD need access to treatments to reduce both the frequency and severity of breathing exacerbations and improve quality of life for patients.

Indiana implemented a similar payment structure in a previous waiver demonstration. The evaluation report[4] from the waiver demonstration found that over half of Medicaid enrollees failed to make at least one payment. The report also found that 29 percent of Medicaid eligible individuals either never enrolled because they did not make a payment or were disenrolled for failure to make payments. Coverage losses on this scale, especially for patients needing access to life-saving and life-sustaining treatment, would be dire. For lung cancer patients, health coverage can mean access to recommended screenings, catching cancer at an early, treatable stage. Lung cancer five-year survival is only 5 percent for those diagnosed at a late (distant) stage after the tumor has spread, but increases to 56 percent for those diagnosed at an early (local) stage before the tumor has spread.[5] Without coverage, patients with lung disease would not be able to get the recommended screening and treatment when diagnosed, the consequences of which could clearly be deadly.

The waiver, as originally approved by CMS, also provides enrollees with a funded $1,000 deductible account. The funds will be used to cover any non-preventive healthcare services. The STC states, "The deductible account acts as an educational tool to encourage appropriate health care utilization." Unfortunately for patients with lung disease, utilization of healthcare services is not a choice but a necessity and can be a matter life or death.

Enrollees will would also have a second account - the My Rewards Account - to pay for dental and vision coverage and over-the-counter medications. Enrollees are able complete activities to earn money for this account, and up to $500 of unused deductible account funds can roll over to the My Rewards account. These accounts can limit the access to needed treatments both if an enrollee does not have enough funds in the My Rewards Account to access needed care, or by creating an incentive to not seek treatment needed for one medical reason so there is money available from the deductible account to be rolled over.

Ultimately, all of these changes will create confusion and significant barriers for patients that will jeopardize their access to needed care.

<u>Waiving Retroactive Eligibility</u>
Kentucky asked for and CMS approved the proposal to remove retroactive eligibility in Kentucky. Retroactive eligibility in Medicaid prevents gaps in coverage, by covering individuals for up to 90 days (or quarter of the year) prior to the month of application, assuming the individual is eligible for Medicaid coverage during that time frame. It is common

that individuals are unaware they are eligible for Medicaid until a medical event or diagnosis occurs. Retroactive eligibility allows patients who have been diagnosed with a serious illness, such as lung cancer or asthma, to begin treatment without being burdened by medical debt prior to their official eligibility determination. A delay in treatment for lung cancer patients can cause the cancer to develop to a more advanced stage.[6]

Medicaid paperwork can be burdensome and often times confusing. A Medicaid enrollee may not have understood or received a notice of Medicaid renewal and only discovered the coverage lapse when picking up a prescription or going to see their doctor. Without retroactive eligibility, Medicaid enrollees could then face substantial costs at their doctor's office or pharmacy. For example, when Ohio was considering a similar provision in 2016, a consulting firm advised the state that hospitals could accrue as much as $2.5 billion more in uncompensated care as a result of the waiver.[7] Patients should not be left to choose between massive medical bills and treating their illness.

Waiving Non-Emergency Transportation (NEMT) Benefits

Kentucky proposed and CMS approved waiving Non- Emergency Transportation (NEMT) benefits for the Medicaid expansion population. Removing this benefit will harm patients. Individuals with asthma and COPD, for example, need to attend regular visits with their doctors to manage their medications and treatments before breathing problems become more acute and severe.

NEMT allows patients to keep appointments with doctors and other healthcare providers. For example, one study found patients with asthma, hypertension or heart disease who needed multiple visits to a medical professional to maintain their health were more likely to keep their appointments if they had NEMT.[8] This benefit helps patients maintain key appointments to manage their conditions and stay healthy.

Work and Community Engagement Requirements

Kentucky's waiver was the first waiver CMS approved that conditioned Medicaid coverage on hours worked. The STC detail that individuals between the ages of 19 and 64 would be required to either demonstrate that they work at least 80 hours per month or meet exemptions. One major consequence of this proposal will be to increase the administrative burden on all patients. Individuals will need to attest that they meet certain exemptions or have worked the required number of hours on a monthly basis. Increasing administrative requirements will likely decrease the number of individuals with Medicaid coverage, regardless of whether they are exempt or not. For example, after Washington state changed its renewal process from every twelve months to every six months and instituted new documentation requirements in 2003, approximately 35,000 fewer children were enrolled in the program by the end of 2004.[9] Battling administrative red tape in order to keep coverage should not take away from patients' or caregivers' focus on maintaining their or their family's health.

Failing to navigate these burdensome administrative requirements could have serious – even life or death – consequences for people with serious, acute and chronic diseases, including patients with lung disease. After an initial three-month period, if the state finds that individuals have failed to comply with the new requirements for one month, they will be locked out of coverage until they either complete a health or financial literacy class, make up the missing hours in the next month or complete the required 80 hours of work in the next month. People who are in the middle of treatment for a life-threatening disease, rely on regular visits with healthcare providers or must take daily medications to manage their chronic conditions cannot afford a sudden gap in their care.

The American Lung Association is also concerned that the current exemption criteria may not capture all individuals with, or at risk of, serious and chronic health conditions that prevent them from meeting these requirements. No exemption criteria can circumvent this problem and the serious risk to the coverage and health of the people we represent.

Administering these requirements will be expensive. Kentucky and other states including Tennessee and Virginia have estimated that setting up the administrative systems to track and verify exemptions and work activities will cost tens of millions of dollars.[10] These costs would divert resources from Medicaid's core goal – providing health coverage to those without access to care.

These requirements do not further the goals of the Medicaid program or help low-income individuals improve their circumstances without needlessly compromising their access to care. Most people on Medicaid who can work already do so.[11] A recent study, published in JAMA Internal Medicine, looked at the employment status and characteristics of Michigan's Medicaid enrollees.[12] The study found only about a quarter were unemployed (27.6 percent). Of this 27.6 percent of enrollees, two thirds reported having a chronic physical condition and a quarter reported having a mental or physical condition that interfered with their ability to work.

Ultimately, the Kentucky HEALTH program will harm patients with lung disease. Leading public health and health policy deans and professors estimated the coverage loss as a result of the waiver would be between 175,000 and 300,000 people once the waiver is fully implemented.[13] This is unacceptable for patients with lung disease, as they need access to quality and affordable healthcare. This waiver will not provide that.

To inform CMS's decision on this waiver, the Lung Association is submitting additional articles and studies for the record that contain important information on the impact of Kentucky's proposal on Medicaid enrollees.

The American Lung Association believes healthcare should affordable, accessible, and adequate. The Kentucky HEALTH program does not meet that standard, and the Lung Association urges CMS not to re-approve the waiver. Thank you for the opportunity to provide comments.

Sincerely,

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CC: Demetrios L. Kouzoukas
Principal Deputy Administrator
Centers for Medicare and Medicaid Services

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[3] Artiga, Samantha, Petry Ubri and Julia Zur. The Effects of Premiums and Cost Sharing on Low-Income Populations: Updated Review of Research Findings. Kaiser Family Foundation. June 1, 2017. Accessed at: https://www.kff.org/medicaid/issue-brief/the-effects-of-premiums-and-cost-sharing-on-low-income-populations-updated-review-of-research-findings/

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[10] Misty Williams, "Medicaid Changes Require Tens of Millions in Upfront Costs," Roll Call, February 26, 2018, https://www.rollcall.com/news/politics/medicaid-kentucky.

[11] Rachel Garfield, Robin Rudowitz, and Anthony Damico, "Understanding the Intersection of Medicaid and Work," Kaiser Family Foundation, February 2017, http://kff.org/medicaid/issue-brief/understanding-the-intersection-of-medicaid-and-work/.

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