October 20, 2018

Jennifer Lee, MD
Secretary
Virginia Department of Medical Assistance Services
Attn: Virginia COMPASS
600 E Broad Street
Richmond, VA 23219

Re: Virginia Department of Medical Assistance Services 1115 Demonstration Extension Application – Virginia COMPASS: Creating Opportunities for Medicaid Participants to Achieve Self-Sufficiency

Dear Dr. Lee:

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 Section 1115 Demonstration Waiver request for the Virginia COMPASS program. Our comments address our concerns with the proposed work requirement, monthly premium and copay policies that will ultimately limit access to care for low-income individuals in Virginia living with cancer. For the reasons outlined in this letter, we have serious concerns with Virginia’s 1115 waiver request and urge the Commonwealth to withdrawal it.

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 $40 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.

Cancer patients face a wide variety of barriers in access to quality and comprehensive care. Almost all patients report experiencing barriers in accessing care, regardless of their income-level, location, and health plan. Low-income cancer patients however are particularly at risk as they face obstacles in qualifying for, accessing, and maintaining health care coverage for
essential services. Of the patients surveyed in the *Access to Care in Cancer 2016* study conducted by CSC, only 4.8% had gained access to coverage through Medicaid. Of the patients who reported being uninsured, 43% said they could not afford health insurance, and 31% said they were not eligible for Medicaid. According to a report from the Center on Budget and Policy Priorities, 400,000 additional Virginians will be eligible for Medicaid coverage with the recent Medicaid expansion. The same report estimates that the more than $20 million a year cost to administer these requirements, impacting 120,000 enrollees (according to the state's proposal), will result in 33,000 Virginians losing coverage. After a long battle to expand health care options to so many, these additional barriers in access to care will set back progress and harm cancer patients who struggle to maintain coverage while undergoing difficult, life threatening, and time consuming treatment regimens.

I. Work Requirements do not meet the requirements for a Section 1115 Waiver

Federal law does not permit the implementation of work requirements in the Medicaid program, as the core mission of the Medicaid program is to provide comprehensive health coverage to people whose income and resources are “insufficient to meet the costs of necessary medical services.” Section 1115(a) of the Social Security Act was created to allow the Secretary of the Department of Health and Human Services to waive certain provisions of the Medicaid program as long as the initiative is “likely to assist in promoting the objectives of the program”. The Virginia proposal does not fulfill the requirement as it will create significant access barriers for low-income Virginians.

The state is seeking to implement work requirements to “improve Medicaid enrolled adults’ health, well-being, and financial stability.” However, according to a 2017 study by the Kaiser Family Foundation, 8 in 10 Medicaid recipients already live in working families and a majority are working themselves. The Medicaid program is designed to provide coverage for those that are unable for a variety of reasons, to find or maintain employment that can provide for their health care needs. Medicaid enrollees who are not working most often reported that the major impediments to their ability to work included illness, disability, or caregiving responsibilities. In a study done by The Ohio Department of Medicaid, it was reported that three-quarters of Medicaid beneficiaries who were looking for work said that Medicaid made it easier for them to do so. For those who were currently working, more than half said that Medicaid made it easier to keep their jobs.

Health care and the ability to maintain good health is itself critical to an individual’s ability to retain employment. A 2018 Kaiser Family Foundation study concluded that, “access to affordable health insurance has a positive effect on people’s ability to obtain and maintain employment, while lack of access to needed care, especially mental health care and substance abuse treatment, impedes employment.” It goes on to explain that low-income adult Medicaid enrollees have high rates of chronic conditions, and that these individuals are better able to hold a steady job if these conditions are treated or controlled, but work may become impossible if these conditions go untreated. Health setbacks often lead to job loss, which would lead to loss of access to health care and treatment, which would in turn make it more difficult for individuals to retain employment.
II. Vague exemption categories will harm individuals living with cancer and their caregivers

The Virginia waiver would be disproportionately detrimental to cancer patients and their families. The application outlines 16 categories of enrollees that would be exempt from the requirements. These exceptions are ill-defined and vague, likely leaving many patients unsure of whether they will qualify as exempt. Though the proposal includes exemptions for those classified as “medically frail” or those that are caregivers to family members or disabled/elderly individuals, there is no clear exemption for cancer patients and survivors, nor any detail as to how participants must document or qualify for these exemptions. Many individuals living with cancer are not classified as “severe” enough by the Medicaid program to qualify for a disability exemption, but are facing significant health problems that would make it extremely difficult or impossible to fulfill these requirements. Treatment for cancer may not always produce “severe physical or mental impairments” that will easily and explicitly qualify patients for disability or medical frailty, but can greatly impede their health and ability to maintain steady employment. Patients often face symptoms of their disease as well as difficult side effects of medications such as extreme nausea, fatigue, diarrhea or constipation, nerve damage, heart problems, pain, etc.

Virginia’s proposal includes a “good cause” exemption that includes such circumstances as hospitalizations or serious illness, but it is not sufficient to protect patients. Under a similar waiver demonstration recently implemented in Arkansas, many individuals were unaware of the new requirements and therefore unaware that they needed to apply for such an exemption. In August the state granted just 45 good cause exemptions while terminating coverage for 4,353 individuals at the end of that month. No exemption criteria can circumvent this problem and the serious risk to the health of cancer patients and survivors.

III. Premiums, cost-sharing, and additional co-payments punish patients

The Virginia COMPASS program proposes to charge premiums ranging from $5- $10 per month to some expansion enrollees. Those who fail to pay their premiums after a three month grace period will have their coverage suspended, only to be reactivated after they are able to make one premium payment or meet an exemption. Premium payments will be placed in a health and wellness account (HWA). Further, enrollees with incomes between 100-138% of FPL are required to meet a $50-$100 deductible, as well as participate in at least one designated “healthy behavior” to receive a rebate from their premium payments, or gain access to the funds in their HWA, to be used only for non-covered medical or other health related services. This proposal is restrictive, unnecessarily confusing, and will reduce rather than improve access to coverage for the most vulnerable populations. The implementation of premiums has been shown to increase the number of enrollees who lose Medicaid coverage and discourage eligible people from enrolling in the program. When Oregon implemented a premium in its Medicaid program, with a maximum premium of $20 per month, almost half of enrollees lost coverage. For cancer
patients and survivors, maintaining access to comprehensive coverage is vital to ensure access to timely, life-saving treatments.

The waiver application also includes a proposal to charge individuals with incomes between 100-138% of FPL to pay a $5 co-payment for each non-emergent or avoidable emergency department visit. This policy could discourage cancer patients from seeking necessary care in an emergency, which could have serious impacts on their short term and long term health. When people do experience severe symptoms, they should not need to try to self-diagnose or worry that they may be financially penalized and unable to afford to seek necessary care.

IV. Conclusion

We appreciate the opportunity to provide comments on the Virginia COMPASS 1115 Waiver Demonstration Request. For the reasons above, we urge the withdrawal of this proposal, to ensure that vulnerable populations retain access to necessary and affordable healthcare. A program that was designed provide for the health care needs of low-income individuals without other options, should never be provisional based on unattainable goals or detrimental to the health of its citizens. Please reach out to me at efranklin@cancersupportcommunity.org if you would like to discuss any of the above in more detail.

Respectfully Submitted,

Elizabeth Franklin, LGSW, ACSW
Executive Director, Cancer Policy Institute
Cancer Support Community
References


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