February 19, 2019

The Honorable Seema Verma
Administrator
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue, SE
Washington, DC 20201

Re: Proposed HHS Notice of Benefit and Payment Parameters for 2020 (CMS-9926-P)

Dear Administrator Verma:

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 HHS Notice of Benefit and Payment Parameters for 2020 (NBPP).

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.

We agree with the goal of reducing the health care cost burden facing patients but we are concerned that many of the proposed changes in the NBPP 2020 may ultimately hinder the ability of patients to access high-quality, timely, and affordable cancer care.

Changes to Cost Sharing in the Prescription Drug Benefit

CMS has proposed several policy changes to cost-sharing requirements that will likely have a negative impact on cancer patients’ access to the appropriate treatments. First, CMS proposes that in health plans that cover both a brand name prescription and its generic equivalent, the plan does not have to count the brand name version of the drug as an essential health benefit (EHB). If a health plan follows this designation and an enrollee needs a brand name drug when a generic equivalent is available, only the amount of the enrollee cost-sharing that would have been paid for the generic will count toward their annual limit. This proposal would also allow health plans to set lifetime and annual dollar limits on such brand name drugs that are no longer considered EHB. CSC is concerned that these lifetime and annual limits, as well as the changes to the amount of cost-sharing applied to the limit, and the lacking definition of what may be considered
a generic equivalent, could restrict cancer patients’ access to appropriate therapies. In this scenario, patients are likely to reach their annual or lifetime limits early in the year, leaving them to cover the cost of treatment entirely, or to go without and risk their health and their lives. According to a National Survey of Households Affected by cancer, prior to the enactment of current protections under the Affordable Care Act (ACA), one in ten cancer patients reached the limit of what their insurance would pay for their cancer treatment. Every cancer patient is different, with different values, needs, and preferences. Patients need access to the appropriate therapy chosen by their healthcare team, and cannot afford delays in access to drugs due to high cost-sharing and limits. Furthermore, this policy should not preempt state laws regarding cost-sharing between generic and brand name drugs. As the Administration has emphasized in previous proposals, states are unique and require different regulations to appropriately provide for their populations. States that enact legislation to ensure that patients have equal access to brand or generic medications should not be overridden by this policy.

The Administration is also proposing to allow plans to implement “accumulator adjustment programs” or “copay accumulators” wherein the copay assistance a beneficiary receives from the drug manufacturer will no longer count toward their deductible or out-of-pocket maximum. Many cancer patients rely on these copay assistance coupons to access their treatments, and to help them meet their deductible or out-of-pocket maximum. CSC is further concerned with the way CMS will identify and limit the use of copay assistance from a manufacturer versus alternate copay assistance programs like nonprofit foundations or support from family or another benefactor. There are a variety of third party assistance options that patients rely on to help them access treatment other than manufacturer assistance that are not mentioned in the proposal, and CSC is concerned that this policy may put access to these types of support at risk.

### Allowance of Mid-Year Formulary Changes

CSC appreciates the Administration’s proposal to allow insurers in the individual, small group, and large group markets to add a generic equivalent of a drug that becomes available to a formulary in the middle of the plan year. We are concerned, however, about the flexibility for plans to remove the equivalent brand name from the formulary or move it to a different cost-sharing tier in the middle of a plan year. Though the proposal includes an exception request process in addition to a 60-day notice of changes to drug tiers or availability, these policies could disrupt a patient’s treatment regimen, which may increase side effects, adverse reactions, or cause setbacks in recovery.

Furthermore, many cancer patients and survivors choose their health plans based on what is included in the coverage at the start of the plan year. This proposal would give plans the ability to change that coverage in the middle of the plan, while a patient is still locked in for the remainder of the plan year. The proposal states that despite the possibility of a disruption in patient’s access to a needed medication, the generic will now be available and “generally more affordable” than the brand name drug. As noted above, every cancer patient is different, and the generic alternative to a brand name medication may not meet his or her medical needs. Cancer patients need access to the most appropriate treatment chosen by their healthcare provider, and forced, mid-year, non-medical switching could have serious, and even life threatening consequences.
If CMS were to go forward with this policy, we would request that when adding a new generic formulation to a plan mid-year, plans should not be allowed to remove the brand equivalent or move it to a different tier in the middle of the plan year. CMS should also provide sufficient notice to allow patients to work with their medical team to choose a new treatment, or a new health care plan before the start of the next plan year, as well as a speedy and simple appeals process for patients who can demonstrate that they need access to the brand equivalent.

**Changes to Essential Health Benefit Benchmarking and Network Adequacy Standards**

Within this proposal, CMS proposes to allow states to update or change their EHB benchmark plan annually beginning in 2020. EHBs were created through the Affordable Care Act (ACA) to ensure that beneficiaries would have access to the ten benefit categories deemed essential, and could not be discriminated against based on age, disability, or pre-existing condition. The NBPP proposes that states that want to change their benchmark, the base line by which they must match the minimum coverage options, be allowed to adopt the benchmark used by any other state in 2017, retain their 2017 benchmark but replace one or more benefit categories with that of another state, or create a completely new EHB benchmark. This proposal would give states total control over the baseline level of coverage offered, putting at risk enrollees guaranteed access to an appropriate level of coverage for EHBs.

Furthermore, the proposal maintains the approach adopted for plan year 2018 that gives states responsibility for network adequacy reviews of Qualified Health Plans (QHPs) in the federally facilitated exchanges. This means that a state can deem a plan adequate when it meets the “reasonable access” standard defined in the ACA. However, in this designation, states are not require to use any specific metrics like time spent in transit or distance from provider in their assessment of reasonable access. This would allow a state to use whatever metrics it chooses to evaluate the adequacy of access, putting patients’ access to healthcare at risk. Many cancer patients live in rural areas, or lack the resources needed to travel to and pay for appropriate cancer treatments. This proposal will only serve to further risk patient access to care by allowing states to deem that a plan provides reasonable access without evaluating the true impact to patients.

The protections put in place through the EHBs are meaningless without the proper enforcement. With more flexibility, insurers are able to design plans that are still discriminatory and could limit patient access to necessary care such as prescription drugs, mental health services, emergency services, and more.

**Changes to the Navigator Program**
Currently, the navigator program operating in federal exchanges requires that navigators be trained in and provide post-enrollment assistance including such issues as filing an eligibility appeal, applying for an exemption, and developing basic health literacy. The proposal would also eliminate the requirement that navigators be trained in at least 15 explicit subjects, instead creating four broad and ill-defined categories of required training. According to the National Assessment of Adult Literacy, assessed by the U.S. Department of Health and Human Services, only 12% of American adults have proficient health literacy. Approximately 14% of adults, or 30 million people, reported below basic health literacy, and were more likely to report their health as poor. Americans enrolling in the marketplace need reliable assistance from navigators to choose appropriate and comprehensive health coverage for themselves and their families. Further cuts to the funding for navigators and the training requirements will only serve to increase health literacy disparities and leave consumers to fend for themselves in a fight for their access to quality healthcare.

**Silver loading and Auto Re-enrollment**

We appreciate CMS’s proposal to allow “silver loading” as well as auto re-enrollment to continue. Without Congressional action to appropriate cost-sharing reduction payments that help low-income consumers access care, silver loading ensures that people have access to a health plan that will suit their needs. Auto re-enrollment helps to ensure that consumers have continuous health coverage and helps to maintain a balanced risk pool in the marketplace. Individuals who purchase their coverage through the exchange have come to count on auto re-enrollment to guarantee continued coverage, and may lose coverage or risk interrupted care if the practice were discontinued.

**Premium Adjustment Percentage**

CMS is proposing that the premium index for the 2020 benefit year use CMS Office of the Actuary (OACT) estimates of projected private individual and group market health insurance premiums instead of using employer-sponsored insurance premiums used in previous years. This change would result, by CMS’ own estimation, in an increase in private individual and group market health insurance premiums of approximately 29.7% over the period from 2013 to 2019. This is an increase of almost $200 per year in premiums for a family of 4 earning $80,000. Approximately 7.3 million Americans would be impacted by this change, and the Administration estimates that 100,000 people would lose coverage because of these increases in premiums. Though the Administration has designed these benefit and payment parameters with a goal of decreasing health care costs, it would result in higher health care costs for exchange enrollees, leading to increased maximum out-of-pocket limits, higher deductibles and co-pays, and an ultimate loss of coverage for thousands.

In conclusion, CSC appreciates the opportunity to provide comments on the Notice of Benefit and Payment Parameters for 2020. We urge CMS to withdraw or amend the sections highlighted above as the impacts would be felt nationwide, and most acutely by those with pre-existing conditions like cancer. 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

