

# CANCER LEADERSHIP COUNCIL

A PATIENT-CENTERED FORUM OF NATIONAL ADVOCACY ORGANIZATIONS  
ADDRESSING PUBLIC POLICY ISSUES IN CANCER

January 30, 2023

The Honorable Xavier Becerra  
Secretary  
Department of Health and Human Services  
200 Independence Avenue, SW  
Washington, DC 20201

The Honorable Chiquita Brooks-LaSure  
Administrator  
Centers for Medicare & Medicaid Services  
Department of Health and Human services  
200 Independence Avenue, SW  
Washington, DC 20201

Re: CMS-9899-P, Patient Protection and Affordable Care Act, HHS Notice of Benefit and Payment Parameters for 2024

Dear Secretary Becerra and Administrator Brooks-LaSure:

The undersigned organizations representing cancer patients, health care professionals, researchers and caregivers offer comments below on the proposed rule related to the Notice of Benefit and Payment Parameters (NBPP) for 2024. We appreciate the opportunity to comment on the proposed 2024 standards for health insurers and Marketplaces under the Affordable Care Act (ACA).

As a nation, we have made important strides in reducing deaths from cancer, through a combination of prevention, early detection, and more effective therapies. The cancer death rate for men and women combined fell by 33% from 1991 to 2020. The toll of cancer is still significant, with a total of 1.958 million new cancer cases expected in the United States in 2023. In that same year, 609,820 cancer deaths are expected. The progress in cancer mortality “increasingly reflects advances in treatment.”<sup>1</sup> However, progress is threatened by rising incidence for breast, prostate, and uterine cancers, which are also the cancers that have the largest racial disparities in mortality.

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<sup>1</sup> Siegal RL, Miller KD, Wagle NS, and Jemal A, Cancer statistics, 2023. CA Cancer J Clin 2023; 73:17-48.

To continue progress in prevention, early detection, and treatment of cancer from diagnosis through the cancer trajectory, cancer patients must have access to adequate and affordable health care. Their insurance coverage must assure them access to the multi-disciplinary care they require at a cost that will not bankrupt them and deter them from receiving care. In our comments below, we comment on provisions of the proposed rule that advance this fundamental goal of protecting access to adequate and affordable care and recommend additional actions to protect cancer patients' access to quality care.

### ***Network Adequacy***

We commend the efforts of the Department of Health and Human Services (HHS) to establish in the final 2023 NBPP enhanced network adequacy standards for plans offered through the Federally Facilitated Marketplace (FFM) and State-Based Marketplaces that use the federal platform (SBM-FF). In the 2023 NBPP, the Department chose to delay implementation of appointment wait time standards, citing the compliance burden on issuers. We are pleased that HHS proposes to implement in 2024 the appointment wait time standard and to put issuers on notice that they must collect data to ascertain their compliance with the wait time standard.

During the COVID-19 pandemic, some cancer patients confronted delays in screening services. There are some indications of more cancer diagnoses at a later stage, when prognosis may be worse and required treatment may be more extensive than for those diagnosed at an earlier stage of disease. Delays in screening and care, including those that might result from long delays in appointments (not related to the pandemic), must be prevented. We are pleased that appointment wait time standards will be implemented in 2024 and compliance will be monitored.

As HHS continues its efforts to improve network adequacy, we urge that the Department consider network standards that will ensure access to care that is culturally competent and linguistically appropriate. As we noted above, progress in our efforts to reduce the burden of cancer – both diagnoses and deaths – is threatened by disparities in access to care. To address these disparities, HHS must evaluate networks and propose standards to ensure that networks can provide access to culturally appropriate care to people of color, immigrants, LGBTQ individuals, rural citizens, and others who are medically underserved. After such standards are developed and implemented, it will be critical for plans to provide potential enrollees with detailed information about their networks and providers in those networks.

### ***Prohibiting Mid-Year Terminations for Dependent Children Who Turn 26***

We support the HHS decision to codify the requirement that dependent children maintain coverage until the end of the plan year in which they turn 26. The marketplaces make advanced premium tax credits (APTC) eligibility determinations for families for the entire plan year, and it is reasonable for those who turn 26 to retain their coverage and their families retain the APTCs for the full plan year. For young adults with cancer, this continuity of coverage is critically important. Disruptions in coverage as a 26-year-old seeks enrollment in a new plan may result in interruption of cancer care, with adverse effects. Permitting young adults to retain coverage for the plan year in which they turn 26 will mitigate these interruptions in care.

### ***Special Enrollment Periods***

Enrollment in ACA plans for 2023 has set a record of 16.3 million enrollees. Almost one-quarter of enrollees are new to ACA plans. Even as the nation achieves this impressive record, health care experts warn that we could be entering a period of health insurance enrollment churn, in part due to expected loss of Medicaid coverage for some Americans. Considering this likely development of enrollment “churn,” we applaud the steps that HHS has taken to expand special enrollment periods (SEPs). These important changes include: 1) requiring qualified health plan (QHP) issuers to start coverage one month earlier in the case where the old coverage ends before the end of the month; and 2) expanding the “loss of coverage” SEP following the loss of Medicaid coverage from 60 days to 90 days.

HHS has indicated that it is considering whether to offer an SEP to consumers whose providers leave a network in the middle of the year. We endorse providing an SEP to patients who lose their doctor in the middle of a plan year. For cancer patients, losing their doctor during treatment seems to fit the standards for an enrollment exception, and they should be permitted to seek another plan through an SEP. As HHS notes, Medicare Advantage enrollees who experience a significant change in their plan’s provider network are permitted to enroll in another Medicare Advantage plan.

### ***Standardized Plan Options***

We support the movement toward more standardization of plans, which can promote informed decision-making. We commend HHS for taking these steps: 1) requiring issuers to offer at least one standardized plan at every product network type, metal level, and in every service area where the issuer offers non-standardized plans; and 2) requiring plans to have uniform cost-sharing parameters. We also support the use of copayments instead of coinsurance and the proposal to limit the number of non-standard plans that insurers can offer. Our community has learned from past enrollment periods that plan overload may confuse consumers. A smaller set of non-standardized plans might encourage more informed decision-making.

### ***Drugs Classified as “Non-Essential” Health Benefits***

Cancer patients and their care teams are increasingly being confronted with situations in which plans – which are required to follow essential health benefits standards – are designating certain medicines as non-essential. Cancer patients and their cancer care providers are finding that medicines that are necessary for their cancer treatment – “essential” in a regulatory sense and in a clinical sense – are classified as non-essential. Cancer patients are being directed to enroll in an alternative program that is not considered an insurance plan. The administrators of these so-called alternative programs are apparently patching together manufacturers’ assistance, grants and charity funding, and other programs to “pay for” patients’ drugs.

This trend, now experienced frequently in the cancer care setting, at the very least causes anxiety for patients and providers, who find out at a very difficult time that essential drugs are not really essential, according to their health plans. But the harm in many cases is more significant, as the offer of an alternative payment program may also delay care or cause patient and provider to reconsider an agreed upon course of treatment. It is also important to note that the alternative streams of payment are not always seamless in the way they are executed, potentially causing more anxiety and care disruption.

The new trend toward declaring drugs “non-essential” health benefits is consistent with and an almost predictable development related to the so-called copayment accumulator adjustment programs. We have in the past described these programs as ones that put vulnerable patients who need prescription drugs (sometimes expensive and sometimes on a chronic basis) between third-party payers and pharmaceutical manufacturers. In the case of cancer patients, the sometimes life-saving drugs that they are prescribed have high list prices. Those patients are left to try to manage their coinsurance responsibilities in the event that they are insured. Then, third-party payers establish “programs” that complicate the ability of patients to receive and fully take advantage of patient assistance.

To date, we have pleaded with policymakers, third-party payers, and pharmaceutical manufacturers for solutions that honor the needs of patients for affordable access to critical prescription medications.

We now write to suggest that HHS can help resolve this untenable situation for patients. We analyze this situation as a matter of essential health benefits and benefit design. Issuers make plan offerings. Patients choose from those offerings. In the case of cancer patients, if they have been diagnosed at the time of choosing a plan, they make difficult decisions about plans, the drug coverage standards of plans, and the cost-sharing responsibilities that they as consumers will bear. Often, they find the available offerings woefully inadequate because of the cost-sharing maximums. But they make their decisions.

During the plan year, cancer patients may find that the assumptions that they made and the choices they made about their plans and the standards for coverage are undermined by actions of payers to implement accumulator programs or to declare that prescription drugs are “non-essential.”

It is time for HHS to take action to require issuers to abide by the standards of the plans that they offer and to restrict their ability to fundamentally change their plan offerings through various efforts to restrict prescription drug coverage.

It is time to help patients exit the difficult space between payers and pharmaceutical companies in the battle over patient cost-sharing.

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We commend HHS for establishing and implementing or proposing standards for exchange plans that are patient-centered. We look forward to action on prescription drug coverage and cost-sharing to protect patients' access to critical therapies.

Sincerely,

**Cancer Leadership Council**

Academy of Oncology Nurse & Patient Navigators  
American Society for Radiation Oncology  
Association for Clinical Oncology  
Association of Oncology Social Work  
*CancerCare*  
Cancer Support Community  
Children's Cancer Cause  
Fight Colorectal Cancer  
International Myeloma Foundation  
LUNgevity Foundation  
Lymphoma Research Foundation  
National Coalition for Cancer Survivorship  
Ovarian Cancer Research Alliance  
Prevent Cancer Foundation  
Susan G. Komen