ALL COPAYS COUNT COALITION

July 15, 2026

The Hon. Robert F. Kennedy, Jr.
Secretary, U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

The Hon. Mehmet Oz
Administrator, Centers for Medicare & Medicaid Services
U.S. Department of Health and Human Services
P.O. Box 8013
Baltimore, MD 21244-8013

Attention: CMS-9874-NC

RE: Request for Information; Comprehensive Review of the Essential Health Benefits Framework and Typical Employer Plan Standard, RIN 0938-AW02

Dear Secretary Kennedy and Administrator Oz,

The All Copays Count Coalition (ACCC), on behalf of the 55 undersigned organizations, is writing in response to the Department of Health and Human Services' (HHS) and the Centers for Medicare and Medicaid Services' (CMS) Request for Information (RFI) on Essential Health Benefits (EHB). The ACCC is a coalition of national and state-based 501c3 non-profit, non-partisan patient advocacy and provider organizations representing millions of people living with serious and complex chronic illness. We appreciate the opportunity to provide comments on this RFI and request that as you consider policies related to EHB, HHS and CMS work with the relevant agencies to issue the previously promised rulemaking outlined in this letter. These rules have the potential to address issues of affordability for patients represented by the members of the ACCC, those living with serious and chronic illnesses – such as cancer, hemophilia, HIV/AIDS, arthritis, and more.

The people represented by the members of the ACCC rely on health insurance to afford the health care they need, including specialty medications. But high out-of-pocket costs and inappropriate practices by pharmacy benefit managers (PBMs) and health insurers are leaving too many of them unable to afford their medically necessary drugs, *even when they have health insurance*. Unfortunately, this leads to unmanaged conditions and ultimately, increased costs for the healthcare system as a whole. The ACCC and the millions of individuals our members represent would like to draw your attention to two widespread, disingenuous practices that have enhanced PBMs' and health plans' business interests at the expense of individuals living with serious,

chronic illnesses. We believe you have the existing authority to address these practices and ultimately, to protect patients.

Copay Accumulator Adjustor Programs

The first practice we would like to highlight is referred to as a copay accumulator adjustor program (CAAP) and occurs when a PBM or health plan accepts manufacturer copay assistance but does not count it towards a patients' out-of-pocket maximum or deductible. At some point in a year, the copay assistance will run out and under a CAAP, the patient will be left to pay the full cost of the drug until they reach their deductible or other cost-sharing obligations. For someone living with a serious, chronic illness, such as cancer, MS, or arthritis, this cost-sharing can be prohibitive and is the reason they turned to manufacturer copay assistance in the first place. Unfortunately, CAAPs often cause patients to skip doses or stop taking medications all together.

This issue is not new and has been addressed in a number of regulations issued by HHS and CMS. The 2020 Notice of Benefit and Payment Parameters (NBPP) stated that insurers cannot implement CAAPs for drugs that lack generic equivalents but the 2021 NBPP, issued the following year, included language allowing health plans and PBMs to implement CAAPs without restriction.[1,2] In September 2023, however, the United States District Court of the District of Columbia sided with the patients in *HIV & Hepatitis Policy Institute et al v. U.S. Department of Health and Human Services (HHS)* ruling that insurers can no longer implement CAAPs for drugs that lack generic equivalents.[3] Following the ruling, HHS issued a motion indicating that until the Department issues a final rule to address whether financial assistance provided to patients by drug manufacturers qualifies as cost-sharing, they will not take any enforcement action against insurers or plans based on their treatment of manufacturer assistance. And although in December 2023, the judge ruled that the 2020 NBPP was in force and HHS withdrew its appeal, the Department continued to state that rulemaking on cost-sharing was forthcoming. We have yet to see this rulemaking and plans continue to implement CAAPs; the 2020 NBPP is not being enforced.

Twenty-six states have passed laws banning or limiting the use of CAAPs but we need federal action to ensure everyone is protected. **ACCC calls on HHS and CMS to issue this promised rule**

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[1] Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2020. Effective June 24, 2019. Available at https://www.federalregister.gov/documents/2019/04/25/2019-08017/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2020.

[2] Patient Protection and Affordable Care Act; HHS Notice of Benefit and Payment Parameters for 2021; Notice Requirement for Non-Federal Governmental Plans. Effective July 13, 2020. Available at https://www.federalregister.gov/documents/2020/05/14/2020-10045/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2021.

[3] United States Court for the District of Columbia. HIV and Hepatitis Policy Institute et. al., Plaintiffs v. United States Department of Health and Human Services et al., Defendants. Filed 9/29/23. Available at https://hivhep.org/wp-content/uploads/2023/09/HIV-Hepatitis-Policy-Institute-v.-HHS-DDC-opinion.pdf.

and clarify that any copayment made by or on behalf of an enrollee is counted toward their annual cost-sharing contributions.

Copay Maximizers

The second practice, often referred to as a copay maximizer, occurs when health plans and PBMs deem targeted medicines as covered but non-essential health benefits (non-EHBs). The "non-essential" label in no way reflects the medical value of the drugs at issue; instead, it allows the plan/PBM to set patient copays far above the legal cost-sharing limits that exist to protect patients against crushing cost burdens. Patients who rely on "non-EHB" designated medications covered by their plan are required to enroll in the plan's/PBM's cost-shifting program. That program enrolls the patient in copay assistance and then extracts the full amount of that assistance for the benefit of the plan/PBM. If the patient refuses to participate in this arrangement, they are forced to pay potentially the full cost of the drug to gain access to their medication. Plans and PBMs benefit financially while patients cope with confusing processes, red tape, and delayed care. Unfortunately, it is often individuals represented by ACCC members who experience these abusive tactics.

The Administration has the necessary tools at their disposal to address this practice. The 2025 NBPP prohibited the use of copay maximizers by individual and small group plans.[4] The rule states that covered health plans cannot treat some drugs as EHBs and other drugs as non-EHBs: to the extent that the plan chooses to cover prescription drugs, then all those drugs are considered EHBs and are subject to federal limits on patient out-of-pocket spending. This rule, however, does not apply to large group and self-insured plans. Following the issuance of the 2025 NBPP final rule, the Departments of Labor, Treasury, and HHS stated their intention to undertake rulemaking to ban the use of copay maximizers in all non-grandfathered health plans, but the tri-agencies have not yet done so.[5] We also ask that CMS and its partner agencies enforce both rules to ensure that the patients we represent benefit from these important protections.

The ACCC, and the millions of patients we represent, call on HHS to work with the Departments of Labor and Treasury to issue this promised rule and to enforce the existing and forthcoming ban on copay maximizers.

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[4] Patient Protection and Affordable Care Act, HHS Notice of Benefit and Payment Parameters for 2025; Updating Section 1332 Waiver Public Notice Procedures; Medicaid; Consumer Operated and Oriented Plan (CO-OP) Program; and Basic Health Program. Final rule. Effective June 2, 2024. Available at https://www.federalregister.gov/documents/2024/04/15/2024-07274/patient-protection-and-affordable-care-act-hhs-notice-of-benefit-and-payment-parameters-for-2025.

[5] FAQ about Affordable Care Act Implementation Part 66. April 2, 2024. Available at https://www.dol.gov/agencies/ebsa/about-ebsa/our-activities/resource-center/faqs/aca-part-66.

Conclusion

We appreciate the opportunity to respond to this RFI and urge HHS and CMS to work quickly to end these abusive practices – this will help improve the ability of patients with serious and chronic illness to afford necessary medications that improve quality of life and prevent complications. If you have any questions or require additional information on anything included in this letter, please reach out to Leslie Brady, Federal Policy Advisor for the National Bleeding Disorders Foundation, at lbrady@artemispolicygroup.com.

Sincerely,

AiArthritis
Alliance for Headache Disorders Advocacy
Alliance for Patient Access
Alpha-1 Foundation
ALS Association
American College of Gastroenterology
American College of Rheumatology
Arthritis Foundation
Association for Clinical Oncology
Autoimmune Association
Biomarker Collaborative
Bleeding Disorders Alliance of North Dakota
Bleeding Disorders Council of California
Bleeding Disorders Foundation of North Carolina
CA Rare Disease Access Coalition
Cancer Support Community
CancerCare
Chronic Care Policy Alliance
Coalition of Skin Diseases
Community Oncology Alliance (COA)
Cystic Fibrosis Research Institute
Derma Care Access Network
Diabetes Leadership Council
Diabetes Patient Advocacy Coalition
Eastern PA Bleeding Disorders Foundation
Epilepsy Foundation of America
Exon 20 Group
Foundation for Sarcoidosis Research
Global Healthy Living Foundation
Hemophilia Alliance
HIV+Hepatitis Policy Institute
ICAN, International Cancer Advocacy Network

Immune Deficiency Foundation
Infusion Access Foundation
LUNGevity Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
MET Crusaders
National Alliance for Caregiving
National Bleeding Disorders Foundation
National Infusion Center Association
National Psoriasis Foundation
Nevada Chronic Care Collaborative
NMDP
NRG1 Energizers
Ovarian Cancer Research Alliance
Pacific Northwest Bleeding Disorders
PDL1 Amplifieds
Spondylitis Association of America
Susan G. Komen
The Academy of Oncology Nurse & Patient Navigators
The AIDS Institute
The Coalition for Hemophilia B
Triage Cancer
Western Pennsylvania Bleeding Disorders Foundation