November 23rd, 2021

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Jeff Wu
Director for Policy
Center for Consumer Information and Insurance Oversight, CMS
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Re: Notice of Payment and Benefit Parameters 2022: Co-Pay Accumulators

Dear Director Wu, Deputy Director Grant, and Deputy Administrator Montz,

We at the Global Healthy Living Foundation (GHLF) are writing to you about copayment assistance programs, which are used by millions of patients around the country to lower the costs of expensive therapies and improve their health outcomes. In the upcoming Notice of Benefit and Payment Parameters 2023, it is imperative that the Department of Health and Human Services (HHS) works to maintain the use of these cards, and not allow for copay accumulator adjustor programs that add financial burdens to already overstressed Americans.

GHLF is a 21-year-old 501(c)(3) non-profit patient-centered organization representing people with chronic illness. We work to improve the quality of life for our constituency through research, education, support, and advocating for improved access to healthcare. GHLF represents a diverse community of hundreds of thousands of patients with rheumatoid arthritis, IBD, migraine, psoriasis, multiple sclerosis, cancer, and chronic conditions. You can view our organization’s quarterly reports here, and our COVID-19 reports here.

Many of our hundreds of thousands of patients rely on expensive medications to manage their condition and maintain their quality of life. To afford these treatments, they rely on copay assistance programs which can take many forms, including charitable assistance foundations, a family member, online solicitation, social and civic groups and others. Our specific focus in this letter, however, is copay assistance from drug manufacturers when there is no generic or biosimilar equivalent alternative. It is under this circumstance, when a patient is prescribed a brand name drug, that copay accumulators are most pernicious. These copay assistance programs help millions of patients across the United States access critical medication and treatment, and they have become more important as drug costs the patient pays have trended upwards in recent years.
This is why we care so much about copay accumulators and their negative effects on health. We track the price a patient pays for drugs, not the list price or the heavily rebated price a health insurance company or their pharmacy benefit manager partners pay pharmaceutical companies. According to our data and data from the Kaiser Family Foundation, the price a chronically ill patient pays for their medications has outpaced wage growth and inflation over the last decade. This includes the ever-increasing deductibles, copays and insurance premiums. In addition, in certain parts of the United States patients travel long distances, incurring travel costs and lost pay to access care. While travel and lost wages data is not readily available, they clearly contribute to the cost of treating chronic conditions and support the argument against copay accumulators. Copay accumulators take money from patients and give it to health insurers and pharmacy benefit managers. We think this is wrong both economically and medically.

Without proper and timely treatment, rheumatoid arthritis can cause long-term damage to joints, along with persistent pain and disability. This issue is of immediate concern for our community, as the financial burden of rising costs falls disproportionately on chronically ill patients.

We strongly urge HHS to reverse the prior administration’s decision to allow insurers and pharmacy benefit managers to include copay accumulator adjustment policies in their plans. This policy is especially onerous for patients when a generic equivalent for a prescribed drug does not exist.

To date, 12 states and Puerto Rico have passed legislation prohibiting copay accumulators in their individual marketplace plans. While these are encouraging steps, the state-level, piecemeal approach to policymaking leaves too many patients still falling through the cracks of this fractured system.

States without such protections are riddled with market plans containing a copay accumulator policy. In fact, in 14 states every plan available through the marketplace has a copay accumulator policy. These policies harm patients and make it more difficult for them to achieve health stability.

We believe that patients’ economic and physical health depend on HHS explicitly prohibiting copay accumulators from insurance plans when there is no generic equivalent, so that patients can access the medication their doctor prescribes at a cost that is more in line with their ability to pay.

Thank you for the opportunity to submit our comments regarding this important policy decision.

Respectfully submitted,

Steven Newmark
Director of Policy and Chief Legal Officer

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