



Global Healthy Living Foundation
515 North Midland Avenue
Upper Nyack, New York 10960 USA
+1 845 348 0400
+1 845 340 0210 fax
www.ghlf.org

The Honorable Marty Walsh
Secretary
U.S. Department of Labor
200 Constitution Ave NW
Washington, DC 20210

The Honorable Janet L. Yellen
Secretary
U.S. Department of Treasury
1500 Pennsylvania Avenue, NW
Washington, D.C. 20220

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services (HHS)
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, D.C. 20201

RE: Comments on Pharmacy Benefits and Prescription Drug Costs Request for Information (CMS-9905-NC)

Dear Secretary Walsh, Secretary Yellen, and Secretary Becerra,

Thank you for the opportunity to comment on the *Request for Information Regarding Reporting on Pharmacy Benefits and Prescription Drug Costs (CMS-9905-NC)*.

The Global Healthy Living Foundation (GHLF) is a 21-year-old 501(c)(3) non-profit patient-centered organization representing people with chronic diseases. We work to improve the quality of life for people living with chronic illness through research, education, support, and advocating for improved access to healthcare. We appreciate that the Departments of Labor, Treasury, and Health and Human Services (collectively, the “Departments”) are prioritizing the vital issue of prescription drug costs, and we appreciate the opportunity to provide our comments.

GHLF represents a diverse community of hundreds of thousands of patients across the U.S. living with many chronic diseases, including rheumatoid and other forms of arthritis, IBD, migraine, psoriasis, multiple sclerosis, cancer, and others. Many of our patients rely on expensive medications to manage their condition and maintain their quality of life. Three issues of particular concern from our community are (1) health insurers’ response to the use of copay assistance programs, (2) a commitment to transparency, and (3) the effect of drug rebates on access to care.

1) Health insurers' response to the use of copay assistance programs

Copay assistance programs help millions of patients across the United States access critical medication. These programs have only become more critical as prescription drug prices have trended upwards in recent years. This financial burden falls disproportionately on chronically ill patients.

As out-of-pocket costs and copay assistance programs have increased over the past decade, insurers have responded by implementing copay accumulator adjusters and copay maximizer programs, sometimes called “out-of-pocket protection programs” or “specialty copay solutions.” These programs sound harmless or even beneficial, but they often increase the out-of-pocket costs of medications, creating financial barriers for patients to needed medications.

Creating the conditions through which patients can adhere to their whole treatment plan is critical. Research has shown patients are increasingly likely to abandon their treatment plan when their out-of-pocket expenses increase.^{1 2} Copay assistance programs help patients achieve better, long-term health outcomes by reducing the burden on the patient and allowing them to access the medications that their doctor believes will be most effective. Copay accumulator adjusters and maximizers disrupt the physician-patient relationship. They can cause an increased financial burden for patients, worse health outcomes, and an overall increase in health spending if a patient ends up needing emergency care as a result.

To date, ten states and one territory³ have passed laws prohibiting or limiting the use of accumulator adjusters for individual and small group plans. In addressing prescription drug costs, we urge the Departments to utilize the federal rulemaking process and ban copay accumulator programs or limit their use to medications where a generic, equally effective option is available.

2) A commitment to transparency

One major challenge in advocating for drug pricing affordability is the lack of precise data from insurance companies and pharmacy benefit managers on what medications are covered and to what extent. Without a complete set of data regarding pricing, rebates, and formulary construction, patients cannot fully understand the decisions that insurers are making on their behalf. We urge the Departments, and in particular HHS, to place a stronger emphasis for both insurers and pharmacy benefit managers (PBMs) on reporting requirements and transparency.

¹ Doshi, J., Li, P., Huo, H., Pettit, A. and Armstrong, K., 2018. Association of Patient Out-of-Pocket Costs With Prescription Abandonment and Delay in Fills of Novel Oral Anticancer Agents. *Journal of Clinical Oncology*, 36(5), pp.476-482.

² Hopson, S., Saverno, K., Liu, L., AL-Sabbagh, A., Orazem, J., Costantino, M. and Pasquale, M., 2016. Impact of Out-of-Pocket Costs on Prescription Fills Among New Initiators of Biologic Therapies for Rheumatoid Arthritis. *Journal of Managed Care & Specialty Pharmacy*, 22(2), pp.122-130.

³ Virginia, West Virginia, Arizona, Illinois, Georgia, Arkansas, Oklahoma, Kentucky, Tennessee, Connecticut, and Puerto Rico.



Similarly, we have seen that the lack of consistent terminology used by health plans around policies such as “step therapy,” “non-medical switching,” and “copay accumulator programs” can both confuse and mislead patients. Setting a standard for consistent terminology would allow patients to be better healthcare consumers and advocates.

3) The effect of drug rebates on access to care

Another pressing issue affecting prescription drug costs for our patient community is the role of pharmaceutical rebates. We support the Departments’ initiative to improve data collection and transparency regarding rebates, fees, and other remuneration paid to PBMs from drug manufacturers. The presence and influence of rebates stifle competition, keeping prices artificially high.

We are also concerned about the influence of drug rebates on Step Therapy / Fail First and Non-Medical Switching policies. In exchange for billions of dollars in rebates each year to health plans and PBMs, certain drugs are given preferential availability to patients, creating tiers or steps that require patients to try a PBM’s preferred medication first before providing the medicine their medical provider may determine is best for them. Countless patients in our network have experienced step therapy barriers and expressed how it has hindered their ability to access medication and interfered with the physician-patient relationship.

To most patients, drug pricing is at best mysterious. At worst, it actively prevents access to care. Our current system leaves ample room for improvement. We applaud the Departments of Labor, Treasury, and Health and Human Services for seeking to learn from impacted stakeholders and improve prescription drug pricing and pharmacy benefits.

We appreciate the opportunity to provide comments on this important issue and are available if you want to hear more directly from patients.

Respectfully submitted,



Steven Newmark, J.D., MPA
Director of Policy

