July 16, 2021

Assemblymember Pamela Hunter
National Council of Insurance Legislators
Chair, Health Insurance & Long-Term Care Issues Committee
2317 Route 34 S, Suite 2B,
Manasquan, New Jersey 08736

RE: Accumulator Adjustment Program Model Legislation

Dear Assemblymember Hunter:

On behalf of the steering committee of the All Copays Count Coalition (ACCC), we appreciate the interest of National Council of Insurance Legislators (NCOIL) in adopting model legislation to protect patients from a practice being implemented by various health insurance plans, pharmacy benefit managers (PBMs), and employers. This practice, "copay accumulator adjustment programs," prevents any copayment assistance available to help patients cover their cost-sharing for high-cost specialty drugs from counting towards a member's deductible or maximum out-of-pocket requirements. Although health plans may use different terminology or practices, all pose significant threats to patient access for the communities we represent. The adoption of the All Copays Count Coalition model legislation by NCOIL would continue the great momentum seen at the state level over the past several legislative sessions to protect patients.

Background

Copay accumulator adjustment programs are a utilization management technique employed by insurers and PBMs to steer patients to lower cost or preferred drugs. For patients in our communities with serious, chronic, and rare diseases, there often are no low cost or generic alternatives to treat their conditions. Additionally, many patients seeking to use copay assistance funds to afford their specialty medications have already been subjected to other utilization management techniques, prior authorization, step therapy, and formulary tier placement, to drive them to a lower cost alternative, if available. In turn, many of these patients with high healthcare needs depend on copay assistance programs to afford their specialty prescriptions. As a result of copay accumulator adjustment programs, patients are left with very high out-of-pocket expenses for their medications. When coupled with the rise of high deductible health plans (plans with deductibles of at least $1,400 for an individual) and coinsurance as high as 50%, copay accumulator adjustment programs make it difficult, if not impossible, for patients to adhere to their treatment plans.

There is a direct correlation between patient out-of-pocket cost and treatment adherence: as out-of-pocket costs increase, so do prescription abandonment rates. A recent study clearly showed that when patient costs hit the $250 mark, over 70% of new patients walk away from the pharmacy empty handed.[1]

[1] IQVIA. May 2019. Medicine Use and Spending in the US; A Review of 2018 outlook to 2023.

Further, a survey of more than 700 patients with serious illness and/or family caregivers of patients with serious illness in 2021 found that nearly half of respondents (46%) said they or someone in their immediate household had not been able to afford their out-of-pocket costs in the past year.[2] The need for legislation prohibiting copay accumulator adjustment programs has only been exacerbated as a result of the COVID-19 crisis, as many families have lost a substantial portion of their income and are struggling to pay for basic necessities, including medications.

Copay accumulator adjustment programs have become increasingly common over the last few years. Earlier this year, the AIDS Institute published a report on the programs titled *Double-Dipping: Insurance Companies Profit at Patients' Expense Copay Accumulator Adjustment Policies Nationwide* which detailed the expansion of these programs in the states. The report showed that every state that did not have legislation requiring that funds paid by, or on behalf of, the patient count toward the patient's cost-sharing requirements had at least one copay accumulator adjustment program in a state plan.[3] The report revealed that in 14 states every single insurer had a copay accumulator adjustment program in their health plans. That means that even if a patient were aware of these programs and wanted to avoid them, they would not be able to do so. Lastly, the report detailed that in 32 states at least two-thirds of plans include a copay accumulator adjustment policy.

The increasing utilization of these programs is especially concerning because many copay accumulator adjustment programs have been implemented with little to no notification or explanation to the member. For those patients that do receive notification or an explanation, the language is often vague or can be difficult to understand even for the most seasoned of healthcare experts, let alone the average patient. Patients, therefore, may not truly understand what is happening until they arrive at the pharmacy to pick up their prescription and find out that they must pay for the full cost of the drug as the copayment assistance they received did not count towards their deductible. As a result, many patients are forced to walk away without their medication, and an unknown number may be forced to abandon treatment altogether.

Success of Model Legislation

The All Copays Count Coalition identified a simple policy solution to ensure patients have access to their prescription medications. States could enact legislation that would require payments made by, or on behalf of, a beneficiary to count toward their deductible and out-of-pocket requirements. Prior to entering the 2021 legislative session, five states (Virginia, West Virginia, Illinois, Arizona, and Georgia) and Puerto Rico had enacted legislation to protect patients from copay accumulator adjustment programs. In 2021, almost 25 states in the country introduced legislation to ensure that all copays counted. Of those states, six (Kentucky, Oklahoma, Tennessee, Arkansas, Connecticut, and Louisiana) successfully passed and have enacted legislation, with several bills still active.

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[2] https://www.hemophilia.org/sites/default/files/document/files/NHF%20-%20National%20Patients%20and%20Caregivers%20Survey%20on%20Copay%20Assistance%20%28Key%20Findings%29.pdf

[3] http://aidsinstitute.net/protecting-patients-and-removing-barriers-to-care/copay-accumulators-and-insurance-issues

This legislation has been successful due to the strong leadership of legislators in these states. We have had great champions in each state including many from NCOIL's Health Insurance & Long-Term Care Issues Committee. Notably, Senator Jason Rapert championed r the bill in Arkansas with support from Senator Mark Johnson. In West Virginia, Delegate Steve Westfall co-sponsored the legislation, while Representative Derek Lewis co-sponsored the House companion bill enacted in Kentucky.

This legislation has also been successful due to a strong network of patient and provider organizations working in coalition to support each legislative effort by amplifying patient stories through the media, holding in-person and virtual meetings with legislative offices, providing educational and advocacy materials, as well as testifying in favor of the legislation at hearings. Our coalition is comprised of organizations that have worked tirelessly on this issue and have endorsed this model legislation. Additionally, we have sought input and received support from important leaders the field of health policy such as the American Medical Association, American Cancer Society Cancer Action Network, as well as each of the All Copays Count Coalition steering committee member organizations listed below.

Opposition Arguments

With this legislation having been introduced in so many states, patient advocates have become very familiar with the arguments presented by the opposition. Those arguments focus on attacking third-party assistance programs rather than defending copay accumulator adjustment programs. Defending a program that puts patients at risk and allows insurers and PBMs to "double dip," by collecting money for the same service twice – once from the assistance and then again from the patient, is a difficult argument to make. It is important to note that a recent survey found that 6 in 10 patients and caregivers say they would have extreme difficulty affording their treatments and medications without copay assistance programs being applied to their out-of-pocket costs. Copay accumulator adjustment programs put patients unfairly in the middle of the fight between manufacturers and insurers.

One argument that is often used is that copay assistance steers patients to higher-cost medications; copay accumulator adjustment programs direct patients back to lower cost or generic alternatives. However, this argument fails to acknowledge the reality of the prescription drug landscape. While the vast majority of prescription drugs dispensed in the United States are generics, many patients who utilize copay assistance rely on specialty medications have limited treatment options and often no lower-cost generic alternatives to manage their complex medical conditions. A study of claims data by IQVIA found that 99.6% of copay cards are used for branded drugs that do NOT have a generic alternative.[4] For patients with kidney disease, HIV, rheumatoid arthritis, cancer, hemophilia, multiple sclerosis, and other complex or rare diseases, biologics and other specialty medications are often the only option for effectively treating these diseases. Insurers and PBMs also apply utilization management tools, such as prior authorization and step therapy, as a first course of action to ensure that patients try lower cost alternatives before approving higher cost medications. Patients are not simply choosing a more expensive drug; it is often the only drug available to them as prescribed by their provider. In the absence of copay assistance, these individuals will be unable to afford their treatment, putting their lives at risk.

[4] https://www.iqvia.com/locations/united-states/library/fact-sheets/evaluation-of-co-pay-card-utilization

Another frequently used argument is that copay assistance is not permitted in Medicare. Insurers and PBMs have attempted to equate their private companies with the federal government programs. Although Medicare and Medicaid have restrictions on copay assistance, those programs have vastly different benefit models than private plans. In 2021, deductibles in Medicare Part D may not exceed $445. By comparison, the average deductible for an ACA silver level plan this year is $4,879, with many plan deductibles climbing upwards of $7,000.[5] It would not be an accurate or fair comparison to evaluate the models employed by insurers and PBMs against Medicare and Medicaid.

Lastly, it is often suggested by the opposition that with copay assistance patients do not have "skin the game." This is an inaccurate claim directed at patients managing complex chronic and rare diseases. Pointing back to the shift in benefit design with high deductibles and high coinsurance, insurers have forced patients to put more and more skin in the game; and with copay accumulator adjustment programs, they are putting patients' lives on the line. Furthermore, copay assistance is a finite amount of money; when the assistance runs out during the plan year the patient is responsible for any remaining cost-sharing, whether it is their deductible, copay, or coinsurance. Copay assistance keeps patients adherent to their treatment and out of the emergency department, which ultimately can help to control costs for the broader healthcare system.

We are deeply concerned about the impact copay accumulator adjustment programs pose to patients with serious, chronic or rare diseases who rely on specialty medications to stay alive, able to live independently and healthy. We are appreciative of NCOIL's willingness to consider the adoption of model language which will ensure patients can afford their medications.

Thank you in advance for your time and for your consideration of this important issue. Please do not hesitate to contact Lindsay Gill with the American Kidney Fund at lgill@kidneyfund.org or Steven Schultz with the Arthritis Foundation at sschultz@arthritis.org with any questions or for more information at any time.

Sincerely,

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[5] The AIDS Institute. http://aidsinstitute.net/documents/2021_TAI_Double-Dipping_Final-031621.pdf

CC: Representative Deborah Ferguson, Vice-Chair
Members, Health Insurance & Long-Term Care Issues Committee
William Melofchik