



Copay Accumulators in Missouri

Background

Many people rely on copay assistance – coupons or charitable assistance from drug manufacturers and non-profit organizations – to afford high-cost medications and medical care. However, insurance companies and pharmacy benefit managers have financial strategies, such as copay accumulator programs, that prevent copay assistance from counting toward a patient's deductible or out-of-pocket payment limits. While copay accumulator programs can reduce costs for these organizations, they leave patients with unexpected and unaffordable pharmaceutical costs once their copay assistance is exhausted.

As copay accumulator programs have become more common in recent years, the lifeline of copay assistance has increasingly been taken away from many patients. The burden of copay accumulator programs is magnified for rare disease patients who often depend on high-cost, lifesaving medications in which there is no generic option and who may require frequent outpatient and inpatient care.

Copay Accumulators and Rare Disease Patients

- In Missouri, more than 3 in 4 of ACA health plans have copay accumulator policies. Nationwide, almost two-thirds of all ACA individual health plans have copay accumulator policies.¹
- Sixteen states have prohibited health insurance companies from using copay accumulator programs, including Arkansas, Illinois, Kentucky, and Tennessee.²
- Lowering the costs of health care, particularly prescription drug therapies, is a critical part of reducing the nearly \$1 trillion burden rare disease patients and their families face. The National Economic Burden of Rare Diseases in the United States in 2019, a study that examined the comprehensive economic burden of a subset of 379 rare diseases, found that the total financial burden of the diseases was \$997 billion. Inpatient care was the top driver of excess medical costs (~15%) while prescription medication was responsible for about 11% of excess medical costs.³
- Copay accumulator programs eat into the already tight budget patients have, forcing some patients to take harmful actions, such as medicine rationing and prescription abandonment. When patient costs pass \$250, over 70% of new patients walk away from the pharmacy empty-handed, highlighting the direct connection between the rise in out-of-pocket costs and prescription abandonment.⁴

¹ The Aids Institute. February 2023. [Discriminatory Copay Policies Undermine Coverage for People with Chronic Illness](#).

² All Copays Count Coalition. [State Legislation Against Copay Accumulators](#).

³ EveryLife Foundation for Rare Diseases. April 2022. [The National Economic Burden of Rare Disease in the United States in 2019](#).

⁴ IQVIA. May 2019. [Medicine Use and Spending in the US; A Review of 2018 outlook to 2023](#).

- Since 2015, deductibles nationwide have more than doubled. In 2023, the average deductible for the most popular level of health plans that offer mid-range coverage is \$5,388.⁵ However, deductibles can be as high as the annual out-of-pocket limit for the year: \$9,100 for an individual and \$18,200 for a family in 2023.⁷ With the proliferation of high deductible health plans, copay accumulator programs can result in higher out-of-pocket costs for the frequent expert outpatient care that rare disease patients require as it takes longer for patients to satisfy the deductible and out-of-pocket maximum requirements.

For questions, please contact Emily Stauffer, State Policy Manager, at estauffer@everylifefoundation.org

⁵ The Aids Institute. February 2023. [Discriminatory Copay Policies Undermine Coverage for People with Chronic Illness](#).

⁶ Avalere, November 2017. [Plans with More Restrictive Networks Comprise 73% of Exchange Market](#).

⁷ Health System Tracker. July 2022. [“ACA’s Maximum Out-of-Pocket Limit is Growing Faster Than Wages](#).