



December 13, 2024

Oregon Prescription Drug Affordability Board
350 Winter Street NE
Salem, OR 97309-0405
pdab@dcbs.oregon.gov

Re: Public Comment for December 18, 2024 Board Meeting

Dear Members of the Oregon Prescription Drug Affordability Board:

The **HIV+Hepatitis Policy Institute** is a leading advocate for equitable and affordable healthcare for individuals living with or at risk of HIV, hepatitis, and other serious or chronic health conditions. As the Board begins reviewing its initial list of prescription drugs, we believe that affordability reviews of HIV medications fail to fully account for the intricacies of the existing HIV safety net, which makes lifesaving HIV treatments affordable for most people. We also want to raise numerous factors in the global HIV drug ecosystem that would be difficult for a state to consider. Finally, we reiterate our support for the proposed legislative policy recommendations that enhance transparency around insurers' use of copay accumulators, maximizers, and the need to consider alternative funding programs.

Affordability Reviews of HIV Medications

Since the onset of the AIDS crisis in the 1980s, our community has tirelessly fought for access to effective treatments, leading to the establishment of vital safety net programs that ensure HIV care and medications remain affordable. Programs such as the Ryan White HIV/AIDS Program provide \$2.5 billion annually to ensure HIV treatments and care to low-income people living with HIVⁱ. The Ryan White Programs generates \$2.8 billion in drug purchases through the 340B programⁱⁱ enabling crucial wraparound services and provide care and treatment to those who cannot afford it. Additionally, drug manufacturers contribute over \$1 billion in rebates directly to state AIDS Drug Assistance Programs-all to help with affordability of HIV drugs.ⁱⁱⁱ

For example, Oregon's ADAP, known as CAREAssist, operates with a diverse funding stream totaling approximately \$50 million, sourced from Part B funding, rebates, and program income. This funding covers essential medications and services for people living with HIV^{iv}. Further affordability is achieved through additional rebate programs, such as Medicaid drug rebates, which help reduce the financial burden on public programs.

Pharmaceutical manufacturers also play a key role, contributing billions through copay assistance, free medication programs, and global initiatives like PEPFAR, which expand access to

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affordable HIV treatments worldwide. While gaps in coverage remain, this robust safety net has been instrumental in ensuring people living with HIV receive the care and medications they need at an affordable rate.

Federal policies have further reinforced this safety net, helping to expand access to preventive care. For instance, the Affordable Care Act (ACA) and recommendations from the U.S. Preventive Services Task Force (USPSTF) have eliminated financial barriers by mandating that PrEP (pre-exposure prophylaxis) be available at no cost to most insured individuals. This policy ensures that those vulnerable to HIV can access lifesaving preventive treatments, complementing safety net programs and helping to reduce the spread of the virus-for free.

Affordability reviews of HIV medications may fail to fully capture the complexity and interdependence of safety net programs, which not only ensure affordability for patients but also sustain the broader HIV care infrastructure. Pricing interventions, such as the imposition of upper payment limits (UPLs), could destabilize this ecosystem, jeopardizing access to care and disincentivizing pharmaceutical manufacturers from continuing the research and development that has driven remarkable progress. The transformative innovations enabled by this investment—including longer-acting treatments, preventive therapies, vaccines, and the hope of an eventual cure—could be at risk if the delicate balance of these systems is disrupted.

The impact of these advancements cannot be overstated. Antiretroviral therapy (ART) has drastically changed the prognosis and quality of life for people living with HIV. When the first highly effective ART became available in 1996, a 20-year-old newly diagnosed with HIV had a life expectancy of just 10 years. Today, thanks to modern therapies, individuals with HIV enjoy lifespans comparable to the general population, with improved tolerability and far fewer side effects. These innovations have transformed HIV from a terminal illness into a manageable chronic condition for millions.

Importantly, high out-of-pocket costs for patients often stem from systemic issues unrelated to drug pricing, such as insurer practices and pharmacy benefit manager (PBM) strategies. Policymakers should focus on addressing these barriers through targeted reforms, such as regulating PBMs, capping out-of-pocket expenses, and ensuring that copay assistance counts toward deductibles. These solutions can improve affordability for patients without undermining the infrastructure and progress that have revolutionized HIV care.

We strongly believe that affordability reviews of HIV medications are unnecessary, given the comprehensive safety net programs that effectively ensure access to lifesaving treatments. Any future pricing interventions, such as the imposition of UPLs, could destabilize this well-established network, threatening access to care for people living with HIV. Programs like the Ryan White HIV/AIDS Program, the 340B program, and manufacturer copay assistance are critical to sustaining the progress and innovation that have transformed HIV treatment.

As we look to the future, it is essential to protect and strengthen these systems that have saved and transformed countless lives. Policymakers must prioritize targeted solutions that enhance

affordability without compromising the stability of the infrastructure that has been pivotal in the fight against HIV. By preserving this delicate balance, we can continue to provide hope and care for millions living with HIV while advancing toward the ultimate goal of ending the epidemic.

Proposed Legislative Recommendations

We support the following legislative recommendations, which focus on increasing transparency, protecting equitable access to medications, and improving affordability through enhanced accountability and patient-centered policies.

Enhance Reporting on Copay Accumulators and Maximizers: Requiring insurers to report on the use of copay accumulators and maximizers is vital for ensuring transparency and accountability in healthcare cost-sharing. These programs are increasingly prevalent, it was estimated that 39% of beneficiaries under commercial insurance were enrolled in plans with copay accumulators^v and 41% in those with copay maximizers.^{vi} In Oregon, five out of six insurers on the marketplace are implementing these programs.^{vii} with 39% of commercially insured patients enrolled in plans with copay accumulators and 41% in plans with copay maximizers as of 2022. In Oregon, five out of six marketplace insurers have adopted these practices. By excluding manufacturer copay assistance from deductibles and out-of-pocket limits, these programs shift significant costs onto patients, often resulting in higher expenses and reduced adherence to essential medications. Moreover, insurers and pharmacy benefit managers (PBMs) frequently collect the copay assistance for themselves while excluding it from patients' cost-sharing calculations, then charge patients additional amounts—a practice commonly referred to as “double dipping.” Mandating detailed reporting would enable the Board to assess these programs' financial and access-related impacts, ensuring patients are not unfairly burdened when relying on financial assistance.

Expand Transparency Requirements to Alternative Funding Programs (AFPs): We recommend the Board extend reporting requirements to include AFPs, which self-funded employer health plans use to shift the cost of expensive specialty medications outside traditional insurance coverage. These programs often classify specialty medications as “non-essential,” forcing patients to navigate third-party assistance programs designed for the uninsured. This process can be complex, time-consuming, and reliant on resources such as manufacturer assistance programs or international pharmacies. AFPs disproportionately impact individuals with chronic or rare diseases by selectively excluding those with higher health risks, raising significant concerns about health equity and access to care.

Although AFPs aim to reduce employer costs, they often lead to significant treatment delays, with severe consequences for patients managing conditions like HIV or hepatitis. Even brief interruptions in treatment can result in viral resistance, rendering medications ineffective and posing broader public health risks. Requiring insurers to disclose the scope and impact of AFPs would provide critical insight into these programs' effects on patient access, treatment delays, and the diversion of charitable resources intended for the uninsured. Increased transparency would ensure these programs do not compromise patient care under the guise of cost savings.

Support Adjustments to Drug Reviews and Patient Assistance Consideration: We also support the proposed adjustments to the number of drugs reviewed annually and the inclusion of patient assistance programs in these reviews. Patient assistance programs play a crucial role in improving medication affordability and ensuring timely access to treatments for those in need.

Thank you for considering these important policy proposals. We look forward to your support in advancing these recommendations to ensure that all Oregonians have access to affordable, effective, and equitable healthcare. If you have any questions or need any additional information, please do not hesitate to reach out via phone at (202) 462-3042 or email at cschmid@hivhep.org.

Sincerely,



Carl E. Schmid II
Executive Director

ⁱ [Ryan White HIV/AIDS Program Funding: FY 2015–FY 2024 appropriations by program](#)

ⁱⁱ [2023 340B Covered Entity Purchases](#)

ⁱⁱⁱ [2024 National RWHA Part B ADAP Monitoring Project Annual Report](#)

^{iv} [KFF: Distribution of ADAP Budget by Source](#)

^v [Fein AJ. Copay Accumulator and Maximizer Update: Adoption Plateaus as Insurers Battle Patients Over Copay Support. Drug Channels.](#)

^{vi} [Pharmaceutical Strategies Group. 2023 Trends in Specialty Drug Benefits Report.](#)

^{vii} [The Aids Institute: Copay Assistance Diversion Programs in Oregon](#)