



March 12, 2024

Health Care Availability & Accessibility Committee  
General Assembly, State of Illinois  
401 S. 2nd St.  
Springfield, IL 62702

**Re: Testimony on the Health Care Availability and Access Board Act (HB 4472)**

Dear Committee Members:

The **HIV+Hepatitis Policy Institute** is a leading national HIV and hepatitis policy organization promoting quality and affordable healthcare for people living with or at risk of HIV, hepatitis, and other serious and chronic health conditions. Given the important nature of prescription drugs to the life-saving treatment of HIV and hepatitis B, and now, the cure of hepatitis C and the prevention of HIV, we have long advocated for affordable access to prescription medications. We appreciate your interest, and the actions that you have taken to date to ensure that beneficiaries can access and afford the prescription medications that their providers prescribe. While we support and share the committee's intent to lower out-of-pocket costs for consumers, **we believe the proposed Health Care Availability and Access Board Act (HB 4472) would neither benefit patients in the long run nor result in reducing patients' costs.**

**The amount consumers pay for their prescription drugs is mainly driven by their insurer and pharmacy benefit manager (PBM).** In addition to monthly premiums, consumers then can pay an annual out-of-pocket cost of up to \$9,450 if they are an individual or \$18,900 if they are a family for most private insurance plans<sup>1</sup>. The amount that is paid for prescription drugs is determined by the insurer and the PBM, that places the drug on various "tiers" that are associated with differing cost-sharing levels. Sometimes, these costs are associated with nominal copays, such as \$10, \$25, or \$35 dollars, while others can be as high as \$250 per month and expressed in terms of co-insurance, or a percentage of the list price of the drug (up to as much as 50 percent). While co-insurance is used in determining patient cost-sharing for prescription drugs, it is rarely used for any other medical service, and no other health care expenditure forces patients to pay based on the list price of an item.

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<sup>1</sup> <https://www.healthcare.gov/glossary/out-of-pocket-maximum-limit/>.

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Plans also have various levels of deductibles before their insurance kicks in. According to CMS, the 2024 silver plan median deductible in 2024 is \$5,726 and for bronze plans, \$7,239.<sup>2</sup>

According to CMS' 2022 National Health Expenditures report, while overall health care spending grew at 4.1 percent in 2022, out-of-pocket spending increased substantially higher at 6.6 percent in 2022 to \$471.4 billion. For prescription drugs, out-of-pocket spending totaled \$56.7 billion, or 14 percent of the total spending on prescription drugs. This represents an increase of 11.6 percent in 2022 after slower growth of 6.4 percent in 2021. However, for hospital care, which accounts for more than three times more of the total spending than prescription drugs, patients were responsible for paying only 2.6 percent. Despite the much smaller total amount of spending for prescription drugs, the out-of-pocket spending for prescription drugs (\$56.7 billion) was higher than all the out-of-pocket spending for hospitals (\$35.1 billion).<sup>3</sup> This is due to insurance benefit design and it is no wonder that the American people are complaining so much about the costs of their drugs, because they are being forced to pay more in out-of-pocket costs by their insurers.

And we know when out-of-pocket cost are too high, patients don't pick up their drugs, which impacts their health and well-being. According to an IQVIA analysis, due in part to high costs, an estimated 92 million prescriptions were abandoned at the pharmacy in 2022 (this compares to 81 million in 2021), with the abandonment rate over one in three for prescriptions above \$75 in out-of-pocket costs. Additionally, for prescriptions with a final cost above \$250, 53 percent are not picked up by patients, as compared with 7 percent of patients who do not fill when the cost is less than \$10.<sup>4</sup>

This is why **we believe policymakers should focus on those issues that directly impact patients, such as PBM regulation and reform, standard plan designs with reasonable deductibles and nominal copays, and ensuring copay assistance counts.** We realize that the State has taken many of these steps already, and that Illinois policymakers are advocating for change at the national level, too, but more can be done.

**Setting a price of an individual drug would be a very complex endeavor to undertake and not a function of state government.** While the federal government is attempting to do it for some drugs in the Medicare program, it is under litigation and proving to be extremely difficult to execute. While we admit that drug pricing is highly opaque, we do know that it is based on multiple complicated factors. Pharmaceutical manufacturers are involved in hundreds of research and development projects at one time in the search for a successful launch of a new drug. Years and years of research and clinical trials go into the development for that one new drug, while at the same time hundreds of molecules and their combinations are studied that do not result in a viable product. This is a long and costly process and the development of that one successful drug can cost \$2 billion.

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<sup>2</sup> "Plan Year 2024 Qualified Health Plan Choice and Premiums in HealthCare.gov Marketplaces," CMS, last modified 10/25/23, <https://www.cms.gov/files/document/2024-qhp-premiums-choice-report.pdf>.

<sup>3</sup> "National Health Expenditure Data," CMS, last modified 12/13/23, <https://www.cms.gov/data-research/statistics-trends-and-reports/national-health-expenditure-data/nhe-fact-sheet#:~:text=NHE%20grew%204.1%25%20to%20%244.5,18%20percent%20of%20total%20NHE.>

<sup>4</sup> "The Use of Medicines in the U.S. 2022," IQVIA Institute, April 2022, <https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/the-use-of-medicines-in-the-us-2022/iqvia-institute-the-use-of-medicines-in-the-us-2022.pdf>, page 47.

Most new drug development results in failures, which are very costly. While there is much attention to the high list price of these successful drugs, the cost of all the failures, and all the other functions of a pharmaceutical company, must be embedded in the that price. So, while a company can make a high level of profit off one drug focusing on one health condition, they can also spend billions of dollars on failures in that same focus area, along with all the other areas of research on other health conditions that do not turn into successful products. Additionally, they are using the profits of today to invest in the successes and failures of tomorrow. Companies in the HIV space are working on longer acting treatment and prevention drugs, vaccines, and even a cure. Many companies are working on a cure for hepatitis B while so many others are working on better cancer treatments, and medications to treat other countless conditions such as Alzheimer's, diabetes, heart ailments, mental illness, arthritis, Lupus, epilepsy, rare diseases, and even aging.

People often call out the manufacturing cost of producing a specific drug. They may say a drug costs as little as a couple of cents to produce. While that is not true for all drugs such as biologics, it does not count the investment and resources needed to research and develop the drug, and construct and run the manufacturing sites.

Additionally, drug manufacturers do not collect the full list price of their drugs, with net prices falling for the last six years.<sup>5</sup> Other players in the drug supply chain receive a large and increasing share of the money. PBMs collect high rebates and there are other mandatory other rebates in the Medicaid and 340B programs. These rebates are especially high in the HIV and hepatitis arena, and then there are additional rebates pharmaceutical manufacturers provide to states through the AIDS Drug Assistance Program.

Companies provide free drugs to people who are uninsured and underinsured, and copay assistance to help people with insurance afford their medications. In fact, according to IQVIA, in 2022 manufacturer copay assistance brought down patient costs by nearly \$19 billion and accounted for 23 percent of their out-of-pocket costs.<sup>6</sup>

Drug companies also operate in a global environment, as exemplified in the HIV and hepatitis arenas, and provide medications to millions of people in underdeveloped and underserved nations. The companies provide drugs to the PEPFAR program at very low costs and have voluntary licensing arrangements in place for generic medications.

On top of it, they must recoup and make all their money on a successful drug in a very limited amount of time before the drug goes generic and other companies can take advantage of the R&D and FDA approval and begin to produce it without any remuneration to the original patent holder. And unlike the PBM industry, the pharmaceutical industry is a very competitive market with hundreds of companies both in the United States and around the world developing new medications.

**Given the many complexities and factors that go into setting a price of a drug, we do not believe it is appropriate or possible for a state to fairly do it.**

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<sup>5</sup> <https://www.drugchannels.net/2024/01/tales-of-unsurprised-us-brand-name-drug.html>.

<sup>6</sup> "The Use of Medicines in the U.S. 2022," page 41.

Thank you for the opportunity to comment on this legislation. 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](mailto:cschmid@hivhep.org).

Sincerely,

A handwritten signature in blue ink, appearing to read "Carl E. Schmid II". The signature is fluid and cursive, with the first name "Carl" being the most prominent.

Carl E. Schmid II  
Executive Director