AIMEDALLIANCE

September 3, 2024

VIA ELECTRONIC CORRESPONDENCE

Senate Majority Leader Kimberly Lightford
Illinois General Assembly
501 S 2nd St
Springfield, IL 62757

Re: Call for Consideration of Alternative Legislative Reforms Beyond PDABs

Dear Majority Leader Lightford:

Aimed Alliance is a not-for-profit health policy organization that seeks to protect and enhance the rights of healthcare consumers and providers. As the Senate begins to plan for the 2025 legislative session, Aimed Alliance urges members to consider legislation that will directly address health care affordability for consumers.

During the 2024 legislative session, the Illinois General Assembly considered legislation that would have created a prescription drug affordability board (PDAB). As explained below, Aimed Alliance urges members of the Senate to consider how PDABs may impact consumers, access, and innovation.

I. PDABs are Experimental and Lack Guaranteed Consumer Savings

Legislation to establish PDABs aims to control the rising costs of prescription drugs by setting caps, known as Upper Payment Limits (UPL) for select prescription drugs. However, UPLs restrict the amount that *payors* reimburse pharmacy benefit managers (PBM) for a prescription drugs. As such, without specific requirements to pass cost-saving to consumers, any savings may not impact what consumers pay at the pharmacy counter.

New research has also revealed that UPLs may increase patient access and affordability challenges. For example, a recent study published by Avalere found that health plan representatives anticipate greater implementation of utilization management tactics, such as step therapy and prior authorization in response to UPLs being set on certain prescription drugs.[1] Plan representatives also anticipate adjustments to formularies, such as reassigning selected drugs and therapeutic alternatives to different tiers.[2] These changes have the potential to increase costs and hinder patients' access to essential medications, underscoring the need to use caution and explore alternative approaches to enhance prescription drug affordability.

II. PDAB Alternatives Can Have a Direct Impact on Consumer Affordability

[1] Kate Sikora, et al., *Research Explores Health Plan Perceptions of PDABs and UPL*s, AVALERE (April 2, 2024), https://avalere.com/insights/research-explores-health-plan-perceptions-of-pdabs-and-upls.
[2] *Id*.

Currently, no state PDAB has completed the drug selection and UPL-setting process. As such, PDABs are experimental initiatives with significant upfront costs that provide no guarantee that any cost-savings generated from these programs will lower costs for health care consumers. As stated above, the way many PDABs are structured, any savings accrued would likely only benefit payors, as UPLs restrict what *payors* reimburse PBMs, without any requirement these savings be passed down to the consumers through prescription drug costs or premiums.

Given the uncertainty regarding whether PDABs will effectively lower costs for consumers, Aimed Alliance urges Members to consider alternatives for reducing consumers' out-of-pocket expenses such as PBM reform.

A. PBM Transparency

PBMs are middlemen who negotiate with pharmaceutical manufacturers to determine which medicines will be included in health insurance companies' formularies and how much plans will pay the manufacturers for those medicines. PBMs also determine consumers' cost-sharing requirements for medications.[3] These practices are often opaque and lack transparency, which results in payors negotiating payments without a full understanding of the actual cost of the medications. Consequently, regulating PBM activities presents an opportunity to address key factors that impact costs within health insurance.

Other states have begun to recognize the need to regulate PBMs and ensure greater transparency in their practices. For instance, in 2023, Colorado enacted legislation that banned spread pricing, a practice where PBMs negotiate lower drug prices but charge higher rates to policyholders. By eliminating spread pricing alone, affected employers are predicted to save an average of 10-25 percent on their prescription drug costs.[4] PBM reform may also include legislation that requires PBM to pass rebates directly to employers and consumers to ensure savings are maximized and alleviate the financial burden of healthcare expenses.

While the Illinois General Assembly has already taken steps to regulate PBM practices, by banning copay accumulator and step therapy, as well as prohibiting gag clauses on pharmacies contracts, Aimed Alliance urges the Illinois General Assembly to continue to protect consumers by passing legislation that increases PBM transparency by limiting spread pricing or requiring all rebates and related-savings are passed down to consumers.

III. PDABs Must Prioritize Patient Access and Affordability

If the Illinois General Assembly does reconsider PDAB legislation in 2025, Aimed Alliance urges Members to ensure that a PDAB is required to prioritize patient input by

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[3] The House Committee on Oversight and Reform, *A View from Congress: Role of Pharmacy Benefit Managers in Pharmaceutical Markets* (Dec. 10, 2021), https://oversight.house.gov/wp-content/uploads/2021/12/PBM-Report-12102021.pdf.

[4] Colorado Department of Health Care Policy & Financing, *Gov. Polis Signs Legislation to Save Coloradans Money on Prescription Drug Costs* (May 10, 2023), https://hcpf.colorado.gov/legislation-save-coloradans-money-on-prescription-drug-costs#:~:text=Jared%20Polis%20signed%20HB23%2D1201,this%20affordability%20law%20as%20well.

including a consumer or patient representative on the Board, mandate ongoing consumer engagement, and require that UPL-derived cost savings be passed on to patients.

A. Prioritize Patients' Perspectives and Lived Experiences

Research consistently highlights the benefits of actively involving patients in healthcare decisions. For example, studies have found that patient inclusion has created positive effects on improving health outcomes, enhancing satisfaction with the care experience, and lowering health care costs.[5] Including patients in health policy decisions can also improve the quality of healthcare delivery and improve accessibility.[6]

Moreover, given that patients are the intended beneficiaries of these medications, their perspectives are essential for accurately assessing the value of these medications. Involving patients in the decision-making process can also provide insights into disease management, access challenges, treatment preferences, and other pertinent considerations associated with various medications.[7] Their firsthand experiences can help ensure that healthcare policies address the needs of those they aim to serve.[8] It also enables PDABs to access a wealth of firsthand knowledge that is essential for making well-informed and patient-centered decisions about prescription drug affordability and value.[9]

To ensure the patient, caregiver, and provider perspectives are appropriately valued and considered, Aimed Alliance urges Members to ensure that any PDAB legislation mandates that a member of the Board be a consumer/patient representative. Providing a permanent and formal position for this perspective will ensure the development of PDAB surveys, questions, and processes are consumer-friendly and inclusive. Moreover, appropriately valuing lived experiences of consumers with chronic conditions can help ensure that healthcare policies address the needs of those they aim to serve.[10]

Recently, the federal government has recognized the value of ensuring a permanent position for the patient perspective by requiring all Pharmacy & Therapeutics (P&T) Committees to include *at least* one patient representative as a Member of the Committee. In making this decision, the government recognized that consumer representatives can provide "insights into real consumer experiences unknown to P&T committees."[11] Thus, a similar permanent position could be equally as valuable and beneficial for an Illinois PDAB.

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[5] Lisa Baumann, et al., *Public and patient involvement in health policy decision-making on the health system level – A scoping review*, 126 HEALTH POL. 1023-38 (Oct. 2022), https://www.sciencedirect.com/science/article/pii/S0168851022001919.
[6] *Id.*
[7] Alex Krist, et al., *Engaging patients in decision-making and behavior change to promote prevention*, 240 STUDENT HEALTH TECHNOLOGY INFORMATION 284-302 (2017), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6996004/.
[8] *Id.*
[9] *Id.*
[10] *Id.*
[11] 2025 NBPP; *See also,* Lisa Baumann, et al., *Public and patient involvement in health policy decision-making on the health system level – A scoping review*, 126 HEALTH POL. 1023-38 (Oct. 2022), https://www.sciencedirect.com/science/article/pii/S0168851022001919.

B. Mandate a Continuous Consumer Engagement and Oversight Process

The obligation to engage the patient, provider and caregiver community should not be satisfied simply by creating a Board member position for consumers. Any drug selection and UPL-setting process should have a continuous obligation to actively seek input from a broad range of stakeholders, including patients, caregivers, and community representatives. The continuous inclusion of these voices and perspectives can help ensure the development of a fair and comprehensive drug review framework.

Furthermore, it is imperative to acknowledge that the governmental entity responsible for developing the drug selection process has a shared responsibility in engaging these communities. Patients and caregivers must manage work and family commitments, and their treatment regimens, while striving to navigate complex healthcare systems to ensure optimal care for themselves or their loved ones. Therefore, the responsibility to be aware of and engage in the drug selection and UPL-setting process cannot rest solely on consumers to advocate for their needs; the board must have an affirmative obligation to engage these communities.

Additionally, the engagement process must extend beyond the initial review stage. Once the Board establishes a UPL, the Board should continuously monitor its impact on access and affordability. Establishing clear channels for consumers to voice concerns and grievances regarding any access barriers stemming from pricing policies is critical to ensuring equitable access to essential medications. By fostering a culture of transparency and responsiveness, a Board can effectively address emerging challenges following the adoption of UPLs.

C. Require Payors and PBMs to Pass UPL-derived Cost Savings to Patients

UPLs serve as a cap on what *payors* can reimburse for a drug. Without precise legislative language mandating that these savings be passed down to consumers, payors are likely to retain the benefits of these savings without alleviating the financial burden on patients. Therefore, PDAB legislation should incorporate statutory language requiring any cost savings resulting from UPLs to be passed on to consumers through reduced prescription drug costs, lowered cost-sharing requirements, or decreased premiums.

D. Prohibit the Use of QALYs in PDAB Assessments

Determining the value of a medication is a challenging endeavor that can lead to the creation of formulaic, mathematical "value assessment frameworks" that can inhibit patient access to care by applying a singular value to a product or service regardless of individual consumers' needs or circumstances.

Quality-adjusted life years (QALY) are a measure used to quantify the health benefits of medical interventions or healthcare programs that are often used in decision-making to ration healthcare resources.[12] Aimed Alliance reiterates its longstanding recommendation against relying on QALY measures to evaluate any treatment. The use of QALY measures to evaluate the

[12] Gabriel Andrade, *Ethical Shortcomings of QALY: Discrimination Against Minorities in Public Health*, CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS 1-8 (Jan. 15, 2024).

value of a treatment raises significant ethical concerns, as these measures place a price tag on the value of human life that merely reflects the individual's diagnosis and deems those with chronic, debilitating, and rare conditions as being less valuable than those with common conditions. They treat individuals' lives and health as a commodity and ignore patients' and practitioners' individualized concept of the value of treatments.[13] Therefore, Aimed Alliance urges you to prohibit the use of QALYs throughout the PDAB processes.

IV. Conclusion

In conclusion, Aimed Alliance urges you to consider alternatives to PDABs that can directly impact consumer access and affordability. Moreover, we urge Members to ensure that any PDAB legislation provides a permanent, consistent, and genuine process for valuing patient and provider perspectives and lived experiences through the above recommendations.

Please contact us at policy@aimedalliance.org if you have any questions or would like to further discuss our concerns.

Sincerely,

Olivia Backhaus
Staff Attorney

[13] *Id.*