



March 18, 2025

Via Electronic Correspondence

Chair Natalie A. Manley
Health Care Availability & Accessibility Committee
Illinois House of Representatives

RE: House Bill 1443 – Creates the Health Care Availability and Access Board Act

Dear Chair Manley:

Aimed Alliance is a not-for-profit health policy organization that seeks to protect and enhance the rights of healthcare consumers and providers. We are writing to provide comments on House Bill 1443, which aims to address rising prescription drug costs by establishing the Health Care Availability and Access Board Act and empowering the Board to set upper payment limits (UPLs) for certain drugs identified as posing affordability concerns. While we share the bill's goal of improving patient access to affordable medications, we urge the Committee to consider the potential unintended consequences of the legislation and to consider alternative legislative solutions.

I. Consider the Unintended Consequences of Setting a UPL

House Bill 1443 attempts to address rising prescription drug costs by creating the Health Care Availability and Access Board (Board) which would empower the Board to set upper payment limits (UPLs) for certain drugs deemed to present affordability concerns. However, UPLs only apply to the amount payers reimburse pharmacy benefit managers (PBMs), not the prices patients pay at the pharmacy counter. These caps only affect one point in the supply chain, so changes in price do not necessarily translate into lower copayments or premiums for consumers.

Moreover, existing research suggests UPLs may produce adverse effects on access and affordability. A recent *Avalere* study found that health plans anticipate increasing the use of utilization management tools, such as step therapy and prior authorization, when UPLs are imposed on certain drugs.¹ Plans also expect to modify formularies by shifting drugs and their therapeutic alternatives into different tiers.² These changes risk raising costs for patients and restricting access to necessary medications, underscoring the need for caution when implementing UPLs.

UPLs may also undermine patient access in other ways. Providers may stop dispensing medications if reimbursement rates fall below acquisition costs. Payers may also prioritize drugs that are not subject to UPLs or may steer patients toward alternative therapies, as many rebates are tied to the drug's price, reducing PBMs' incentives from offering these options. Conversely, even if UPLs operate as intended, patients who are clinically stable on therapeutic alternatives may be

¹ Avalere Health, *Update: Health Plans' Perceptions of PDABs and UPLs* (Mar. 28, 2025), <https://advisory.avalerehealth.com/insights/update-health-plans-perceptions-of-pdabs-and-upls>.

² *Id.*

subject to non-medical switching to drugs targeted by UPLs. In each of these scenarios, continuity of care may be disrupted, health outcomes compromised, and safety-net providers strained, ultimately increasing overall healthcare costs.

II. Consider Alternative Drug Pricing Reform

Given the concerns outlined above, we urge the Committee to pursue alternatives to UPLs by advancing comprehensive PBM reforms that address the root causes of high patient costs and meaningfully increase accountability within the system. Strengthening PBM oversight, such as delinking rebates from prescription drug prices, banning clawbacks, increasing transparency, and requiring PBMs to share critical pricing and reimbursement information with health plans, would help ensure that system-wide savings are passed through to consumers rather than retained by intermediaries. Without these structural reforms, UPLs are inherently ineffective at reducing patient out-of-pocket costs. Together, these reforms offer meaningful, patient-centered strategies to improve affordability without risking the access disruptions anticipated with UPLs.

III. Illinois Must Prioritize Patient Access and Affordability

If Illinois chooses to move forward with HB 1443, Aired Alliance urges the Committee to require that the Board evaluate the potential impacts of implementing a UPL and genuinely prioritize patient input by including a dedicated consumer or patient representative, mandating ongoing engagement with patient communities, and ensuring that any UPL-derived cost savings are directly passed on to patients.

A. Conduct a Comprehensive Study Before Implementing UPLs

Given the significant challenges facing regulators in valuing and reconciling patient, provider, and caregiver feedback, as well as the uncertainty surrounding the real-world impact and savings of UPLs for consumers, Aired Alliance respectfully urges the Committee to amend House Bill 1443 to require the Board to conduct a comprehensive study before any UPL policy is adopted in Illinois. As currently drafted, UPLs may not function as intended and could worsen affordability and access challenges for patients.

Importantly, a study on affordability and prescription drug costs may also identify additional forms that are needed to better address consumer affordability and determine whether UPLs could directly benefit consumers. For instance, the study could examine whether a UPL would impact consumers without passing additional PBM reforms, such as delinking rebates from prescription drug prices. In addition to evaluating effects on patient access and affordability, the study should assess how to ensure meaningful and effective patient engagement in any future affordability framework. This could include a review of how U.S.-based affordability boards have reversed and reformed policies to better include patients, as well as an examination of international efforts aimed at improving patient participation, feedback, and reconciliation. Illinois has an opportunity to learn from these examples by proactively determining how to integrate patient perspectives into the design, implementation, and oversight of any affordability policies.

B. Prioritize Patients' Perspectives and Lived Experiences

To ensure that patient, caregiver, and provider perspectives are meaningfully incorporated, Amed Alliance urges the Committee to require that HB 1443 include a dedicated consumer or patient representative on the Board. Establishing a permanent position for this perspective will help ensure that the Board's surveys, questions, and processes remain consumer-focused and inclusive. Valuing the lived experiences of individuals with chronic conditions is essential to developing policies that genuinely reflect the needs of those they are intended to serve.³

Research consistently shows that patient involvement in healthcare decision-making improves health outcomes, enhances satisfaction with care, lowers healthcare costs, and strengthens the quality and accessibility of health service.⁴ Patients, who are the ultimate beneficiaries of these medications, provide critical insights into disease management, access challenges, treatment preferences, and other real-world factors that traditional evaluations may overlook.⁵ Incorporating this firsthand experience would enable the Board to make more informed and patient-centered decisions about drug affordability and value.⁶ It also enables the Board to access a wealth of firsthand knowledge that is essential for making well-informed and patient-centered decision about prescription drug affordability and value.⁷

The federal government has similarly recognized the importance of the patient voice by requiring all Pharmacy & Therapeutics (P&T) Committees to include at least one patient representative, acknowledging that consumer representatives offer "insights into real consumer experiences unknown to P&T committees."⁸ A comparable requirement for the Board would provide Illinois with the same benefits and help ensure that affordability policies truly serve the patients who rely on these medications.

C. 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 continuing 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,

³ *Id.*

⁴ 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>.

⁵ 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/>.

⁶ *Id.*

⁷ *Id.*

⁸ 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>

all 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 also 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.

D. Require Payers and PBMs to Pass UPL-derived Cost Savings to Patients

UPLs serve as a cap on what *payers* can reimburse for a drug. Without precise legislative language mandating that these savings be passed down to consumers, payers are likely to retain the benefits of these savings without alleviating the financial burden on patients. Therefore, the 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.

IV. Conclusion

In conclusion, Aired Alliance commends the Committee for its commitment to addressing the rising cost of prescription drugs for Illinois patients. We urge the Committee, however, to proceed thoughtfully, carefully evaluating potential unintended consequences, considering alternative legislative solutions, and ensuring that patient input remains central throughout the process. Specifically, we urge the Committee to ensure that HB 1443 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,

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