



October 18, 2024

Legislative Policy Committee
Department of Legislative Services
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Via Electronic Correspondence

RE: Prescription Drug Affordability Board's Upper Payment Limit Plan

Dear Members of the Legislative Policy Committee:

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 written testimony on the Maryland Prescription Drug Affordability Board's Upper Payment Limit Action Plan.

As the Legislative Policy Committee reviews the Action Plan, Aimed Alliance urges the Committee to require the Board to revise its plan to:

- (1) Incorporate patient perspectives;**
- (2) Mandate ongoing consumer engagement;**
- (3) Ensure that any savings are passed directly to consumers; and**
- (4) Prohibit the use of quality-adjusted life years (QALYs).**

I. Prioritize Patients' Perspectives and Lived Experiences

Currently, the cost review study process established within the draft Action Plan would assess prescription drugs to determine if the drug "has led or will lead to affordability challenges for the State health care system or high out-of-pocket costs for patients." Among the many factors that the Board would consider during the review, it would consider patient access, cost-sharing, and public input. Aimed Alliance appreciates these efforts to include the patient perspective and urges the Board to take additional steps to ensure the patient perspective and lived experience are appropriately weighted and considered during the review study process.

Research consistently demonstrates the benefits of involving patients in healthcare decisions. Studies show that patient inclusion leads to improved health outcomes, greater satisfaction with care, and reduced healthcare costs.¹ Including patients in health policy decisions also enhances the quality and accessibility of care.² Because patients are the primary beneficiaries of medications, their perspectives are necessary for accurately evaluating the value of these treatments. Engaging patients in decision-making provides valuable insights into disease

¹ 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>.

² *Id.*



management, access barriers, treatment preferences, and other important factors related to medication use.³ Their firsthand experiences can help ensure that healthcare policies address the needs of those they aim to serve.⁴ Including patient, provider and caregiver perspectives also enables the PDAB to access a wealth of firsthand knowledge that is essential for making well-informed and patient-centered decisions about prescription drug affordability and value.⁵

To ensure that the perspective of patients, caregivers, and providers are properly valued and included, Aimerd Alliance urges the Committee to require the Board to explain in its report how consumer feedback was considered in rendering a decision on “affordability.” Moreover, we urge the Board to work with advocacy and patient organizations to collect robust data on the impact of prescription drug costs on consumers. Importantly, the Board must make affirmative efforts to engage patients, providers, and caregivers, and cannot rely solely on advocacy organizations to bring these perspectives to the Board. Lastly, we urge the Board to exercise diligence when reviewing data from surveys and responses as many consumers may share information that is not applicable to the state’s determination of affordability. For example, a Medicare beneficiary living in Maryland may comment on the affordability of a prescription drug despite their health insurance cost-sharing being established by the federal government. Ultimately, prioritizing the experiences of consumers with chronic conditions will help ensure the Board better address the needs of the populations these policies are meant to serve.⁶

II. Mandate a Continuous Consumer Engagement and Oversight Process

Aimerd Alliance applauds the Committee for considering a variety of policy recommendations once a prescription drug has been deemed unaffordable. The drug pricing system in the United States is complex and UPLs may not directly impact the cost of prescription drugs for consumers. As such, diverse approaches are needed to ensure that consumers can afford and access their necessary medication.

While the proposal states the Board will consider public written comments throughout the UPL setting process, it does not address how the Board will monitor the impact of the UPL on access and affordability. Therefore, Aimerd Alliances urges the Committee to ensure the Board’s obligation to engage patients, providers, and caregivers extends beyond the UPL setting process to ensure UPLs do not impair or impede access to therapeutics with UPLs. Specifically, we urge the Committee to require the Board maintain an ongoing commitment to actively seek input from a diverse array of stakeholders, including patients, caregivers, providers and other community stakeholders.

As stated above, the obligation to continuously seek feedback on access and affordability for UPL selected prescription drug must include an affirmative obligation for the Board to engage these communities. Patients and caregivers often juggle work, family commitments, and treatment plans while also navigating complex healthcare systems to ensure optimal care for

³ 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/>.

⁴ *Id.*

⁵ *Id.*

⁶ *Id.*



themselves or their loved ones. Therefore, the responsibility to be aware of and engage in the UPL-setting process should not fall solely on consumers; the Board should share the responsibility to engage these communities.

Ultimately, establishing clear channels for consumers to voice concerns regarding any access barriers from the implementation of UPLs is critical to ensuring equitable access to essential medications. By fostering a culture of transparency and responsiveness, the Board can effectively address emerging challenges that may arise following the implementation of UPLs.

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

PDABs are intended to lower the cost for state payors and consumers. Currently, the proposed UPL process does not guarantee any savings for consumers. Because UPLs serve as a cap on what payors can reimburse for a drug, precise language is needed in the UPL Action Plan to ensure these savings are passed down to consumers. Under the currently proposed program, payors are likely to retain the benefits of these savings without alleviating the financial burden on patients. Therefore, the UPL-setting plan should incorporate statutory language requiring any cost savings resulting from UPLs to be passed on to consumers through reduced prescription drug costs or lowered cost sharing requirements.

IV. Prohibit the Use of QALYs in PDAB Assessments

Under the proposed Action Plan, the Board may use “cost-effectiveness analysis” when setting the UPL for a prescription drug. Typically, cost-effectiveness analysis requires assessors to determine how much improvement in health outcomes is gained per dollar spent on a prescription drug. These frameworks can limit patient access to care by assigning a fixed value to a medication, without considering individual needs or circumstances. For example, quality-adjusted life years (QALYs) 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.⁷

Aimed Alliance reiterates its longstanding position against using QALYs to evaluate any treatment. The use of QALY measures raises significant ethical concerns, as these measures effectively place a monetary value of human life based solely on a diagnosis, suggesting that individuals with chronic, debilitating, and rare conditions are less valuable than those with common conditions. This approach treats individuals’ lives and health as a commodity and ignores patients’ and practitioners’ individualized perception of the value of a specific treatment. Therefore, Aimed Alliance urges the Committee to mandate the Board to prohibit the use of QALYs throughout the UPL-setting process and in any cost effectiveness analysis.

V. Conclusion

In conclusion, we urge the Legislative Policy Committee to require the Board to revise its UPL Action Plan to prioritize patients by integrating patient perspectives, mandating continuous

⁷ Gabriel Andrade, *Ethical Shortcomings of QALY: Discrimination Against Minorities in Public Health*, CAMBRIDGE QUARTERLY OF HEALTHCARE ETHICS, 1-8 (Jan. 15, 2024).



consumer engagement, requiring that any savings benefit consumers directly, and prohibiting the use of QALYs.

We appreciate the opportunity to provide written testimony. If you have any questions or would like to further discuss our concerns. Please contact us at policy@aimedalliance.org.

Sincerely,

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Aimed Alliance