



February 25, 2024

Oregon Prescription Drug Affordability Board
Labor & Industry Building
350 Winter Street NE
Salem, OR 97309

Re: Call for Inclusion of Patient Voice and Lived Experience in Drug Review Process

Dear Members of the Oregon Prescription Drug Affordability Board:

Aimed Alliance is a not-for-profit health policy organization that seeks to protect and enhance the rights of healthcare consumers and providers. We appreciate the opportunity to comment on the Oregon Prescription Drug Affordability Board's affordability review process. Aimed Alliance urges the Board to consider the following recommendations:

- 1. Prioritize patient voice and lived experience in the drug review process;**
- 2. Ensure the drug review processes embraces diverse community perspectives;**
- and**
- 3. Adopt an exclusion for rare disease drugs.**

I. Introduction

The escalating costs of healthcare in the United States poses a significant challenge for healthcare consumers nationwide. In response to this pressing issue, numerous states have introduced legislation establishing prescription drug affordability boards (PDABs) aimed at addressing the prices of prescription medications and ensuring equitable access to affordable drugs. Typically, these boards are tasked with setting upper payment limits (UPLs) for specific prescription drugs.¹

As PDABs undertake the task of reviewing drug affordability, it is imperative that they uphold their commitment to ensuring prescription drug affordability for *healthcare consumers*. This commitment is essential for enhancing healthcare accessibility, alleviating financial burdens, advancing public health outcomes, and promoting equity within the healthcare system.

II. Oregon's PDAB Should Prioritize Patient Access and Affordability

As advocates for patient-centric health care policies, Aimed Alliance urges the Board to consider the role of the patient voice and lived experience in the drug review process. Involving patients in the decision-making process can provide insights into disease management, access challenges, treatment preferences, and other pertinent considerations associated with various prescription drugs.²

¹ Aimed Alliance, *Enacted Prescription Drug Affordability Boards*, <https://aimedalliance.org/wp-content/uploads/2024/01/AA-PDAB-Enacted-Chart-Jan-2024.pdf>.

² 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/>.



Moreover, research consistently highlights the benefits of actively involving patients in healthcare decisions. For instance, studies demonstrate engage patients has a positive effect on improving health outcomes, enhancing satisfaction with the care experience, lowering costs, improving quality of care, and increasing accessibility.³ By incorporating patients in the drug review process, the Board can help ensure that their voices are heard and their needs are recognized.⁴ It also enables the Board to access a wealth of firsthand knowledge, that may not be documented in empirical data, that is essential for making well-informed and patient-centered decisions.⁵

Aimed Alliance also encourages the Board to ensure that the drug review process incorporates a multitude of diverse community perspectives. Recognizing the unique needs and challenges faced by different communities is crucial to fostering inclusivity and equity within the decision-making processes.⁶ For instance, individuals living in rural areas confront significant barriers to accessing health care due to sparse provider availability and extended travel distances to seek care, while individuals in more urbanized areas may experience different access challenges.⁷

Importantly, in Oregon, 16 percent of the state, approximately 660,000 residents, live in rural areas.⁸ For many, the nearest clinic is located more than 100 miles away.⁹ In these areas, financial hardship and limited access to health care services impact health care access and the ability to manage chronic conditions, significantly impacting overall health outcomes for residents.¹⁰ Thus, it is imperative that the Board takes into account these complex realities when evaluating drug access and affordability in Oregon.

By actively seeking input from a broad range of stakeholders, including patients, caregivers, and community representatives, the Board can develop a fair and comprehensive drug review framework. In recognizing the multifaceted challenges faced by patients and caregivers, it is imperative that the Board also acknowledge its shared responsibility in engaging these communities. Patients and caregivers must manage work and family commitments, treatment regimens, and financial strains—all while striving to navigate complex healthcare systems to care for themselves or their loved ones. Therefore, the onus cannot solely rest on consumers to advocate for their needs; the Board must actively reach out and involve these stakeholders in the decision-making process. To ensure these efforts reach the intended communities, the Board

³ *Id.*; 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>.

⁴ Alex Krist, et al., *Engaging patients in decision-making and behavior change to promote prevention*, 240 STUDENT HEALTH TECH. INFO. 284-302 (2017), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6996004/>.

⁵ *Id.*

⁶ *Improving Cultural Competence to Reduce Health Disparities for Priority Populations*, EFFECTIVE HEALTH CARE, <https://effectivehealthcare.ahrq.gov/products/cultural-competence/research-protocol> (Jul. 8, 2014).

⁷ *Why Health Care Is Harder to Access in Rural America*, U.S. Gov. ACCOUNTABILITY OFF., (May 16, 2023), <https://www.gao.gov/blog/why-health-care-harder-access-rural-america>.

⁸ *Id.*

⁹ *Id.*

¹⁰ *Id.*



should engage local stakeholders and leaders who are already connected, trusted, and working within these communities.

Lastly, the process of engagement must extend beyond the initial review stage. Once the Board establishes a UPL, the Board should continuously monitor how the UPL impacts access and affordability. Establishing clear channels for consumers to voice concerns 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, the Board can effectively address emerging challenges following adoption of the UPL.

III. Rare Disease Exclusion

Aimed Alliance urges the Board to consider creating an exclusion for rare disease drugs within the drug review framework. Patients with rare diseases often face significant challenges in accessing life-saving medications due to the substantial research and development costs involved, coupled with the relatively small patient populations they serve.¹¹ In fact, the development of drugs for rare diseases is particularly scarce; with the U.S. Food and Drug Administration (FDA) reporting that, of the approximately 7,000 known rare diseases, less than 10 percent have an FDA-approved treatment available.¹² Given the high prices and limited treatment options for rare diseases, the establishment of a UPL by the Board carries heightened significance in this context and could decrease access to these treatments, and disincentivize investment and research into rare disease treatments. Therefore, Aimed Alliance urges the Board to recognize the unique challenges confronting patients with rare disease and consider creating an exclusion for rare disease drugs from the drug review process.

IV. Conclusion

In conclusion, Aimed Alliance encourages the Oregon Prescription Drug Affordability Board to champion a drug review process that centers on patient voice and lived experience, embraces diverse community perspectives, and excludes rare disease drugs from consideration. We appreciate the opportunity to comment on this issue and commend the Oregon Prescription Drug Affordability Board for its efforts to improve access to affordable prescription drugs for the residents of Oregon.

Sincerely,

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Counsel

¹¹ Takeya Adachi et al., *Enhancing Equitable Access to Rare Disease Diagnosis and Treatment around the World: A Review of Evidence, Policies, and Challenges*, 20 INTERNATIONAL JOURNAL OF ENVIRONMENTAL RESEARCH AND PUBLIC HEALTH (Mar. 2023), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10049067/>.

¹² *Rare Disease Cures Accelerator*, U.S. FOOD AND DRUG ADMIN., <https://www.fda.gov/drugs/regulatory-science-research-and-education/rare-disease-cures-accelerator#:~:text=However%2C%20of%20the%20approximately%207%2C000,and%20progression%20of%20each%20disease.>