

February 14, 2025

Oregon Prescription Drug Affordability Board Department of Consumer and Business Services 350 Winter Street NE Salem, OR 97309-0405

RE: Public Comments on Drug Selection Criteria and Cost Reviews

Dear Members and Staff of the Oregon Prescription Drug Affordability Board:

The Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC) is a two-part coalition that unites patient organizations and allied groups (EACH), as well as patients and caregivers (PIC), to advocate for drug affordability policies that benefit patients.

We appreciate the decision of the board to pause affordability reviews last year due to the complex nature of the task. We applaud the board for acknowledging the significance of the work, responding to stakeholder feedback, and committing to improve the review process.

To date, we are unclear about what concrete improvements to the cost review process have been made to prevent the same obstacles that the board faced in 2024 from recurring in 2025. Before the board proceeds with drug selection and cost reviews, we urge board members to clearly present to the public what changes have been implemented and allow additional stakeholder feedback before finalizing the new process and proceeding with reviews. Furthermore, we urge the board to clearly outline metrics and define affordability to ensure that reviews are performed with consistency and a clear focus on patient benefit.

We look forward to engaging with the board to improve the cost-review process and ensure it ultimately benefits the patients who rely on the drugs under review. We respectfully urge the board to consider the suggestions of patient organizations outlined in this letter. We offer our coalition as a resource to board members seeking to connect with patient organizations and patients.

Integrate Patients and Patient Organizations into Cost Review Process

We urge the board to put significant emphasis on gathering input from patients throughout the cost review process. This will ensure that the board is appropriately identifying and addressing real patient problems and that patients' lived experiences are addressed by board proposed policy solutions.

We feel the board should be required to hold meetings, focus groups, or other scheduled events at varied times and locations to get input on the drugs under review. This will ensure members of the public are given adequate opportunity to attend and provide patients with the opportunity to share their experiences on each drug directly with board members and staff. Also, focus groups and surveys should have basic parameters for both structure and participant numbers to be considered representative of the viewpoints of the public.

ENSURING ACCESS THROUGH COLLABORATIVE HEALTH

We appreciate the board publishing the proposed request for information forms; however, we are concerned that the current draft of the patient form is not very friendly to a layperson/patient audience and therefore will not achieve the desired result from patient input. For an in depth, patient-led review of the questions, which includes detailed recommendations for improvements, please refer to the letter submitted by the Patient Inclusion Council (PIC).

Additionally, we recommend a separate form for patients to avoid overwhelm and any potential confusion regarding what is expected from their participation. We also think the board should establish a minimum threshold for patient information submissions on each drug to ensure that they are receiving adequate input from patients.

Because of the complex nature of this process and the information being sought, we appreciate the inclusion of patient organizations as a stakeholder group representing patient voices. There are many proven methods patient organizations have used to collect meaningful, unaltered data from patients (including discussion sessions, surveys, etc.) that we could facilitate, acting as a bridge to enable more voices to be heard. We could combine these efforts with those conducted by the board, in a transparent way that ensures the raw patient data is untouched, thus increasing real-world evidence without any perceived bias of data submission.

Focus Policies on Patient Burdens and Affordability

Ultimately, we know that defining affordability is a key aspect of the drug review process that the Oregon board is seeking to improve. We urge the board to prioritize patient costs as a key aspect and focus of any affordability measurement, specifically out-of-pocket costs. To the extent that is possible within statute, we implore the board to focus on defining affordability based on patient-reported costs and concerns.

Furthermore, we urge the board to focus on patient-reported obstacles to care and address the underlying factors that contribute to patient hardship in affording and accessing their needed medications. Failing to resolve the underlying factors that lead to higher costs for patients can result in short-term relief and uneven benefits – aiding some but potentially leaving others with higher costs and drug accessibility challenges.

Patient Access Cannot Be Compromised

We urge the board to implement a methodical and thoughtful approach to reviewing and implementing the drug selection criteria that will be used for cost review. Due to statutes set for drug selection criteria, many of the medications subject to review are biologics or specialty drugs.

The majority of patients who rely on biologics or specialty medications are those with chronic conditions, which are incredibly complex to treat. Each patient faces a unique experience and should be able to work with their doctor to identify the treatment that works best for them. Substituting or requiring patients to change drugs based on cost considerations instead of medical needs can disrupt the continuity of care and result in complications and higher overall medical costs.

For these patients, therapeutic alternatives may not be alternatives at all. Very often drug interactions or other health conditions would prevent individual patients from being able to switch to an alternative medication that, on paper, seems like it would be an appropriate







treatment. Further, patients with chronic conditions can build up a tolerance to medications over time, so they must retain access to all treatments in a class of drugs to prolong their treatment.

Cost Reviews Could Compromise Patient Access to Medications

At their core, cost reviews necessitate selecting individual drugs for review and potentially implementing market interventions for the selected drugs. This puts PDABs in a position of picking winners and losers between drugs and within the broader population of Oregon patients. Individual drug reviews unnecessarily create inequities between patient populations.

We are concerned that interventions on individual drugs will create a new incentive structure for payers that could compromise patient access to the selected medications due to increased utilization management or reshuffling of formularies. We don't know yet how either insurers or manufacturers will react to state-by-state interventions and encourage the board to utilize its mandate to interview industry stakeholders to determine how cost reviews will impact patient access before proceeding with reviews.

Sound Health Policy is Founded on Patient Perspectives

Finally, we urge this board to keep as a primary focus the needs of patients and work diligently to ensure that access to all treatments is protected. We strongly urge the board and staff to utilize the authority of the board to fully explore with all healthcare stakeholders how cost reviews will be implemented and identify in advance any adverse impact to patients.

Additionally, we invite the board to utilize this organization and its members as a direct conduit to understanding and incorporating patient and caregiver perspectives, as well as those of patient organizations who have an understanding of the life cycle of disease from the lens of prevention, diagnosis, and disease management.

We appreciate your laudable efforts to improve our health system and your steadfast commitment to protecting patients. We look forward to working together to achieve these goals.

Sincerely,

Tiffany Westrich-Robertson

Iffany Westrick - Pobertson

Ensuring Access through Collaborative Health (EACH) Coalition



