



September 11, 2026

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

RE: Comments on Cost Reviews, Policy Recommendations and Patient Feedback Form

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 opportunity to provide comments as the board begins final decision-making for its 2026 annual report. As the board begins making affordability determinations for the drugs selected for review and continues developing policy recommendations, we respectfully urge the board to keep patient costs, access, and experiences at the center of both efforts.

### **Establish Clear and Patient-Centered Affordability Determinations**

Throughout the 2026 review process, EACH/PIC has encouraged the board to establish a clearer and more consistent framework for determining when a prescription drug presents an affordability challenge. As the board now enters final deliberations, we continue to believe that affordability determinations should be based on clear, understandable, and repeatable parameters that allow patients and other stakeholders to understand how the board reached its conclusions.

Most importantly, those parameters should reflect how patients actually experience affordability. As we have previously shared with the board, according to results from our [Patient Experience Project](#), affordability is not determined by drug price alone. Patients experience affordability within the context of what they actually pay, their insurance coverage, cumulative healthcare expenses, access to financial assistance, and their ability to consistently obtain the treatment that works for them. Critically, the research found no single universal price threshold separated an affordable medication from an unaffordable one.

As the board deliberates on each drug, we urge members to determine whether patients are actually experiencing affordability challenges, understand what is driving those challenges, and apply clear and consistent criteria across all drugs under review. Doing so will make the review process more transparent and provide a stronger foundation for determining which policy solutions are appropriate.

### **Ensure Policy Recommendations Resolve Patient Obstacles to Care**

The same principle should guide the board's policy deliberations. The ultimate measure of an affordability policy should be whether it meaningfully addresses the problems patients experience affording and accessing their medications.



As we noted in June, patient experiences point toward reforms that make healthcare costs more predictable and manageable, improve access to financial assistance, address harmful utilization management, and better align incentives throughout the prescription drug supply chain.

We appreciate the board's continued consideration of policy options and look forward to learning more about the deliberations that have occurred over the past several months. We also encourage the board to provide patients and patient organizations with a meaningful opportunity to review and comment on proposed policy recommendations before they are incorporated into the final annual report.

### **Continue Strengthening Patient Engagement**

Finally, we appreciate the board's continued efforts to strengthen patient engagement. In particular, we applaud the decision to refine the patient feedback form and make it available throughout the year. Creating an ongoing opportunity for patients to share their experiences is an important step toward ensuring that patient perspectives inform the board's work.

We continue to believe, however, that the form can be improved to make participation more patient-friendly and to generate more informative responses. Carefully designed questions can help identify why a patient is experiencing affordability challenges, giving policymakers in Oregon better information to address the underlying causes of that hardship.

#### **Our recommendations include:**

**Address privacy concerns.** *"We may share information from this feedback publicly in our reports or through public records requests. **Important:** Please do not include personal information you do not want shared publicly, such as names, contact details, medical record numbers, or other information that could identify you or another person."*

- **Recommendation: Reword** the overview to clarify personal information (name and contact details) **will not** be shared publicly. *"While we may share information from the feedback you submit in our public reports or records, your personal information, such as name and contact details, will remain confidential."*
- **Recommendation: Add a short section with simple directions**, moving *"Since responses will not be edited, please do not include personal identifying information in your responses, such as names or affiliations that could identify you or another person,"* to the instructions section.
- **Recommendation:** At the end of the form, under Final Questions, add Name and Email and make these **optional**. **Add a statement** that clarifies this information is only needed if the respondent would be open to being contacted by staff for more information.

**Ensure the survey uses neutral and inclusive language for those representing patient perspectives.** In Q1, the form asks to identify the respondent's role or point of view. The choices state *"Member of an advocacy group"*.

**Recommendation:** Reword using *"Representing a patient community."* This more neutral language focuses on the respondent's role and avoids singling out advocacy organizations in a way that could imply bias.

**Keep the intent to collect experiences, then use those to guide board decisions.** The purpose of the form should be to collect information about patients' experiences and affordability challenges, not to ask patients to make a procedural determination about whether a drug should be reviewed. Because patients may not understand the distinction or what a nomination entails, the board should focus on reviewing the information submitted and determining for itself whether the information warrants further exploration of the drug.

- **Recommendation: Remove** option two from Q2 and the corresponding break out section. The information that would be collected in the branching will be captured in the other parts of the survey.

**Determine if the board is only interested in obtaining information from those currently taking a prescription drug.** As currently worded, the form only asks questions pertaining to the present.

- **Recommendation:** If the board is interested in understanding more about recent past prescription use, such as why a person may have stopped taking a treatment, add verbiage to clarify both scenarios. Example: *"How often do you **or did you** refill..."*

**Other edits (suggested changes to existing text in bolded font):**

- Q4: *"What condition **or conditions** do you use the drug to treat?"* Many people have comorbidities that are treated by the same drug, which differentiates one prescription from potential therapeutic alternatives.
- Q6: *"How much do you pay **out-of-pocket** each time you refill your prescription or receive a treatment?"*
  - **Recommendation: Add a follow up statement:** *"Include all out-of-pocket amounts you pay or paid for the lifetime of using this prescription drug."* In our Patient Experience Project, one of the most eye-opening findings came from asking patients to report every out-of-pocket cost they paid for the same drug over time. This enabled us to determine cost barriers unrelated to only the current coverage year.
- Q6: *"Include any cost sharing you pay yourself such as copays or coinsurance. Do not include costs paid by someone else such as your health insurance or a patient assistance program."* Even after reading this statement numerous times, we were unable to determine how a patient should answer this question.
  - **Recommendation:** Reword for clarity.
  - **Recommendation: Add** *"Which out-of-pocket costs were affordable or unaffordable and why?"*
- Q7: *"Do you use **or have you used** a **financial** assistance or discount program to help pay for the drug?"* Through our extensive work conducting patient-facing surveys, we have realized too many terms related to financial assistance (i.e., copay plans, patient assistance programs, patient assistance, etc) has led to respondent confusion. Additionally, largely due to insurance barriers and plan changes, some patients may utilize financial assistance for the drug at one point in time, then cannot utilize it at another point in time.
  - **Recommendation:** Adopt the term "financial assistance" as an umbrella term.
  - **Recommendation:** Revise the answers to include "Yes, *always*" and "Yes, *sometimes*."

- Q8: “How much does/did the **financial** assistance program pay each time?”
- Q9: “What cost or access problems have you experienced?”
  - “The price increased.” **Revise to** “The out-of-pocket cost increased,” because “price” could be viewed as list or net price.
  - **Add:** “High premium”
  - “The drug was not available.” **Revise to** “The drug was not available due to a shortage.” Without clarifying the statement could mean to a patient that insurance did not cover it.
- Q11: “In the last 12 months, have you stopped taking this medication or taken less of it because you could not afford it?” In our Patient Experience Study, of those who did not stop taking their medications due to medical reasons, 95% who cited ‘cost’ as the issue explained in open-ended responses it was related to insurance barriers.
  - **Revise to** “In the last 12 months, have you stopped taking this medication or taken less of it because you could not afford it? **If so, explain what happened that made it unaffordable.**” **Remove** yes/no options.

As the board continues refining its approach, we encourage it to design patient engagement around the information necessary to identify actionable barriers and potential solutions. EACH/PIC remains willing to share lessons from our Patient Experience Project and work with the board and staff on patient-facing question design.

We appreciate the board's continued attention to prescription drug affordability and its willingness to refine its processes as this work evolves.

Sincerely,



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