



July 13, 2026

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

RE: Comments on Policy Recommendations and Patient Engagement

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 additional information as the board develops policy recommendations for inclusion in its 2026 Annual Cost Review Report and explores additional opportunities for patient engagement.

To support these discussions, we are submitting resources for the board's consideration:

- The [EACH/PIC Patient Experience Survey 2.0 Findings](#), which summarize patient-reported drivers of affordability and unaffordability;
- The [EACH/PIC Patient Driven Policy Recommendations](#), which details patient-informed policy recommendations; and
- The [EACH/PIC Patient Experience Survey Design](#), which outlines the methodology and question design used to collect patient perspectives on affordability and access.

We hope these resources are helpful as the board continues its cost reviews and explores ways to ensure Oregonians can access and afford their needed medications.

Continue Focusing on the Drivers of Patient Affordability

We continue to urge the board to promote policies that directly improve affordability and access for patients by addressing the factors patients themselves identify as creating affordability challenges. Our national Patient Experience Survey found that affordability is shaped by much more than the price of an individual medication. Insurance design, including benefit structure, coverage decisions, utilization management requirements, and changing out-of-pocket costs, often determines whether patients can consistently afford and access their prescribed treatment.

We appreciate the Board recognizing the EACH/PIC coalition's extensive work on patient-facing data collection. During the board's June meeting, we welcomed the discussion regarding insurance and encourage further exploration of how plan design determines patient access and costs. We also noted staff's observation that many of the patient comments received through the board's community forums focused on insurance-related challenges when discussing prescription drug affordability. These discussions reinforce the importance of continuing to examine the broader factors that influence patient affordability as the board develops policy recommendations.



As the board continues evaluating policy options, we encourage it to prioritize reforms that directly address these patient-reported barriers. Based on our survey findings, these include policies that improve cost predictability, strengthen and protect financial assistance programs, prohibit copay accumulator and maximizer programs, improve transparency throughout the prescription drug supply chain, reform PBM incentives, and protect patients from insurance practices that unnecessarily disrupt access to effective treatments. These recommendations were developed from patients' reported experiences and are intended to directly address the barriers they identified through the survey.

Strengthen Patient Engagement

We also appreciate the board's continued efforts to strengthen patient engagement. The limited participation in the recent community forums highlights the challenges many PDABs have experienced when attempting to gather representative patient input.

We were encouraged to hear the board discuss developing a standing patient survey, expanding outreach through patient advocacy organizations, and engaging patients through existing community events. These are important steps toward ensuring the board hears from a broader and more representative group of patients.

To support those efforts, we are resubmitting the findings from the EACH/PIC Patient Experience Survey, and also providing the survey design itself. The survey was intentionally developed to move beyond simply asking whether a medication is "affordable" and instead identify the factors that determine affordability from the patient's perspective. By combining quantitative questions with open-ended responses, the survey captures the context behind patients' experiences, including the role of insurance design, financial assistance, utilization management, and changing out-of-pocket costs.

While we have used lessons learned from our study to design a third version of the survey, we encourage the board to use our survey methodology as a starting point as it develops its own standing patient survey. Referring to these questions or utilizing a similar question design would allow the board to collect richer, more actionable information about the drivers of patient affordability while creating greater consistency in how patient experiences are measured over time.

We would also welcome the opportunity to share additional information regarding our survey methodology and to work with board staff as they develop future patient engagement tools. We believe leveraging proven patient-centered survey methods can help the board collect more meaningful information while reducing the time and resources required to develop new engagement approaches.

Likewise, we encourage the board to continue partnering with patient advocacy organizations to expand participation and ensure engagement opportunities reach patients where they already receive information and support. These partnerships can complement the board's own outreach efforts while helping ensure that future policy recommendations are informed by a broader range of patient experiences.

We appreciate the board's continued commitment to identifying policy solutions that improve affordability for Oregon patients. We are encouraged by the board's ongoing efforts to better



understand patient experiences, strengthen patient engagement, and evaluate policies that address the underlying causes of affordability challenges.

We look forward to continuing to serve as a resource as the board advances this important work and appreciate your consideration of the attached materials.

Sincerely,

A handwritten signature in dark ink, reading "Tiffany Westrich-Robertson".

Tiffany Westrich-Robertson

tiffany@aiarthrititis.org

Ensuring Access through Collaborative Health (EACH) Coalition Lead

A handwritten signature in dark ink, reading "Vanessa Lathan".

Vanessa Lathan

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Patient Inclusion Council (PIC) Coalition Lead