EACH PIC
COALITION

March 19, 2026

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

Patient Experience Study Findings and Opportunities for Collaboration

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 truly benefit patients.

We are pleased to share the updated results from our Patient Experience Project: Patient-Reported Affordability & Unaffordability Survey 2.0. This national, patient-led initiative was designed to address gaps in how affordability is currently measured by policymakers. We shared the results from our initial pilot survey in August 2025, and we are pleased to share updated findings from our expanded research study that confirmed those findings and revealed new drivers of patient-reported prescription drug affordability challenges.

This work has also enabled our coalition to successfully design and test a robust patient affordability data collection question tool that will aid those looking to capture meaningful patient-reported insights that can guide effective, patient-centered solutions.

The goal of our work is straightforward: to establish a robust, patient-facing data collection tool that will help PDABs to better understand *why* patients report medications as affordable or unaffordable, and so the data collected ensures policy solutions are grounded in putting patient needs first.

WHAT WE LEARNED

Context is critical to understanding patient-reported affordability

- Our findings show that patients define affordability as “the ability to consistently obtain medications within *their essential* monthly household budget, considering income, total healthcare costs, and life circumstances.”
- Confirming findings from the pilot survey, insurance barriers, high cumulative medication costs, income, perspectives on how much medication should cost, and evolving life experiences were all primary drivers of reporting a drug as unaffordable.

- The data also revealed existing and often stark health inequities as people of color were far more likely to report on brand or generic drugs and experienced affordability challenges at a higher rate than their white counterparts for specialty and generic drugs.

Patient-centered affordability assessments, grounded in reported experiences, are essential to understanding these dynamics. Reducing affordability to the price of individual drugs risks missing the root causes of patient hardship.

Insurance is a key determinant of patient-reported affordability and access to treatments

- Patients reporting drugs as unaffordable described insurance barriers, not simply cost.
    - 95% of patients who stopped taking their medication cited insurance-related challenges, not cost, as the primary cause.
    - 72% who never started taking their medication cited insurance-related challenges, including denial of coverage and high out-of-pocket costs even with insurance.

- No single drug emerged as causing broad patient affordability challenges due to volatile insurance-driven cost-sharing inconsistencies.
    - Almost one-quarter of all 537 respondents reported paying more than one out-of-pocket cost for the same drug at some point over time (OOP cost shifting).
        - Of those patients, 51% also reported their drug as being affordable at one point and unaffordable at a different point (affordability shifting).
        - Of those patients, 55% reported their OOP costs shifting between three or more ranges (i.e., $0-$10, $11-$25, $26-$50, etc.), with 15% reporting ranges between $0-$10 and $1001+.
        - As a result, many lost access to their treatment (access shifting).

To meaningfully reduce patient hardship, health reforms must move beyond drug price controls and directly address insurance-driven instability that create shifting costs and disrupt patients' access to effective treatments.

Savings should not come at the expense of patient necessities.

Among respondents who tried multiple treatments, over 80% described their medication as valuable, often "exceptionally valuable," with most emphasizing its unique value to them rather than general effectiveness.

Patients reported that non-medical switching - an insurance practice that requires patients change medications to save the system money, not for medical reasons - caused them harm due to disease recurrence, side effects, worsened health outcomes, and adverse events when required to switch medications due to insurance plan design.

Maintaining access to preferred and effective treatments should be weighed as heavily as cost in health policy decisions.

IMPLICATIONS FOR PDAB PROCESSES

Focusing narrowly on the price of a single drug will not solve patient-reported affordability challenges. Affordability reviews that overlook the patient-identified reasons people struggle to access care are unlikely to meaningfully reduce patient out-of-pocket costs. Further, policies that lead to upper payment limits are likely to exacerbate these known barriers by triggering more utilization management, care delays, and pressure to move patients off the treatments that work best for them.

Enhance Patient Engagement

Our coalition has worked to design and test patient questions that truly allow patients to share fully any barriers or obstacles they face when accessing their prescription drugs. Rather than relying primarily on yes/no or multiple-choice questions, the survey incorporated open-ended responses that allowed patients to explain their out-of-pocket costs, how those costs fit within their overall financial reality, and *why* they considered a medication affordable or unaffordable.

Our work on the Patient Experience Project spanned 18 months and was aimed, in part, to advise those conducting patient-facing data collection how to design questions that will produce substantive responses and accurate analysis.

We strongly encourage all PDABs to substantially revise their current patient surveys by adopting our survey questions or referencing our survey as a design model. Doing so would strengthen the quality of patient input collected during affordability reviews and better equip the board to fulfill its core purpose: identifying and resolving the real-world challenges patients report when trying to access the medications they rely on.

Our coalition stands by your work to help patients afford their medications and will continue to offer our services to assist in making these important and necessary changes.

Focus on Patients

Good health reforms should improve patients' lives and protect access to needed care; cost savings to states or other stakeholders should never come before or compromise patient care. Therefore, PDAB affordability reviews should prioritize patient experience, particularly patient-reported out-of-pocket costs and access challenges, as core metrics for evaluating both need and impact.

Our research demonstrates that affordability is shaped by insurance design, cost-sharing variability, and access barriers, not price alone. Policies which fail to account for these factors risk missing the drivers of patient hardship. While we recognize that PDABs operate within statutory constraints, where authority exists, boards should ensure that their actions do not exacerbate known challenges such as utilization management, coverage restrictions, or instability in access that patients consistently report.

Finally, improving patient engagement will be essential to achieving these goals. This includes adopting more robust survey designs that capture the "why" behind patient experiences, conducting meaningful listening sessions and roundtables, and partnering with patient organizations to ensure that policy decisions are grounded in real-world patient needs and lead to measurable improvements in access and affordability.

Resolve Patient-Reported Barriers to Care

We recognize that boards share the goal of reducing patient costs and improving access to care. While statutory limitations may constrain the actions boards can take, we encourage you to evaluate the findings of our report and where possible, pursue patient-driven reforms that better address their real-world barriers to care.

Our findings show that patients consistently struggle with unpredictable and unmanageable costs driven by insurance design, not price alone. Making costs more manageable and predictable through limits on out-of-pocket spending, lower deductibles, and cost-smoothing mechanisms that spread expenses over time directly address patient barriers. Expanding and simplifying access to financial assistance is also critical, as these supports often determine whether patients can initiate and maintain treatment.

At the same time, reforms must account for structural drivers of patient hardship within the healthcare system. Patients reported that utilization management, coverage restrictions, and non-medical switching can disrupt care and undermine access to effective treatments. These experiences point to broader systemic issues, including misaligned incentives within PBM and insurance structures that can increase patient costs without improving care.

By focusing on these patient-reported barriers and ensuring that any savings translate into meaningful relief for patients, boards can help advance more effective, patient-centered approaches that improve access and reduce real-world affordability challenges.

Thank you for your ongoing work to improve drug affordability. We look forward to the opportunity to work alongside you to ensure that affordability reviews translate into meaningful improvements in patient access, equity, and health outcomes.

Sincerely,

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Attachments:

- *Patient Experience Survey: Prescription Drug Affordability and Unaffordability (Version 2.0)*