



August 18, 2025

Maine Prescription Drug Affordability Board
Office of Affordable Health Care
109 Capitol Street
11 State House Station
Augusta, ME 04333

Patient Experience Survey Findings and Opportunities for Collaboration

Dear Members and Staff of the Maine 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 results of our [Patient Experience Survey: Prescription Drug Affordability and Unaffordability](#), a national, patient-led initiative designed to address gaps in how affordability is currently measured by policymakers. The survey was created by patients and research partners after recognizing that the simplified surveys often used by boards and lawmakers fail to capture the deeper context behind patient affordability challenges.

Our goal is to ensure that policy interventions, particularly those developed by Prescription Drug Affordability Boards (PDABs), are informed by the realities patients face in affording and accessing their medications.

Why We Conducted This Survey

Patients across the country have reported that the way affordability is currently assessed often does not reflect their lived experience. Common tools tend to ask yes/no questions about whether a single drug is “affordable,” without asking why a patient perceives it that way. This lack of qualitative insight can lead to affordability determinations and policy responses that do not address the underlying drivers of hardship.

To fill this gap, the Patient Inclusion Council worked with research partners and patient advocacy organizations to design a 51-question survey incorporating both quantitative measures (cost data, insurance status, assistance program usage) and qualitative responses (open-ended narratives to capture personal context behind the missing ‘why’ related to affordability and unaffordability.).

What We Learned

- 1. Affordability is personal, and it often is not directly correlated to drug price.**
Twenty percent of patients paying just \$0–\$10/month for their prescriptions still described their medications as unaffordable. But why? Because of insurance changes, copay accumulators, cumulative costs, low income, or fear that assistance might

disappear. Many thought of affordability in terms of overall medical costs, not their actual out-of-pocket costs for the prescription drug.

2. **“Unaffordable” often means inaccessible.** When patients labeled drugs unaffordable, they were often describing access issues, not cost alone. One hundred percent of patients who stopped taking a drug “due to affordability reasons” actually cited insurance barriers in the open-ended comments, like denials, step therapy, or being forced to switch off assistance. Seventy-five percent of those who skipped or stretched doses pointed to insurance-related delays.
3. **Insurance and copay assistance—not drug type or price—were the strongest predictors of affordability.** Among those taking specialty drugs, seventy-one percent with financial assistance said their medication was affordable, and eighty-eight percent of patients who reported paying \$0–\$10 per month used financial assistance. *No individual drug emerged as singularly creating hardship.*

Implications for PDAB Processes

Our findings demonstrate that focusing narrowly on the price of an individual drug will not address the full scope of patient affordability challenges. As a result, PDABs are creating reforms that fail to address the root causes of why patients struggle. Affordability reviews do not address the patient-identified reasons for being unable to access their needed medications and are unlikely to lower patient out-of-pocket costs.

Worse, affordability reviews that lead to the implementation of upper payment limits could worsen the existing barriers that patients face by increasing utilization management, delaying access, or forcing patients off the therapies that work best for them.

We recommend that the board:

- **Enhance patient engagement:** Incorporate in-depth, patient-led data collection, pairing quantitative data with qualitative narratives before and during affordability reviews to better direct board efforts, including which, if any, medications are posing affordability issues for patients.
- **Broaden definitions of affordability:** Include cumulative health-related costs, insurance barriers, and personal financial context in addition to drug price.
- **Co-design engagement with patient organizations:** Use patient-led listening sessions, focus groups, and surveys to capture unfiltered experiences, ensuring diverse participation and adequate representation of vulnerable populations to address patient-identified issues.
- **Assess downstream impacts of policies before implementation:** Engage insurers, PBMs, providers, and patients to anticipate how affordability policies may affect coverage, access, and continuity of care.



Invitation to Partner

We share the board's commitment to lowering prescription drug costs for residents of Maine. Achieving that goal requires a process that starts with and ends with patients—their lived experience, their real barriers, and addressing the challenges they report are the cause of affordability issues

We would welcome the opportunity to:

- Present the full survey findings to the board and advisory committees.
- Collaborate on designing improved patient engagement processes for future reviews.
- Support outreach to ensure meaningful and representative patient participation.

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,

A handwritten signature in cursive script, reading "Tiffany Westrich-Robertson".

Tiffany Westrich-Robertson

tiffany@aiarthritis.org

Ensuring Access through Collaborative Health (EACH) Coalition Lead

A handwritten signature in cursive script, reading "Vanessa Lathan".

Vanessa Lathan

vanessa@aiarthritis.org

Patient Inclusion Council (PIC) Coalition Lead

Attachments:

- *Patient Experience Survey: Prescription Drug Affordability and Unaffordability Report*
- *Policy Brief*