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Patient-Led Survey Reveals Insurance Barriers and Personal Factors Contribute Significantly to Patient Affordability Concerns

EACH/PIC Coalition Urges Policymakers to Better Identify and Address Patient Challenges

August 4, 2025 — The Ensuring Access through Collaborative Health and Patient Inclusion Council (EACH/PIC) has released the findings of its new report, [*Patient Experience Survey: Prescription Drug Affordability and Unaffordability*](#), which captures how patients and caregivers define and experience prescription drug affordability.

The results challenge conventional cost-review frameworks by showing that focusing on the affordability of individual drugs often misses critical patient context about patients' broader challenges. Policymakers risk overlooking the burdens that make medications inaccessible, including insurance design, cumulative healthcare costs, and complex personal circumstances.

The report highlights that affordability, as defined by patients, is not limited to drug price or out-of-pocket (OOP) costs. Rather, it reflects broader personal experiences, evolving circumstances, and individual interpretations. Results of the study indicate that insurance design, financial assistance, and the overall burden of managing chronic illness play a significant role in patient considerations of affordability.

The survey findings point to clear areas for policy reform to reduce financial stress, improve adherence, and better align affordability efforts with patient needs. A companion [policy brief](#) offers actionable recommendations.

Key findings include:

- **Affordability Is Deeply Personal and Often Subjective.** Survey responses indicate that affordability does not neatly correlate with income level or OOP drug costs. Instead, affordability hinges on each individual's unique life circumstances, health burdens, and financial responsibilities, including cumulative costs for all healthcare needs.
 - 20% of patients paying \$0-\$10 per month still reported their medications as unaffordable. Some reasons included insurance transitions, accumulators, low income levels, or high list prices.

- One patient described affordability not as a dollar amount, but as whether a cost could be managed “even after shifting around your budget.”
- **Perceived Affordability Often Reflects Broader Financial Anxiety.** Many patients labeled their medication as unaffordable even when reporting low monthly OOP costs, often due to factors beyond what they directly paid. Many affordability judgments are made in the context of systemic costs, current life situations, additional health costs, or anticipated future hardship, not just current medication costs.
 - Across various OOP cost levels, including those paying \$0-\$10 a month, several cited their cost ‘unaffordable’ based on list prices and not true OOP costs.
 - 77% of participants reported additional OOP medical costs for doctor visits, labs, imaging, or assistive devices—expenses that compound financial strain and influence perceptions of affordability.
- **Affordability and Access Are Often Intertwined.** When patients say a drug is “unaffordable,” they may be describing access problems caused by insurance barriers, not just financial strain. Access delays and insurance rules, not cost alone, are often the real barriers hidden behind “affordability” labels.
 - 100% of patients who said they stopped taking a drug due to affordability cited insurance-related reasons: denials, prior authorizations, step therapy, or exclusion of copay assistance on Medicare.
 - 75% of patients who skipped or stretched doses also reported at least one instance of care disruption due to insurance delays, not price.
 - Only 14% cited OOP drug cost alone as the reason for missed doses, and even these patients often had low costs.
- **Insurance and Financial Assistance Programs Shape Patient Perceptions of Affordability.** The strongest predictors of whether a patient found their medication affordable were the type of insurance they had and whether they had access to financial assistance programs. Insurance status and assistance program eligibility—not income or drug type—were often the decisive factors in whether patients felt they could afford their medications.
 - Among those taking specialty drugs, 71% with financial assistance said their medication was affordable. Only 38% without financial assistance felt the same.
 - Of those paying \$0-\$10 per month, 88% used financial assistance.
 - Patients on Medicare were disproportionately represented among those who paid \$250+ per month.

This survey was developed after patients recognized a serious disconnect between their real-world experiences and the results of short and overly simplified surveys used by affordability boards. The survey is the PIC’s first step towards gathering meaningful input from

patients and caregivers to identify real-world patient challenges and ensure that affordability efforts deliver real value to the people they are intended to help.

“Affordability isn’t a price tag—it’s a lived experience,” said Tiffany Westrich-Robertson, EACH/PIC Coalition Founder and a person living with axial spondyloarthritis who is treated with specialty medications. “When policymakers focus only on retail prices, they overlook the true experience of patients. We’re calling for policies that address the full scope of what makes medication inaccessible for patients.”

The survey report and accompanying [policy brief](#) identify core factors that shape patients’ ability to access and afford prescribed medications and outline clear areas for policy reforms to reduce financial strain on patients and ensure access to needed treatments. **Suggested reforms include:**

- **Expand Access to Financial Assistance Programs:** Expand and protect state and federal Patient Assistance Programs (PAPs) for individuals with low incomes, disabilities, or those who lack insurance coverage. Increase awareness and enrollment in manufacturer Copay Assistance Programs (CAPs).
- **Streamline and Protect Copay Support:** Ensure that copay assistance counts toward deductibles and out-of-pocket maximums.
- **Improve Insurance Processes:** Advance reforms to reduce administrative delays and denials that limit access to needed medications.
- **Address Underinsurance:** Many patients reported affordability challenges even when OOP costs for medications were relatively low due to other factors, including cumulative health costs.
- **Integrate Holistic Cost Management:** Expenses for lab work, imaging, specialist visits, and assistive devices all contribute to the perception and reality of financial burden.

“Only by correctly identifying patient needs can we ensure that policy remedies appropriately address critical issues and resolve patient barriers,” said Westrich-Robertson. “We urge policymakers to adopt a patient-centered approach that ensures health reforms are delivering real results for patients.”

The [Patient Experience Survey: Prescription Drug Affordability and Unaffordability](#) was executed by the PIC in partnership with patient research partners (PRPs), patient organizations, and a research consultant. The 51-question tool, based on 8 endpoints, captures quantitative and qualitative data. The survey was conducted between August and December 2024. The PIC plans to expand this research in the coming months to expand responses and improve diversity.

The [report](#), [policy brief](#), and [survey questions](#) can be found on the EACH/PIC Coalition website: www.eachpic.org.

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*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.*

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