

POLICY BRIEF



PATIENT EXPERIENCE SURVEY: PRESCRIPTION DRUG AFFORDABILITY AND UNAFFORDABILITY

DETERMINANTS OF AFFORDABILITY: WHAT PATIENTS SAY MATTERS MOST

After recognizing a serious disconnect between their real-world experiences and the results of short and overly simplified surveys, the Patient Inclusion Council (PIC) created the Prescription Drug Affordability—Patient & Caregiver Survey.

Through this survey, patients identified the core factors that shape their ability to access and afford prescribed medications—**factors that are often overlooked in traditional affordability reviews.**

Insurance Design and Disruptions Shape Affordability

Insurance coverage—or the lack of it—was one of the most frequently cited reasons behind affordability challenges. Patients pointed to coverage denials, prior authorizations, step therapy, and insurance changes as major barriers to staying on necessary medications.

- 100% of patients who stopped taking a medication due to affordability described insurance-related reasons, not personal financial strain.
- 75% of those who skipped or stretched doses reported insurance delays like reauthorizations or plan restrictions.

Financial Assistance Programs Make the Difference

Patients who had access to manufacturer copay assistance or patient assistance programs overwhelmingly reported their medications as affordable, regardless of the drug's retail cost.

- Among patients on specialty drugs:
 - 71% with financial assistance said their medication was affordable.
 - Only 38% of those without financial assistance said the same.
- Of patients paying \$0–\$10/month, 88% used financial assistance.

Total Health Costs Matter, Not Just an Individual Drug

Even when one drug's OOP cost was low, many patients reported affordability challenges due to the cumulative burden of managing chronic disease.

- 77% of respondents reported additional out-of-pocket expenses, most commonly for doctor visits (81%), procedures (71%), and imaging (60%)
- Some respondents noted that costs from other prescriptions, medical devices, or care needs pushed them beyond what they could afford.

WHAT PATIENTS NEED: NEXT STEPS FOR POLICYMAKERS

These patient-identified factors represent clear opportunities for policymakers to have the greatest impact for patients by reducing financial strain and ensuring access to the treatments patients need.

The following recommendations reflect the needs and priorities that patients identified through the survey:

Improve Patient Support Programs

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.

Those administering patient programs should also simplify application processes and ensure patients are aware of available resources through public education campaigns that include outreach to healthcare providers.

Streamline and Protect Copay Support: Ensure that copay assistance counts toward deductibles and out-of-pocket maximums. Patients facing accumulator policies, where assistance doesn't apply to insurance cost-sharing, frequently reported affordability challenges, even when their monthly cost appeared low.

Reform Patient-Identified Barriers

Improve Insurance Processes: Advance reforms to reduce administrative delays and denials that limit access to needed medications. Patients repeatedly cited prior authorizations, step therapy, non-medical switching, and refill delays as key drivers of medication adherence and affordability strain.

Address Underinsurance: Recognize that being insured does not guarantee affordability. Many patients reported affordability challenges even when OOP costs for medications were relatively low due to other factors and cumulative health costs.

Integrate Holistic Cost Management: Affordability must be considered in the full context of chronic disease management. For many patients, drug costs are only one part of the financial picture. Expenses for lab work, imaging, specialist visits, and assistive devices all contribute to the perception and reality of financial burden.

By adopting a patient-centered approach that reflects these realities, policymakers can advance reforms that improve access, reduce harm, and ensure that affordability efforts deliver real value to the people they are intended to help.



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.

The EACH/PIC Coalition aims to be a primary resource of information to help policymakers and advocates alike navigate the government drug affordability review process and address real patient issues.

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