

**PATIENT EXPERIENCE PROJECT:
PATIENT-REPORTED AFFORDABILITY &
UNAFFORDABILITY SURVEY 2.0**



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**KEY FINDINGS AND
POLICY
RECOMMENDATIONS**

KEY FINDINGS

By focusing on the affordability of a single prescription drug, decision-makers miss critical context about patients' broader challenges. Our survey set out to fill that gap, clearly understand the reasons patients consider their drugs unaffordable, and most importantly, determine how to solve patient-identified problems.

Patients experience affordability as the ability to keep taking the medication that works for them without it overwhelming their overall finances, not simply as the price of a drug. Survey responses show that insurance rules and whether financial assistance is applied consistently often determine whether patients can maintain access over time.

Policies that address these insurance-driven barriers and protect access to effective, preferred treatments are therefore more likely to reduce patient hardship than approaches focused only on drug price.

1. CONTEXT IS CRITICAL TO UNDERSTANDING PATIENT-REPORTED AFFORDABILITY

Patients broadly defined affordability as **“the ability to consistently obtain medications within *their essential* monthly household budget, considering income, total healthcare costs, and life circumstances.”**

Affordability thresholds were subjective. Out of 197 patients, responses about a threshold for unaffordability ranged from "anything over \$0" (low/fixed income respondents) to \$100+ (exclusively among those with household incomes >\$100,000).

Drug price alone does not determine affordability. Confirming findings from the pilot survey, insurance barriers, high cumulative medication costs, perspectives on how much medication should cost, and evolving life experiences were all primary drivers of reporting a drug as unaffordable.

Affordability shifted even among the same respondents due to changing out of pocket costs. Of 537 responses, 41% (221 people) reported paying more than one price for their drug at some point in time. Shifting out-of-pocket (OOP) costs (“OOP cost shifting”) contributed to 51% of those respondents reporting one drug as affordable and unaffordable at different points in time (“affordability shifting”).

Hardships were not directly linked to affordability. Patients reported hardships at every income level, but 56% still reported their drugs as affordable, and 47% linked hardship to cumulative OOP drug costs.

Efforts to improve health equity must focus on patient-reported hardships. Patients 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 and at a similar rate for brand-name drugs. *This highlights other findings that patients may not aware of financial assistance plans for specialty medications that often make prescriptions affordable.*

Affordability is not defined by price alone, but by how medication costs fit within a patient's overall financial reality and essential budget. Patient-centered affordability assessments, grounded in reported experiences, are essential to understanding these dynamics.

Policies that address insurance barriers and protect access to effective, preferred treatments are more likely to reduce patient hardship than strategies focused solely on lowering drug prices.

KEY FINDINGS – CONT'D

2. INSURANCE IS A KEY DETERMINANT OF PATIENT AFFORDABILITY AND ACCESS

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 OOP costs even with insurance.

No single drug emerged or can emerge as causing broad patient affordability challenges due to volatile cost-sharing inconsistencies.

- 51% of patients whose OOP costs changed for the same drug reported their drug as being affordable at one point and unaffordable at a different point (affordability shifting).
- 55% of patients whose OOP costs changed for the same drug reported OOP cost shifting between three or more ranges, with 15% reporting ranges between \$0-\$10 and \$1001+. As a result, many lost access to their treatment (access shifting).

Delayed or denied financial assistance leads to affordability challenges. Patients reported the inability to apply financial assistance to offset drug costs due to insurance rules as a contributor to unaffordability. In contrast, 71% of patients stated financial assistance was the reason why their medication was affordable.

To meaningfully reduce patient hardship, health reforms must move beyond drug price controls and directly address insurance-driven instability—including coverage decisions, cost-sharing variability, and restrictions on the use of financial assistance—that create shifting costs and disrupt patients' access to effective treatments.

3. 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.

Patient-reported value is highly individualized. For the same drug, different respondents found the drug to be “life-changing” while others reported it as ineffective, underscoring that treatment value cannot be generalized.

- Reasons for value included fewer side effects; other medications not working as well or having stopped working; easier administration (e.g., pill versus injection); a unique characteristic that better suited the patient; and better management of comorbidities.

Drugs are not interchangeable. Among 60 patients with rheumatoid arthritis:

- 82% cycled through multiple medications,
- 49% had comorbidities affecting treatment choice.

Non-medical switching caused patient harm. Patients reported 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.

PATIENT-DRIVEN REFORMS: RECOMMENDATIONS FOR POLICYMAKERS

To truly improve prescription drug affordability, policymakers must move beyond narrow definitions of cost and center reforms on the lived experiences of patients. Affordability is not just a matter of price. It is shaped by insurance design, access to support programs, system complexity, and the individual needs of each patient. The following recommendations reflect the needs and priorities that patients identified through the survey:

MAKE PATIENT COSTS MANAGEABLE AND PREDICTABLE

- **Directly Address Patient Costs:** Limit patient cost exposure through caps on out-of-pocket spending, lower deductibles, reasonable annual maximums, and limits on premium increases tied to inflation. These protections help ensure patients can anticipate and plan for their medication costs rather than face sudden or unmanageable expenses.
- **Implement Cost-Smoothing or Payment Plans:** Allow patients to spread out-of-pocket costs evenly over the course of the year instead of concentrating expenses at the beginning of coverage periods. Cost-smoothing mechanisms can reduce financial shock, improve adherence, and support continuity of care for patients managing chronic conditions.

PROVIDE SUPPORT TO AVOID CATASTROPHIC COSTS

- **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 for those commercially insured.
 - Those administering patient financial assistance 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.

ADDRESS STRUCTURAL DESIGNS THAT CAUSE HARDSHIP

- **Protect Patients from Harmful Utilization Management Practices:** Insurance practices intended to manage costs should not disrupt care or destabilize patients who are doing well on their current treatment. Policymakers should limit non-medical switching for long-term treatments, require clear and timely appeals processes for coverage denials, and increase oversight by requiring disclosure of formulary changes, prior authorization, and step therapy requirements.
- **Align Incentives Within the Healthcare Marketplace:** Affordability reforms should address misaligned incentives that drive up patient costs without improving care. This includes prohibiting spread pricing, replacing percentage-based Pharmacy Benefit Manager (PBM) compensation with flat-fee service models, ensuring negotiated rebates and discounts are passed to patients, and increasing transparency around PBM contracts, rebate flows, and formulary design.

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.

CAPTURING PATIENT EXPERIENCES TO DRIVE BETTER POLICY SOLUTIONS

To create truly effective drug affordability policies, decision-makers must start by understanding how patients define and experience affordability. These insights will be shared with policymakers, affordability review boards, and stakeholder councils to support smarter, more equitable solutions.

IMPROVE PATIENT ENGAGEMENT

Create Spaces for Dialogue: Surveys alone aren't enough. Patient insights should also be gleaned from direct conversations through roundtables, listening sessions, or moderated discussions, which allow for deeper exploration of policy barriers in real-world terms.

Partner with Patient Organizations and Patient Research Partners (PRPs): Design, collect, and analyze patient data using proven, transparent methods that capture meaningful context behind affordability experiences. Leveraging these partnerships can address past limitations in survey design, improve outreach and participation, and provide the Board with unbiased, real-world patient insights despite staff time and budget constraints.

Clearly Define Affordability Determinants and Intended Reform Outcomes: Prior to reviews, how affordability will be defined and who will benefit from policy changes should be clearly determined, tested for efficacy, and disclosed to patients. Post engagement, participants should be provided a report explaining how their input was incorporated and informed decision-making processes. Further, reforms should be monitored closely in to determine any impact on patient access to treatments.

IMPROVE DATA COLLECTION

Build Better Surveys: Traditional surveys rely heavily on yes/no or multiple-choice questions, missing the depth behind a patient's answer. Both the original PIC pilot survey and this updated version showed the power of pairing quantitative data with qualitative context, giving patients space to explain how insurance, health status, and financial strain shape what feels "affordable." Furthermore, open-ended responses capture missing context that helps identify not only that a person reports an OOP cost as affordable or unaffordable, but also can identify the driver behind it.

Incorporate Patient-Defined Affordability and Known Drivers of Affordability Challenges: Use the PIC's patient-informed definition of affordability that accounts for individual financial circumstances, cumulative health-related expenses, and changing life events. Affordability reporting should distinguish between retail price, OOP costs, and perceived burden.

Understand the Full Patient Experience: Data collection efforts should be guided by clear endpoints and include questions on diagnosis and treatment history, out-of-pocket spending for the entirety of prescription use, financial trade-offs and perceptions of affordability, and barriers to adherence (e.g., delays, switching, denials). Those analyzing the data should have a clearer understanding of drivers, the *why* a person reports their drug affordable or unaffordable at any given point in time. Follow-up questions to clarify drivers behind OOP costs and affordability (i.e., insurance type, why they discontinued or never used a drug past cost alone), should also be implemented when able.

Align Data with Decision-Making Authority: Policymakers should ensure that the data they collect and analyze is directly relevant to the programs and policies within their jurisdiction. When data reflects programs outside of that scope, such as Medicare at the state level, it should not be used to justify policy decisions that state agencies cannot implement. Instead, that information should be clearly separated in analyses, with the understanding that different programs often serve different populations, operate under different rules, and face distinct challenges.



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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