

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



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PUTTING PATIENT VOICES FRONT AND CENTER

The work of policymakers must be centered on the real-world challenges patients face in affording and accessing their prescribed medications. Meaningful input from patients and caregivers is critical to ensuring that policy remedies appropriately address patient needs.

Background. We are dedicated to helping ensure price-setting policies are guided by patient-reported hardships. The Patient Inclusion Council (PIC), led by patients and patient organizations, supports efforts to improve drug affordability, but remains concerned that many current approaches overlook critical patient realities and fail to capture the deeper context behind *why* patients experience medications as affordable or unaffordable. **Processes that do not first consider patient-reported unaffordability drivers - the “why” behind affordability challenges - will fail to meaningfully incorporate the perspectives of the patients most affected by challenges and solutions will remain focused on benefitting others.**

Rationale. In 2024-2025, the PIC designed and published results of the [Patient Experience Survey: Prescription Drug Affordability and Unaffordability](#) pilot project, an effort that originated after patients recognized a serious disconnect between their real-world experiences and the results of simplified surveys used during affordability reviews. More specifically, they cautioned that without directly listening to patients and capturing the “why” behind affordability challenges, policy and programmatic solutions may focus on the state and healthcare system benefits, rather than helping patients.

To confirm the pilot’s findings central conclusion that affordability does not directly align with drug price, and to better understand the underlying drivers of patient-reported affordability challenges, the PIC expanded this effort to a broader and more diverse audience.

Methods. Drawing on lessons learned in the pilot and in preparation for a broader audience, patient representatives from the PIC, AiArthritis (International Foundation for Autoimmune & Autoinflammatory Arthritis), and a data scientist developed a shorter, more focused survey instrument. The goals were to reduce completion time, lower respondent burden, and increase participation while preserving analytic depth.

Study endpoints.

- Diagnosis and Comorbidities
- Prescription Drug Usage (current, past, never used) and reasons for discontinuation
- Out-of-pocket costs (1 prescription per survey)
- Patient-reported “affordability” assessment (“the why” a drug is affordable or unaffordable)*
 - Barriers: insurance coverage, cost, financial assistance, lifestyle circumstances, hardships*
 - **Definition of affordability and associated patient-identified affordability threshold**
- **Prescription Drug Value**
 - **Impact/value of this drug**
 - **Therapeutic Alternatives (if there are multiple drug options, does this drug have more value to you than others? If so, why?)**

*Captured in open-ended responses. Endpoints added to the original pilot endpoints are **bolded**.

Distribution and Targeted Participation. Like the original survey, the update was distributed through advocacy networks and word-of-mouth. For this iteration, we focused on soliciting responses from individuals with conditions that were likely to be treated by specialty and high-cost medications and who resided in states with an active Prescription Drug Affordability Review Board (PDAB) or states considering establishing one (Colorado, Maryland, Minnesota, New Jersey, and Washington, Virginia). To ensure a sufficiently large and analytically robust sample we also solicited paid responses using SurveyMonkey Audience.

See Appendix for details related to methodology, survey questions and changes from the pilot, and initial Patient Research Partner survey design analysis and recommendations that, after being dismissed, ultimately led to our studies.

**PATIENT EXPERIENCE PROJECT:
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UNAFFORDABILITY SURVEY 2.0**

**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.

**PATIENT EXPERIENCE SURVEY:
PRESCRIPTION DRUG AFFORDABILITY
AND UNAFFORDABILITY**

**RESPONDENT
DEMOGRAPHICS**

POPULATION SNAPSHOT

Of our initial 982 responses, 537 were analyzed after removing incomplete and duplicate responses from 445 respondents.

537
PATIENTS

225
DRUGS

94
DIAGNOSES

88%
COMORBIDITIES

453 of the 537 participants reported being diagnosed with one or more additional conditions (comorbidity).

COMPARING PAID AND UNPAID RESPONDENTS

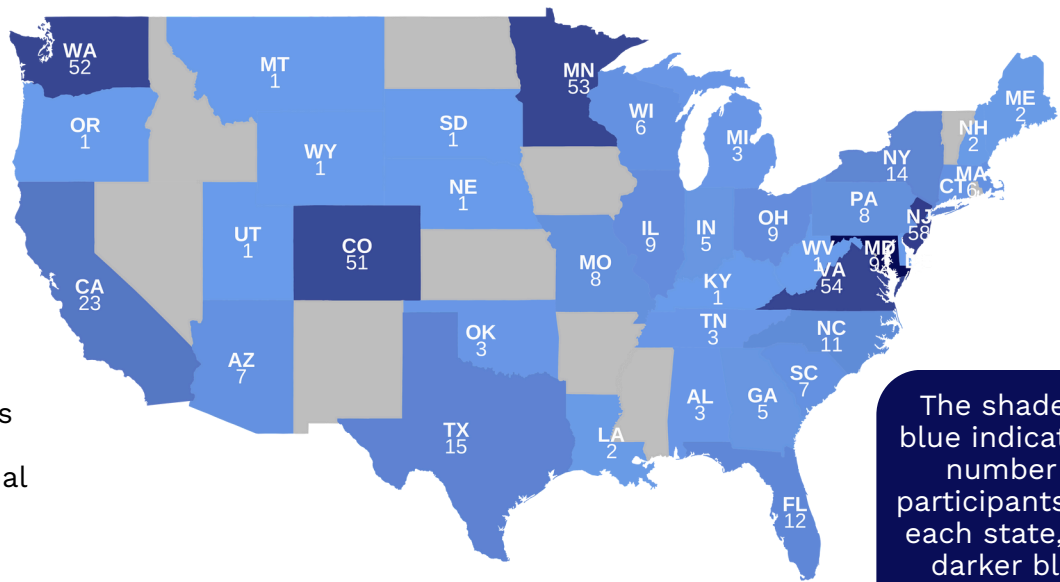
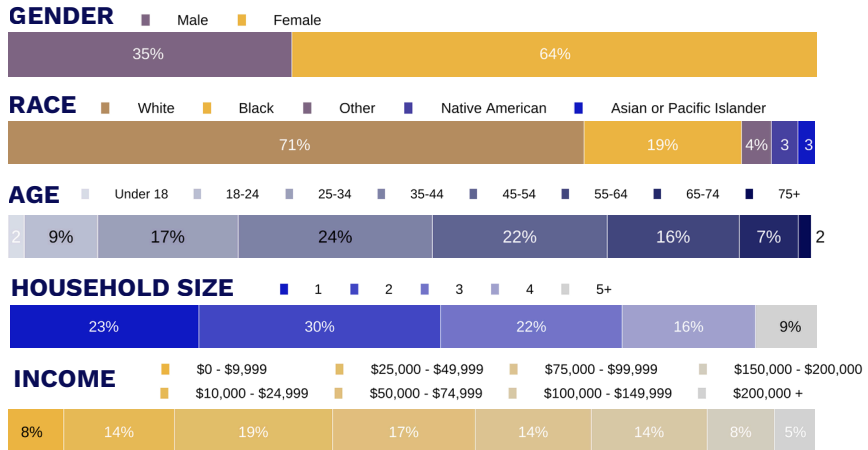
Survey responses came from paid participants and unpaid volunteers (often recruited through patient advocacy organizations).

Key demographic differences between the groups included:

- **Geographic Distribution:** Unpaid respondents represented 38 U.S. states and Washington, D.C.; we targeted paid respondents in just six states (Colorado, Maryland, Minnesota, New Jersey, Virginia, and Washington), which resulted in the highest overall participation rates.
- **Gender:** Unpaid respondents were overwhelmingly female; paid respondents had a balanced gender distribution.
- **Race:** Unpaid respondents were disproportionately white; paid respondents better reflected national demographic trends.

Overall, paid respondents strengthen generalizability by including men, racially diverse communities, and middle-income families, groups underrepresented among volunteers.

PATIENT DEMOGRAPHICS



The shades of blue indicate the number of participants from each state, with darker blues representing more respondents.

PATIENTS' PRESCRIPTIONS

Drugs were categorized as Specialty (biologics, biosimilars, GLP-1s, high-cost therapies), Brand, or Generic. Prescription medications also available over the counter (reported by x people) were included with generics based on similar insurance tiering.



MOST COMMON DRUGS

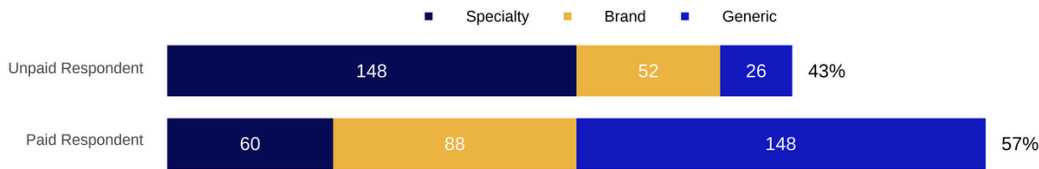
SPECIALTY
Adalimumab (Humira) – 23
Semaglutide (Ozempic) – 14

BRAND
Glucophage (Metformin) – 34
Apixaban (Eliquis) – 10

GENERIC
Albuterol – 30
Prednisone – 8

DRUG TYPE REPORTED BY PAID AND UNPAID RESPONDENTS

Percent (number) of paid or unpaid respondents reporting each drug type



Total Responses: 522

66% of **unpaid respondents** reported on **specialty drugs** while just 12% reported on generics. By contrast, 50% of **paid respondents** reported on generics, while only **20%** reported on **specialty drugs**.

Using paid survey services allowed us to diversify respondents that better represent the real world population. In doing so, findings indicate that prescription affordability is much broader than those commonly selected for affordability reviews. This suggests that broader health reforms would be more effective at addressing the needs of more patients.

RACIAL DIFFERENCES IN PRESCRIPTION DRUG ACCESS

Known systemic biases in healthcare and prescription drug access lower rates of access to and utilization of specialty drugs for people of color*. Our results reflect this pattern:

- **40%** (127 respondents) of **non-Hispanic white patients reported on specialty drugs** versus **55%** (174 respondents) reporting on **brand or generic drugs**.
- In contrast, only **28%** (49 respondents) of **patients of color reported on specialty drugs** versus **71%** (124 respondents) reporting on **brand or generic drugs**.

In our survey, 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.

* <https://pubmed.ncbi.nlm.nih.gov/38174355/>

* <https://www.kff.org/racial-equity-and-health-policy/racial-and-ethnic-disparities-in-access-to-medical-advancements-and-technologies/>

* <https://intercept.health/insights/blog/understanding-specialty-drugs-and-their-impact-on-health-plans/>

**PATIENT EXPERIENCE SURVEY:
PRESCRIPTION DRUG AFFORDABILITY
AND UNAFFORDABILITY**

SURVEY RESULTS

DECISIONS MADE FOR PATIENTS MUST BE GUIDED BY PATIENT-DEFINED "AFFORDABILITY"

Prescription drug affordability reviews have been underway since 2023, yet there is still no consensus on what "affordable" means to patients, where the line between affordability and unaffordability falls, or how patients make that distinction. These results will help shape a better patient-centered understanding of "affordability."

PATIENT-CENTERED DEFINITION OF AFFORDABILITY

"The ability to consistently obtain medications within my essential monthly household budget, considering income, total healthcare costs, and life circumstances."

We asked, **"What does affordability mean to you? How would you define it for people deciding if your medication is affordable or unaffordable for you?"** Qualitative analysis and topic modeling of 191 responses revealed key themes in patients' responses. The following concepts lend themselves to our patient-centered definition of affordability:

The ability to meet basic needs within a household budget

- Most respondents defined affordability as any amount that would impact their monthly essential budget (i.e., food, housing, utilities, internet).
- Others expanded the threshold to include any amount that would impact their monthly discretionary budget (i.e., entertainment, bills related to lifestyle preferences).
- One person with chronic illness said medications are included in an essential budget.

Affordability relative to income and price

- Income commonly influenced how patients defined affordability. Several cited *"income at the time."* One said, *"This is not a one-size-fits-all-answer. [Affordability] is a moving target."*
- Many people mentioned OOP cost affordability depends on how many medications taken per month and broader healthcare cost considerations (i.e., copays, deductibles, and doctor visits).

The ability to sustain monthly medication costs over time

- Some patients included the ability to save for the future (i.e., college funds, retirement).
- Others mentioned the cost cannot cause them to live outside of their means (i.e., use existing savings or credit cards).

DETERMINING AN OOP COST THRESHOLD

In a further attempt to define affordability in terms of price alone, we asked respondents to identify an OOP amount that would be affordable when filling one prescription. Based on 197 respondents:

- Any amount **between \$0-\$50 OOP per month** per prescription was broadly perceived as manageable across income levels. *However, there were still outliers:*
 - *"Anything over \$0 is unaffordable."*
 - 10% (19 respondents) considered had a threshold of \$100+ OOP as affordable. All of these respondents reported household incomes >\$100k.
- **When a drug was perceived as high value, the OOP amount they considered affordable increased.** Several people noted that a medication's importance to maintaining their health shaped how they defined affordability: *("\$100-\$150 co-pay monthly is affordable for this type of drug.")*.

Overall, **no single price emerged as a threshold for (un)affordability** because answers were based on personal situations at a specific moment in time (i.e., *"this is my maximum OOP cost... right now"*). Most drugs, including those universally classified as affordable, showed substantial cost variation across patients and for the same patient over time. **These patterns indicate that searching for a universal affordability threshold, rather than patient-reported context, misstates how affordability is actually experienced.**

CONTEXT IS CRITICAL TO UNDERSTANDING PATIENT-REPORTED AFFORDABILITY

Many patient-facing surveys assessing prescription drug affordability fail to capture the context behind patients' experiences. To address this gap and better align policy efforts with patients' most pressing needs, we asked:

- Thinking of the **last time** you took [drug], what was the monthly out-of-pocket cost you paid?
- Thinking of your **most recent monthly out of pocket cost** for [drug], do you consider this affordable or unaffordable?
- Based on your previous answer, explain in detail why you reported the out of pocket cost(s) of [drug] affordable or unaffordable.

69% AFFORDABLE

31% UNAFFORDABLE

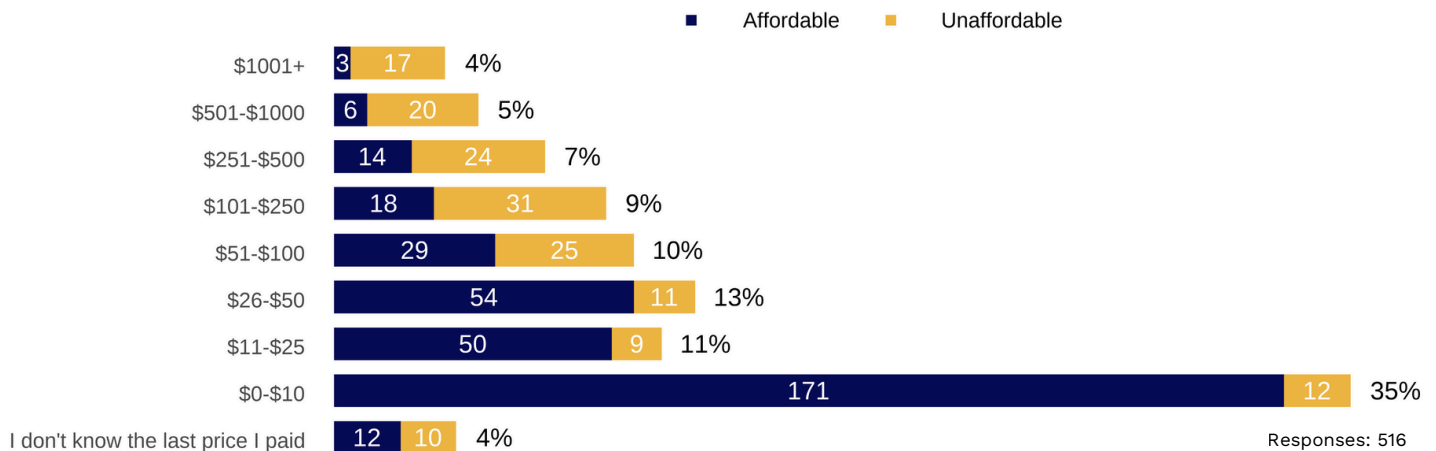
69% of patients (357 respondents) reported their medication as affordable, while **31%** (159 respondents) reported their medication as unaffordable.

BUT WHY?

As with our pilot study, some patients at every price point struggle with the cost of their medication due to **insurance barriers, high cumulative medication costs, evolving life experiences, and perspectives on how much medication should cost**. Additionally, our results confirmed that while patients who pay more for their drugs are more likely to say those drugs are unaffordable, **affordability does not solely align with drug price.**

AFFORDABILITY BY MOST RECENT OOP DRUG COST

Percent (number) of patients who report their medication is affordable/unaffordable by monthly drug cost



Our expanded research also showed a substantial number of patients struggle with access at some times, but not at other times, if they have paid multiple prices for the same drug over time. This unfolded as a result of also asking those reporting multiple prices over time if those OOP costs were affordable or unaffordable and why. Here's what we found:

31% (160 patients) reported their medication as **currently unaffordable**. Of those, **41%** (90 respondents) paid multiple OOP costs for the same drug over time ("**OOP cost shifting**") and **57%** (51 of those 90) **also reported this drug was affordable at some other point in time ("affordability shifting").**

Asking about the affordability of one prescription drug, and solely considering the OOP cost associated with a snapshot in time, decision-makers overlook critical information and drivers behind patient prescription access and affordability challenges.

INDIVIDUALS REPORTING PAYING \$0-\$10 PER MONTH

35% (183 people) of survey respondents (537 people) reported paying \$0-\$10 OOP **the last time** they took the prescription drug (76 specialty, 47 brand, 57 generic, 3 unspecified).

93%

7%

93% (171 people) reported this amount was **affordable**.
7% (12 people) reported this OOP drug cost was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT UNAFFORDABLE?

- **Insurance barriers.** 58% (7 of 12 respondents) reported the prescription was affordable under a different insurance plan. 17% of them (2 respondents) reported paying \$0-\$10 once they received financial assistance and only after meeting high deductibles or paying high copays or coinsurance, resulting in credit card debt.
- **Cumulative costs and healthcare burdens.** 42% (5 respondents) cited cumulative medication costs (1), non-drug healthcare costs (including MRIs, CT scans) (1), and insurance premiums (3), as contributing to financial strain.
- **Life transitions and income strain.** 50% (6 respondents) reported job loss, retirement, or insurance transitions creating temporary periods of unaffordability, leading to debt or medication rationing. Two respondents (one on unemployment and one on a fixed income (SSDI)) explicitly cited their income as the primary driver of their unaffordability.
 - 50% (6 respondents) earned under \$25,000 annually.
- **Opinions on drug costs.** 33% (4 respondents) cited concerns unrelated to their actual OOP costs, including the perception that medications would cost hundreds to thousands of dollars without financial assistance.

*“Just because a drug is affordable NOW, it can easily become unaffordable when a person's **circumstances change**.” - Specialty Drug for Psoriatic Arthritis - Employer Insurance - “Affordable”*

*“My out of pocket **cost varies greatly** throughout the year based on if I have met my **health insurance maximum out of pocket annual expense**. At the beginning of the year I have to pay up to \$2,000...I have gone into credit card debt in years.” - Specialty Drug for Rheumatoid Arthritis - Individual Insurance - “Affordable”*

*“**After 3 denials and a lot of paperwork** I was finally approved by my insurance company and for the drug company bridge program! But **most people would have given up**.” - Specialty Drug for Rheumatoid Arthritis - Individual Insurance - “Affordable”*

INDIVIDUALS REPORTING PAYING \$11-\$25 PER MONTH

11% (59 people) of survey respondents (537 people) reported they paid between \$11-25 OOP **the last time** they took the prescription drug (12 specialty, 14 brand, 30 generic, 3 unspecified).

85%

15%

85% (50 people) reported this amount was **affordable**.
15% (9 people) reported this amount was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT UNAFFORDABLE?

- **Insurance barriers.** 67% (6 respondents) reported their insurance did not cover the prescription or changed copay requirements, making a previously affordable drug unaffordable. One respondent identified insurance quantity limits on the number of pills covered per month as contributing to higher OOP costs.
- **Cumulative costs and healthcare burdens.** 22% (2 respondents) reported affordability challenges due to the combined cost of multiple medications.
- **Life transitions and income strain.** 44% (4 respondents) cited job loss, disability (or SSDI), retirement, or household income changes (e.g., spouse job loss or pregnancy), alongside rising costs of living and broader medical expenses, as drivers of unaffordability.
 - 44% (4 respondents) reported annual incomes under \$25,000.

*"I take multiple prescriptions every month and **sometimes** when my prior authorization expires I have to pay out of pocket costs which can equal hundreds of dollars." - Specialty Drug for Crohn's Disease- Employer Insurance - "Affordable"*

*"Compared to other prescriptions, this one is higher... **money is getting tighter each day and having to decide where to cut costs is hard.**" - Over-the-Counter Drug for Allergies (coded as Generic for the purposes of this survey) - Employer Insurance - "Unaffordable"*

*"I had to go without Ozempic then couldn't start Mounjaro for about two years until **I finally qualified for my employer subsidized health insurance.** I think for people without a job or those who can't afford a high monthly premium, the cost is impossible." - Specialty Drug for Type 2 Diabetes - Employer Insurance - "Affordable"*

INDIVIDUALS REPORTING PAYING \$26-\$50 PER MONTH

13% (65 people) of survey respondents (537 people) reported they paid between \$26-\$50 OOP **the last time** they took the prescription drug (15 specialty, 19 brand, 28 generic, 3 unspecified).

83%

17%

83% (54 people) reported this amount was **affordable**.
17% (11 people) reported this amount was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT UNAFFORDABLE?

- **Cumulative costs and healthcare burdens.** 27% (3 respondents) reported that prescription costs were unaffordable when combined with other medications and healthcare expenses.
 - One person taking Ubrelvy for migraines mentioned insurance only covered 10 tablets per 30 days/6 refills per year and that they were allergic to the alternatives. Another cited frequent purchases of over-the-counter Excedrin Migraine contributing to cumulative costs.
- **Life transitions, income strain.** 27% (3 respondents) reported job or insurance loss, insufficient or reduced income, and rising non-medical expenses (e.g., rent, food, household bills, caregiving costs) as key contributors to unaffordability.

*“Even with insurance \$35-\$50 a month is expensive when you take **multiple meds.**” - Brand Name Drug for ADHD - Employer Insurance - “Unaffordable”*

*“Due to **job loss** even \$50 a month was hard for me to afford when we barely had enough to pay rent.” - Specialty Drug for Diabetes - Veterans’ Assistance - “Unaffordable”*

*“I’m being **denied insurance coverage** (limited to 6 fills/year and 10 tablets/30 days) with Navitus. Therefore I will have to pay out of pocket somewhere between \$950-1500 for one refill or 10 tablets.” - Specialty Drug for Migraine - Employer Insurance - “Affordable”*

INDIVIDUALS REPORTING PAYING \$51-\$100 PER MONTH

10% (54 people) of survey respondents (537 people) reported they paid between \$51-\$100 OOP **the last time** they took the prescription drug (16 specialty, 8 brand, 24 generic, 6 unspecified).

54%

46%

54% (29 people) reported this amount was **affordable**.
46% (25 people) reported this amount was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT UNAFFORDABLE?

- **Insurance barriers.** 32% (8 respondents) reported affordability challenges driven by insurance design, including high premiums or deductibles that resulted in near-full-price payments despite coverage, as well as repeated prior authorization requirements that increased OOP costs during approval delays.
- **Coverage limitations by dosage or pharmacy.** 16% (4 respondents) reported that insurance or specialty pharmacy coverage varied by dosage, requiring 90 day refills or insurance only covering higher doses than needed.
- **Cumulative costs and healthcare burdens.** 8% (2 respondents) reported that the need to take multiple medications caused costs to accumulate quickly, making the prescription unaffordable when combined with other ongoing drug expenses.
- **Life transitions and income strain.** 56% (14 respondents) cited employment changes and variable income as contributing to periods of unaffordability, compounded by broader real-world constraints, such as rent, utilities, groceries, and existing debt.
 - 52% (13 respondents) specifically cited **limited or fixed income** as a primary factor in affordability challenges at this OOP level.

*“My **Medicare Advantage Plan only covers the higher dosage of this drug**. This requires me to get this drug compounded resulting in my having to pay full price out of pocket and it’s a hardship on retirement benefits and Medicare.” - Generic Drug for Fibromyalgia - Medicare - “Unaffordable”*

*“Like most freelance jobs, [it] **doesn’t provide steady or significant income**. Often I have to choose between a refill and bills and regularly put off refilling my nerivio until I receive a larger paycheck that allows me to have leftover funds after bills to afford it.” - Brand Drug for Migraine - Medicaid - “Unaffordable”*

*“I used a **manufacturer’s card...which further brought the cost down to \$15 for each of my first 2 doses**. However my most recent refill was \$59.96. I don’t know the reason for this change but **I’m concerned that the manufacturer’s discount card might have reached a limit of what it will cover**.” - Specialty Drug for Migraine - Individual Insurance - “Affordable”*

INDIVIDUALS REPORTING PAYING \$101-\$250 PER MONTH

9% (49 people) of survey respondents (537 people) reported they paid between \$101-\$250 OOP **the last time** they took the prescription drug (16 specialty, 23 brand, 10 generic).

37%

63%

37% (18 people) reported this amount was **affordable**.
63% (31 people) reported this amount was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT UNAFFORDABLE?

- **Insurance barriers.** 39% (12 respondents) reported affordability challenges driven by insurance design, including high premiums, deductibles, OOP maximums, and difficulty getting their prescription covered and reimbursed through their plan.
- **Access to financial assistance.** 16% (5 respondents) cited issues with copay or patient assistance programs, including assistance not counting toward deductibles or OOP maximums, or program elimination (Medicare). One cited insurer delays in applying assistance.
- **Cumulative costs and healthcare burdens.** 19% (6 respondents) reported the cumulative OOP costs of their medications causes affordability challenges.
- **Life transitions and income strain.** Some respondents reported that disability, reduced ability to work, low income (including 4 incomes under \$25,000 annually), and rising costs of living (i.e., groceries, utilities) and non-prescription costs (i.e., surgery) contributed to unaffordability.
- **Opinions on drug costs.** 19% (6 respondents) cited perceptions that drug prices were “excessive” or “overpriced,” independent of their OOP cost.

*“I could not start Rinvoq for 3 months **due to the lengthy process of patient assistance and my primary insurance requires patients pay out-of-pocket 100% and then are reimbursed a fraction of that cost.** Under patient assistance this medicine cost five dollars a day.” - Rinvoq, a Specialty Drug for Rheumatoid Arthritis - Employer Insurance, “Affordable”*

“For my income range being completely disabled by Lupus and unable to work, the cost of this prescription is not sustainable. Some months it’s a choice between having food or electricity or having the Plaquenil prescription.” - Plaquenil, a Brand Name Drug for Lupus - Employer Insurance - “Unaffordable”

“It’s not just about the affordability of one drug. It’s about the affordability of all medications and monthly healthcare premiums.” - Simponi, a Specialty Drug for Rheumatoid Arthritis - Employer Insurance - “Unaffordable”

INDIVIDUALS REPORTING PAYING \$251-\$500 PER MONTH

7% (38 people) of respondents (537 people) reported they paid \$251-\$500 OOP **the last time** they took the prescription drug (16 specialty, 12 brand, 10 generic).

37%

63%

37% (14 people) reported this amount was **affordable**.
63% (24 people) reported this amount was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT UNAFFORDABLE?

- **Insurance barriers.** 50% of respondents (12 people) cited insurance-related challenges, including high deductible health plans (4 respondents) and partial prescription coverage even after meeting deductibles, still leaving medications unaffordable.
 - An additional two respondents reported insurance coverage changes, including one plan removing coverage entirely.
- **Brand drug access.** Two people reported higher costs due to insurance refusal to cover brand-name drugs, even after a doctor appeal claiming medical necessity.
- **Access to or insufficient financial assistance.** Two respondents (8%) reported losing access to patient assistance – one due to manufacturer eligibility changes, and one due to Medicare restrictions. An additional respondent (4%) on a biosimilar for Rheumatoid Arthritis, cited infusion debt “even with patient assistance funds.”
- **Cumulative costs and healthcare burdens.** 25% of respondents (6 people) reported that the combined cost of multiple prescriptions or therapies made their primary medication unaffordable.
- **Evolving life situations and income strain.** Two respondents (8%) cited insurance changes (i.e., employer switching providers, company layoff) including one relying on COBRA with high monthly premiums and OOP prescriptions costs.
 - 21% (5 people) cited low or fixed income, disability, or retirement as contributing factors.

*“The **price dramatically increased from a \$25 copay to 30% co-insurance not subject to deductible due to Aetna’s change** in how they cover this medication.” - Tirzepatide, a Specialty Drug for Type 2 Diabetes - Employer Insurance - “Unaffordable”*

*“I have **spent uncounted hours on the phone, sending faxes, tracking down records, etc., trying to get the patient assistance program back.** I simply can’t afford to pay almost \$400 for a single medication, on top of my other medical expenses.” - Almovig, a Specialty Drug for Migraine - Medicare - “Unaffordable”*

INDIVIDUALS REPORTING PAYING \$501-\$1000 PER MONTH

5% (26 people) of respondents (537 people) reported they paid \$501-\$1000 OOP **the last time** they took the prescription drug (19 specialty, 6 brand, 1 generic).

22%

78%

23% (6 people) reported this amount was **affordable**.
78% (20 people) reported this amount was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT AS UNAFFORDABLE?

- **Insurance barriers.** 52% (10 respondents) reported affordability challenges driven by insurance design, some reporting high deductibles and coverage only after hitting OOP maximums.
 - Five respondents reported their insurance would not cover the prescription at all, one of them who reported paying over \$700 “cash price” because their new insurer would not cover the drug they need.
- **GLP-1 medications** accounted for 30% (6 respondents) at this OOP level. 3 of these respondents include those whose insurance denied coverage.
- **Access to financial assistance.** Three respondents (two with employer coverage, one with individual insurance) did not report using financial assistance, and 1 person on employer insurance claimed Enbrel’s copay support program was discontinued.
 - One respondent relied on a third-party alternative funding program to reduce monthly costs for a brand-name ADHD medication from over \$1,000 to \$500-\$1,000, however this OOP amount was still unaffordable.
- **Cumulative costs and healthcare burdens.** 24% (5 respondents) reported having only one effective medication option, eliminating lower-cost alternatives. Respondents also cited the combined burden of medication costs and other healthcare expenses as contributing to unaffordability.
- **Evolving life situations and income strain.** Affordability varied independently of income, with respondents at both higher and lower income levels reporting drugs as unaffordable.

*“I previously had Anthem [employer insurance] and would get it at a copay of \$15 a month. I now have United Healthcare and **they will not cover [it]**. Out of pocket cash price is over \$700 month. **I can’t use a savings card because that medication must be on their formulary**. I am now **going without this medication and am now having daily migraines.**” - Emgality, a Specialty Drug for Migraine - Employer Insurance/Loss of Insurance - “Unaffordable”*

INDIVIDUALS REPORTING PAYING \$1000+ PER MONTH

4% (20 people) of respondents (537 people) reported they paid over \$1000 OOP **the last time** they took the prescription drug (17 specialty, 2 brand, 1 generic).

15%

85%

15% (3 people) reported this amount was **affordable**.
85% (17 people) reported this amount was **unaffordable**.

Most respondents gave multiple reasons why they reported this drug unaffordable based on their most recent OOP cost.

WHY DID PATIENTS REPORT THIS OOP AMOUNT UNAFFORDABLE?

- **Insurance barriers.** 29% (5 respondents) reported affordability challenges driven by insurance changes, including plan switches, preferred drug list changes, reduced coverage, higher deductibles, and increased OOP minimums.
 - One respondent cited an **insurance accumulator** that resulted in \$3,500 biweekly charges for Stelara, leading to treatment discontinuation.
 - Two respondents with employer coverage reported monthly copays exceeding \$5,000 for specialty drugs (Ocrevis and Xeljanz), with one attributing the increase to deductible and OOP maximum changes.
 - Two people said their insurer would not cover their prescription. One paid in full to access it.
- **Access to financial assistance.** Two respondents reported losing family or third-party financial assistance, rendering the medication unaffordable. One Medicare respondent reported losing assistance after being switched from Humira to a biosimilar, resulting in \$2,000 in monthly OOP costs.
- **Evolving life situations and income strain.** 18% (3 respondents) cited job loss or transition to retirement or fixed income as contributing to unaffordability.
 - Three patients (18%) who reported paying 1001+ OOP did not actually pay this amount; one cited a large increase in premiums may result in insurance loss and one worries about losing access due to job loss.

*“Most insurance companies don’t cover this, and if they do, **you have to back and forth with prior authorizations, denials, appealing the denials.** I feel so much anger, sadness, fear, and hopelessness. **I can’t believe they would deny it when I have been on it so long and they have such a well documented history of [using] it.**” - Botox, a Specialty Drug for Migraine - Individual Insurance - “Unaffordable”*

*“I have recently experience a job loss and am concerned... [that] I **[will] no longer have access...without employer coverage.** Benlysta has a copay program that covers my out of pocket costs up to \$9,000 which financially helps tremendously. **All other out of pocket costs from my other medications has contributed to my medical debt.** The prescription drugs **can cost up to \$1,000 without healthcare coverage...** which quickly becomes expensive and at high risk of significant medical debt.” - Benlysta, Specialty Drug for Lupus - Employer Insurance/Loss of Insurance - “Unaffordable”*

“OOP COST SHIFTING” & “AFFORDABILITY SHIFTING” IMPACT PATIENT-REPORTED AFFORDABILITY OVER TIME

All respondents were asked to report how much they paid OOP the last time they used the drug and to state if they felt that amount was affordable or unaffordable. Those who have paid different OOP costs for the same drug over time were asked to report those amounts and rank those OOP costs as affordable or unaffordable. Open-ended comment boxes were provided to provide more context for their answers.

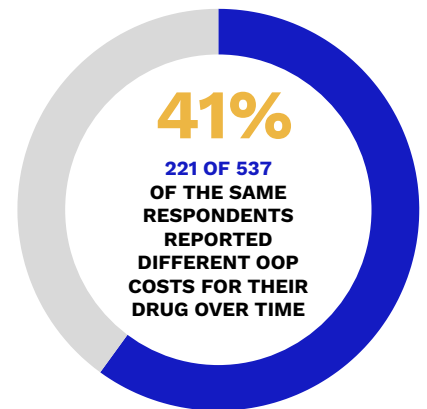
While the original intent of these questions was to identify affordability thresholds, two distinct patterns emerged that shaped affordability reporting. These were defined as:

“OOP cost shifting”: The same person paying at least two different OOP costs for the same drug over time.

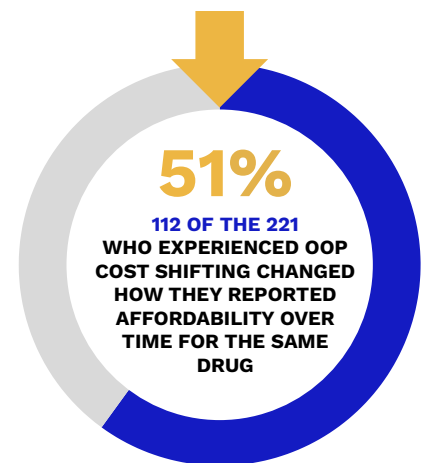
“Affordability shifting”: The same person reporting at least one OOP cost “affordable” and at least another OOP cost as “unaffordable” for the same drug over time.

- Of the 537 responses, 41% (221 people) **reported OOP cost shifting**.
- 51% of them (112 of 221 people) - nearly **one quarter of all respondents - reported** at least one of their OOP costs as “affordable” and at least one of their OOP costs as “unaffordable” (**affordability shifting**).
- Of those who provided additional information regarding *why* OOP costs changed and *why* certain ranges were affordable and others were unaffordable, 28% (20 people) attributed it to **insurance barriers**, 16% (11 people) to **income** or **evolving life situations** (i.e., loss of work). Some reported more than one of these.

This highlights that drug affordability is situational and often changes - even for the same individual. This also underscores the importance of capturing patient-reported affordability *across the full lifecycle of medication use*, rather than at a single point of use. Relying on one snapshot in time risks an incomplete understanding of the drivers of affordability and the access barriers associated with them.



“OOP COST SHIFTING”
OFTEN CONTRIBUTED TO



“AFFORDABILITY SHIFTING”

AFFORDABILITY SHIFTING BREAKDOWN BY OOP COST RANGE

\$0-\$10: 8% (1 respondent) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 93% (171 people) who reported this as their most recent OOP cost and cited this amount affordable, 16% (28 people) found this same drug to be unaffordable at some other point in time.

\$11-\$25: 33% (3 respondents) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 85% (50 people) who reported this as their most recent OOP cost and cited this amount affordable, 16% (8 people) found this same drug to be unaffordable at some other point in time.

“OOP COST SHIFTING” & “AFFORDABILITY SHIFTING” IMPACT PATIENT-REPORTED AFFORDABILITY OVER TIME

\$26-\$50: 36% (4 respondents) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 83% (54 people) who reported this as their most recent OOP cost and cited this amount affordable, 26% (14 people) found this same drug to be unaffordable at some other point in time.

\$51-\$100: 28% (7 respondents) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 54% (29 people) who reported this as their most recent OOP cost and cited this amount affordable, 17% (5 people) found this same drug to be unaffordable at some other point in time.

\$101-\$250: 39% (12 respondents) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 37% (18 people) who reported this as their most recent OOP cost and cited this amount affordable, 17% (3 people) found this same drug to be unaffordable at some other point in time.

\$251-\$500: 38% (9 respondents) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 37% (14 people) who reported this as their most recent OOP cost and cited this amount affordable, 14% (2 people) found this same drug to be unaffordable at some other point in time.

\$501-\$1000: 25% (5 respondents) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 22% (6 people) who reported this as their most recent OOP cost and cited this amount affordable, none found this same drug to be unaffordable at some other point in time.

\$1001+: 24% (4 respondents) who reported this as their most recent OOP cost and cited this amount unaffordable also reported it affordable at another point in time. Of the 15% (3 people) who reported this as their most recent OOP cost and cited this amount affordable, none found this same drug to be unaffordable at some other point in time.

REASONS FOR AFFORDABILITY SHIFTING

Out-of-pocket costs for the same drug fluctuate over time, driven largely by insurance design and coverage rules. Across all out-of-pocket cost ranges, respondents who provided additional context consistently cited **insurance-related barriers as the primary drivers of shifts in affordability:** switching insurers, changes to insurance plans, high OOP deductibles or maximums, and inability to apply financial assistance. A few cited “drug cost” and one mentioned dosage changes.

*“When I was on Medicaid I was able to get a 3 month supply...it was 5 dollars! **I have lost access, I couldn’t afford to get my refill and I don’t sleep** (my lungs filled up with mucus at night, the Albuterol takes care of that,) so sometimes I wake up (if I sleep,) gasping for air and have to get up.” - \$0-\$10 range, Affordable; \$11-\$25 range, Unaffordable*

*“**I’m being denied insurance coverage** (limited to...10 tablets/30 days). Therefore I will have to pay out of pocket for one refill or 10 tablets. **We have tried PA and exception to coverage to try to remedy this but I am being treated as if migraine is not an ongoing chronic illness.**” - \$26-\$50, Affordable; \$501-\$1000, Unaffordable*

VARIABLE OOP COST SHIFTS LEAD TO “ACCESS SHIFTING”

Even as concepts like OOP cost shifting, affordability shifting, and access shifting help explain how insurance design affects patient access, they do not exist in isolation. They often intersect with broader challenges, including income constraints and changing life circumstances. When layered on top of ongoing pricing unpredictability, these factors compound financial strain and create unnecessary anxiety, further undermining patients’ ability to reliably access the treatments they need.

Given that patients assess affordability relative to their “essential monthly budget,” even modest cost increases influenced affordability reporting. As OOP cost ranges expand, the likelihood of affordability shifting increases. Additionally, this study realized that *shifts in cost that change affordability can directly impact a patient’s ability to access their medication.*

Specifically, when insurance-driven price changes push a drug outside of or into a patient’s essential budget, access to that medication is either blocked or restored. Disrupted access can cause patients to delay, switch, or abandon treatment. This realization led to another theme we defined:

“Access shifting”: OOP cost shifting that triggers affordability shifting and, as a result, access to treatments shift.

Volatile cost inconsistencies can exacerbate access shifting. Of the 21% of total survey respondents who experienced **affordability shifting**, 55% (62 respondents) **reported OOP cost shifting between three or more ranges** with 15% (17 respondents) reporting ranges between **\$0-\$10 and \$1001+**. **As a result, many lost access to their treatment.**

Specialty Drug, Rheumatoid Arthritis

OOP amounts reported over time:

Affordable-\$0-\$10, \$51-\$100, \$101-\$250, \$251-\$500; Unaffordable-\$501-\$1000, \$1001+

Reason for OOP affordability shifting.

Changes in insurance coverage—from **employer-sponsored to individual plans—significantly increased out-of-pocket costs. Annual deductibles and cost-sharing** created predictable early-year spending spikes, with January and February requiring thousands of dollars OOP. These expenses forced strict budgeting and, in prior years, **resulted in credit card debt.** *“Anything over \$500 a month is unaffordable in my current financial situation. In years past, given my financial situations at the time, anything over \$250 a month was unaffordable.”*

Amphetamine - Generic Drug - ADHD

OOP amounts reported over time: Affordable - \$0-\$10; Unaffordable-\$251-\$500

Reason for OOP affordability shifting. Loss of **Medicaid coverage caused the medication’s cost to increase** from a \$1 copay to nearly \$300 per prescription, shifting it from affordable to prohibitively unaffordable once full price applied.

Open-ended responses, captured how OOP cost shifts impacted them:

- *“I previously had Anthem and got this medication for a copay of \$15 a month. I now have United Healthcare and they will not cover it. Out-of-pocket cash price is over \$700 a month. I can’t use a savings card because that medication must be on their formulary. I am now going without this medication and am now having daily migraines.” - Ranges from \$0-\$1001*
- *“I was billed \$2000-\$4000 while switching insurance even though I’m enrolled in a copay program.”- Ranges from \$0-\$1001+*
- *“I have had multiple insurances over the 10+ years I’ve been on Rituxan and it has changed depending on that.” - Ranges from \$51-\$500*

Some respondents expressed **anxiety due to the unpredictability, inconsistency, and uncertainty related to OOP costs and anticipated affordability challenges** (including access to financial assistance plans):

- *“I worry that if I lose access my Scleroderma-related lung disease could progress.” -Ranges from \$0-\$1001+*
- *“I am angry that every step of the way in this process is so difficult while I suffer the physical consequences and access to my meds is just one other hurdle... [I] have worried about losing access.” - Ranges from \$51-\$500*

INSURANCE-RELATED CHALLENGES LIMIT MEDICATION ACCESS AND USE

Insurance policies and procedures came up frequently in open-ended questions as a key determinant of prescription drug accessibility and affordability. This section explores the role of insurance across two critical groups: individuals who were never able to start taking a prescribed medication and those who stopped taking their medication. We asked, “**Why did you stop taking [this drug]**” or “**Why were you never able to access [this drug]?**”

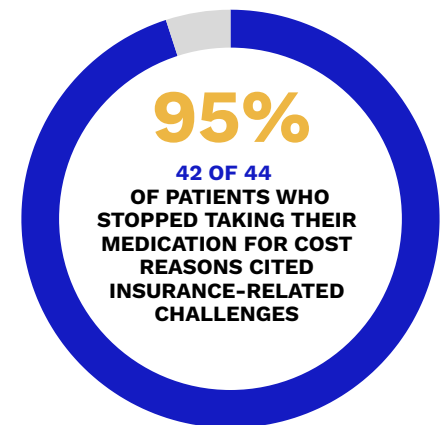
Open-ended responses showed that insurance-related challenges drive most patient concerns, highlighting that insurance policies affect not just out-of-pocket costs but also access to and use of prescribed medications.

PATIENTS WHO STOPPED TAKING A PRESCRIBED MEDICATION

17% of survey respondents (93 people) reported on a medication they stopped taking. Of the 52 respondents who provided a reason for stopping their medication, **85%** (44 people) cited **at least one OOP cost related reason**. 15% stopped for medical reasons.

95% (42 of 44 respondents) who cited at least one cost-related reason for stopping their medication cited **insurance-related challenges**, including:

- 77% (34 respondents) cited the **insurer removed the drug from their formulary, accumulators, step therapy, non-medical switching, and dosage caps**
- 14% (6 respondents) cited **loss of coverage**
- 5% (2 respondents) cited **high deductibles**

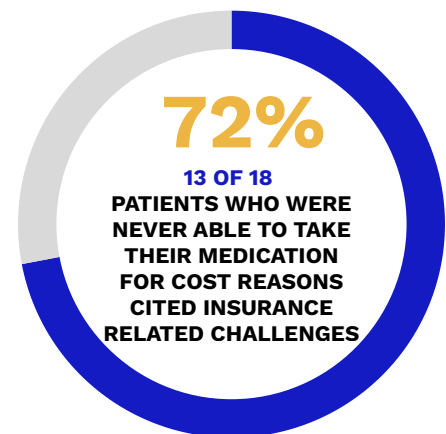


PATIENTS WHO NEVER STARTED TAKING A PRESCRIBED MEDICATION

Only **4%** of survey respondents (22 people) reported on a medication they never started taking. Of the 20 respondents who provided some additional information around their inability to access their medication, **90%** cited **at least one cost related reason**.

72% (13 of 18 respondents) who reported at least one cost-related reason for never taking their medication and who expanded on why in open-ended comments cited **insurance-related challenges**, including:

- 44% (8 people) cited **denial of coverage**
- 28% (5 people) cited **high OOP cost even with insurance**



Patients often cited being unable to pick up their drug because it was “unaffordable,” but open-ended responses **overwhelmingly revealed reasons related to insurance design** (i.e., “My insurance did not cover it”).

Lack of context provides insufficient data. The remaining eight respondents did not expand on their answers other than saying “cost”, “expense”, or a price. This exemplifies the importance of context, as without it analysis is up to interpretation (i.e., “Patients said cost was an issue, the drug is unaffordable”).

DELAYED OR DENIED FINANCIAL ASSISTANCE LEADS TO AFFORDABILITY CHALLENGES

In our pilot study, financial assistance emerged as a key determinant of affordability, yet responses to the multiple choice question revealed widespread confusion and misalignment with insurance coverage. In this survey we revised the structure, **removing the question about financial assistance altogether and, instead, relying on capturing it in open-ended responses as to ‘why’ a drug was affordable, or not.**

“AFFORDABLE” OFTEN MEANS “AFFORDABLE WITH ASSISTANCE”

Of the 208 respondents on **specialty medications**, **33%** (69 people) **mentioned financial assistance programs** (manufacturer copay cards, patient assistance programs, and third-party foundations).

- Of those people, **71%** (49 respondents) stated **financial assistance was the reason why their medication was “affordable”**. *“The only reason it is affordable is because the manufacturer offers a copay assistance program that pays the remaining balance after insurance. Otherwise I would be paying [a] \$500 a month copay which I could not afford.”*

PLAN DESIGN CAN UNDERMINE THE VALUE OF FINANCIAL ASSISTANCE

- 12 patients on specialty medications mentioned that **financial assistance could not be applied until a high deductible was met due to a copay accumulator or maximizer**.
- 16 respondents noted **losing or being unable to access financial assistance**. For context:
 - 6 cited an insurance change caused assistance loss, 3 noted they maxed out the assistance available, 2 cited eligibility assistance rule changes, 2 needed a drug not on their insurance formulary, 2 cited being unable to access copay assistance because they are on Medicare.
- **Medicare** respondents reported significant affordability challenges due to the inability to apply manufacturer copay assistance in the pilot; however, only two respondents made similar claims in this round, **potentially indicating new \$2,000 out-of-pocket caps and associated cost-smoothing policies have eased financial burdens**.

LACK OF KNOWLEDGE ABOUT FINANCIAL ASSISTANCE PROGRAMS POSE AFFORDABILITY ISSUES

As with the pilot, several responses indicated a lack of understanding of financial assistance programs. For instance:

- One patient on employer insurance believed the manufacturer of a biologic drug discontinued their copay assistance program. *Confirmed as of January 2026, the drug continues to offer manufacturer assistance.*
- Others commercially insured cited “the Patient Assistance Plan (PAP)”-a term typically associated with assistance programs for the uninsured, underinsured, or low income patients.

FEAR OF FINANCIAL ASSISTANCE LOSS INCREASES ANXIETY

Changes in copay assistance and plan design variability in applying copay assistance further complicates health care for some patients. 8 patients expressed worry about copay assistance ending or reaching its limit, or no longer being eligible for existing programs.

HEALTHCARE COMPLEXITY DRIVES PATIENT HARDSHIP AND ANXIETY

HARDSHIP IS COMMON

Survey respondents were asked if they experienced any hardships (trouble paying for groceries or rent/housing or if they were in medical debt) due to the OOP cost of drug they reported on or due to cumulative costs of all prescriptions. Of the 340 respondents who responded:

- **71%** (243 patients) reported that the costs **of one or more prescription drugs** led to **one or more of the following hardships**: difficulty affording groceries (36%), difficulty affording housing payments (21%), or medical debt (35%).
 - **46%** (111 people) reported their last OOP was cost between **\$0-\$50**.
 - **40%** (97 people) were on **specialty drugs**, and **60%** reported **brand or generic drugs**.
 - Of the 233 people who reported annual income, **47% earned less than \$50,000 per year; 22%** of those respondents **earned less than \$25,000 per year**
 - **56%** (135 people) reported their drug as **“affordable,” despite identifying one or more hardships**.
- **47%** (159 respondents) cited hardships occurred due to **cumulative OOP costs**, not exclusively as a result of one drug.

INCOME REDUCES RISK—BUT CANNOT ELIMINATE IT

Addressing prescription drug affordability requires reducing the complexity and unpredictability that leaves patients—across income levels—unable to plan for or depend on stable access to the medications they need.

- **Income and hardship.** Higher income is associated with lower likelihood of hardship—each increase in income category reduced the odds of hardship by approximately 30%.
- **High income does not eliminate risk.** Patients at all income levels reported hardship--including 42% of patients in households earning between \$100,000-\$200,000, and 13% of patients in households earning \$200,000 or more per year.
- **Healthcare system complexity matters.** A high-income patient may still face insurance formulary changes, prior authorization requirements, assistance program rules, and the accumulating costs of managing a chronic condition over decades.

EVEN WITHOUT CURRENT HARDSHIP ANXIETY EXISTS

Respondents were given the option to use open-ended comments to describe hardships encountered when accessing or trying to access their drug.

- Of the 29% (97 respondents) who **did not report any hardships associated with the OOP cost of this drug**, 35 of them **still used the open-ended comments to explain what was causing them hardships**:
 - 49% (17 respondents) identified their affordability as conditional on a current situation such as current health insurance coverage, income, or access to financial assistance.
 - 8 expressed anticipatory fear about future affordability or identified their costs as challenging, but short of creating hardship.

*“Although I haven't slipped into any of these categories yet, if I become unable to pay for private insurance through COBRA, then I will **immediately be facing massive hardship with other expenses, including house payments and groceries**. The mental hardship, of course, is priceless.”*

SAVINGS SHOULD NOT COME AT THE EXPENSE OF PATIENT NECESSITIES

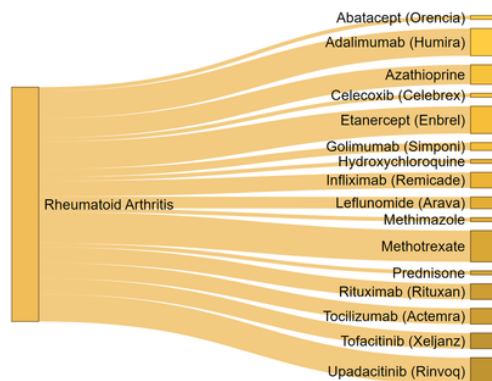
Among the 158 respondents who tried one or more drugs over time and shared additional context about the value of the drug, **over 80% felt the drug said the drug was valuable, but the context of “value” overlapped.** Most reported it valuable to them (“*it’s life altering*”), but some talked about its broad value as a treatment (“*research has shown benefits*”). **Most reasons cited about a drug’s value were less side effects, others did not work as well or stopped working, the mechanism of action was better (i.e., pill versus injection), its unique in its class, and it works with comorbidities.**

Patient-reported “value” is also highly individualized. 29 drugs were reported by more than one respondent. While some medications were consistently described by all respondents as more effective than their alternatives, many responses highlighted the individualized nature of treatment effectiveness. For example, several people on the same biologics reported varied value, ranging from “*I couldn’t live without it,*” to “*Great for others, but not for me.*”

Viewing drugs as interchangeable therapeutic alternatives and assessing affordability based only on retail or net cost overlooks their potential value to patients. Price-only assessments ignore patient-specific needs, particularly for people with heterogeneous diseases, comorbidities, or when multiple drugs exist within the same class, and fail to reflect that treatments are not interchangeable for many patients with chronic conditions. For example:

People diagnosed with heterogeneous diseases often cycle through many treatments before finding the one that works. Disrupting continuity of care can lead to worse outcomes, including developing comorbidities and impeding remission. To demonstrate the difficulty of finding the right treatment, we pulled data from the 60 people in our study diagnosed with Rheumatoid Arthritis (RA):

PATIENTS WITH RHEUMATOID ARTHRITIS (RA) HAD SOME OF THE GREATEST VARIABILITY IN DRUGS TAKEN WITH 16 DIFFERENT DRUGS BEING USED ACROSS 60 PATIENTS



- **82%** who were on **specialty drugs cycled through** more than one medication to find what worked.
- **49% had comorbidities** that could impact which treatments would be best for them.
- **5** people reported they were on a **therapeutic alternative** prior and it **did not work as well** as this drug, *demonstrating what works for one person may not work for the other, even with the same diagnosis.*

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. **Open-ended responses demonstrate how utilization management practices can interfere with patient-valued treatments when therapeutic options are available:**

- “*When I dealt with a forced non-medical switch my life flipped upside down. I went from being in remission for nine years to being debilitated for almost two months, this was extremely upsetting and really messed with my life as a mom of three young kids.*”
- “*The insurance wants you to be on a certain list of medications and my company doesn’t comprehend I’ve been dealing with migraines for over 20 years and over. [I] tried their list and they don’t work.*”

View patient quotes associated with drug value and utilization management practices:
<https://eachpic.org/wp-content/uploads/2026/01/Survey-2.0-UM.pdf>

LESSONS LEARNED AND OTHER CONSIDERATIONS

AFFORDABILITY STARTS WITH THE “WHY”

To develop patient-centered solutions, we must shift away from processes that prioritize system-level costs over patient realities. Current affordability reviews often focus on retail prices and system-wide impact, selecting drugs without first understanding what patients struggle to afford or the factors driving those struggles. As a result, recommended solutions tend to focus on broader healthcare savings, with the assumption that benefits will eventually reach patients.

Our findings are clear. Focusing on the affordability of a single drug obscures the broader financial and insurance-related challenges patients face. Our findings show that patients define affordability as the ability to consistently access the medication that works for them without overwhelming their essential finances, with insurance rules and the reliability of financial assistance often determining long-term access.

- **As found in the pilot and confirmed in this study, no one drug emerged as a hardship for patients because affordability is not solely aligned with drug price.** This is due to insurance barriers, high cumulative medication costs, perspectives on how much medication should cost, and evolving life experiences were all primary drivers to reporting a drug as unaffordable.
- **In this study, we realized no one drug can emerge as creating a hardship for patients because of the newly identified phenomena “OOP shifting”, “affordability shifting”, and “access shifting”.** These drivers also highlight the complexity of the healthcare system and reinforce this conclusion.
- **Our data confirms there is a need to rethink affordability reviews by first understanding the drivers behind their prescription affordability challenges and then implementing solutions based on patient-reported needs.** Failure to do so calls into question whether efforts to address prescription affordability are really about the patients or are they actually about helping save money for the healthcare system in the guise of improving patient lives. Policies that address these insurance-driven barriers and protect access to effective, preferred treatments are more likely to reduce patient hardship than approaches focused solely on drug price.

The “why”. Throughout the analysis, the retail price of no single drug directly caused hardship to patient OOP costs. Instead, the survey demonstrates that patient affordability was dependent entirely on life situations and how insurance plans dictate access.

This highlights the complexity of our healthcare system and the importance of identifying contextual factors (“the why”) driving patient-reported prescription drug OOP cost challenges.

THEMES WITH POTENTIAL FOR FURTHER EXPLORATION

The following themes emerged for the first time in this research study and may warrant additional investigation to more deeply understand drivers behind patient-reported prescription affordability:

- **“OOP cost shifting”, “affordability shifting”, and “access shifting”.** These phenomena emerged thanks to open-ended responses which allowed respondents to share their “why” behind the inability to afford their treatments. Exploration should include further investigation into the interrelationship between these and other known drivers of prescription unaffordability (i.e., income, evolving life situations, cumulative costs).
- **Prescription drug affordability challenges in marginalized communities.** By using paid survey services we were able to diversify respondents to better represent the real world population. In doing this, a theme emerged that questioned why people of color reported higher use of brand and generic medications and affordability challenges related to them. This may lend to a broader investigation into drivers of unaffordability by demographic, including systemic barriers that could impact access to vital medications.
- **High deductible and OOP maximum plans delaying or rejecting financial assistance.** Through reading open-ended responses, we identified over 40 respondents who reported issues affording their medications due to high deductible plans and limitations applying financial assistance to their copays. Given this theme emerged almost entirely in employer-based plans, future research should focus on employer-based insurance.
- **Migraine medication monthly quantity limits cause patient harm.** In open-ended responses, several patients talked about OOP cost shifting and, in turn, both affordability shifting and access shifting, specific to caps on the amount of pills they could access in a month. In reviewing diagnoses associated with these respondents, all were on migraine medications. Those patients repeatedly expressed experiencing unnecessary disease activity and associated disruption of life as a result.
- **Depth of patient understanding of financial assistance in commercial insurance.** In both the pilot and this study, respondents consistently use financial assistance plan terminology interchangeably, which may result in applying for the wrong plan or mistakenly thinking their assistance has ended (i.e., Patient Assistance Plans or PAPs are typically associated with the uninsured or underinsured, not commercial plans). Furthermore, in both studies several respondents commercially insured reported high OOP costs; yet they either cited they were not aware of financial assistance options or they made no mention of them in open ended responses. This realization enforced our discovery in the pilot that more patient education about financial assistance is warranted.

NEXT STEPS

PIC LED PATIENT EXPERIENCE WITH PRESCRIPTION DRUG AFFORDABILITY PROJECT

The PIC, led by patients, is dedicated to ensuring patient experiences drive changes to improve access to treatments, as current efforts, including price-setting policies, focus largely on what will save other stakeholders in the healthcare system money.

Affordability efforts work best when they start, and end, with patients. We invite policymakers, advocates, and partners to use this data, engage with our coalition, and work collaboratively toward solutions that improve access, reduce harm, and reflect the realities patients live every day.

Distribution findings and recommendations nationally. This work is ongoing. EACH/PIC will continue expanding patient engagement, sharing these findings with policymakers, and advocating for reforms that address the patient-reported drivers of hardship.

Increase broader and more diverse patient and caregiver participation in prescription drug affordability reporting. The PIC is dedicated to working with all stakeholder groups, patients, and caregivers to ensure any efforts to address prescription drug affordability are designed with patients in mind first. Our continued efforts aim to:

- Increase participation among diverse populations, particularly those who may experience the most challenges with affordability, but whose voices are not always counted.
- Continue engagement with survey respondents who provided contact information, disseminating results, thanking them for sharing, and extending the opportunity for continued engagement.
- Increase participation of all stakeholder groups involved in prescription drug affordability reform efforts. This includes any and all groups representing patient voices to help identify participants to continue this initiative, regardless of any political or issue divides. Together we are stronger, and together we can work towards solutions that truly benefit patients.

Be recognized as the trusted source and expert in patient-facing data collection efforts. This work demonstrates that the PIC is the leader in patient-facing question design and analysis. We will:

- Serve as a liaison for those who are dedicated to ensuring their patient-facing data collection materials are clear and will produce meaningful data.
- Create a standardized, “best practice” survey (short and long version) and encourage policymakers to use it when conducting affordability reviews.

CHALLENGES, LIMITATIONS, AND ACKNOWLEDGEMENTS

CHALLENGES AND LIMITATIONS

Respondents who did not provide context made analysis challenging, if not impossible. This study aimed to identify the “why” behind patient-reported OOP prescription costs. We provided open-ended comment boxes in an attempt to capture patient rationale so we could target challenges with appropriate solutions. However, some responses were lacked sufficient detail, leaving us with questions about their knowledge of financial assistance programs and/or the details of their insurance coverage. We will follow up with patients who provided contact information to better understand their struggles and connect them to resources.

Issues with paid surveys. The core of our work to uncover patient-reported affordability challenges demonstrated the necessity of including open-ended responses in our survey design. However, as we looked to expand our reach by leveraging paid response platforms, we found most paid survey distributors would not permit more than a few qualitative questions (due to survey respondent fatigue and increased drop off rates that make their model). As a result, we were required to remove the optional open-ended questions (i.e., patient-reported definition of affordability, affordability threshold, etc.) While doing so did not diminish from our findings, paid respondents were unable to provide input on some questions that unpaid respondents could.

Furthermore, unlike unpaid respondents who could provide contact information for follow up, we were unable to collect this information from paid respondents. While we included our email address in the description and offered paid respondents the opportunity to contact us with questions or if they would like us to follow up, we received no emails. In contrast, 63% of the 228 unpaid respondents provided contact information. Patient representatives from the PIC will reach out to disseminate survey findings and invite them to continue sharing experiences in the future.

ACKNOWLEDGEMENTS

Survey contributors. AiArthritis (International Foundation for [Autoimmune & Autoinflammatory Arthritis](#)) and data scientist Misty Knight-Finley, PhD (Senior Managing Partner and Director at Inform Analytics) redesigned the survey questions and led the analysis (with extensive collaboration with Patient Research Partners (PRPs)).

The original pilot survey questions were co-designed by AiArthritis, Arthritis Foundation, Caring Ambassadors, Pacific Northwest Bleeding Disorders, Partnership to Improve Patient Care (PIPC); Patient Research Partners (PRPs) Tiffany Westrich-Robertson and Deb Constien.

Survey dissemination. A special thank you to patient organizations and allied groups participating in the Ensuring Access through Collaborative Health (EACH) side of the EACH/PIC coalition, Health Union, and patient advocates recruited by them.

This project was made possible through support from [AiArthritis](#).

**PATIENT EXPERIENCE SURVEY:
PRESCRIPTION DRUG AFFORDABILITY
AND UNAFFORDABILITY**

APPENDIX

DRUG LIST

Drug Name	Type	n
Abaloparatide (Tymlos)	Specialty	2
Abatacept (Orencia)	Specialty	2
Acetaminophen	Generic	4
Acetaminophen (Paracetamol)	Generic	1
Acetaminophen (Tylenol)	Generic	2
Acetaminophen / Aspirin / Caffeine (Excedrin)	Generic	4
Adalimumab (Humira)	Specialty	23
Adalimumab-aaty (Yuflyma)	Specialty	2
Adalimumab-adaz (Hyrimoz)	Specialty	1
Adalimumab-adbm (Cyltezo)	Specialty	1
Albuterol	Generic	30
Albuterol (Salbo)	Brand	1
Albuterol (Ventolin)	Brand	1
Allopurinol	Generic	1
Alprazolam	Generic	1
Alprazolam (Xanax)	Brand	4

Drug Name	Type	n
Amitriptyline	Generic	1
Amlodipine	Generic	1
Amlodipine Besylate (Norvasc)	Specialty	1
Amoxicillin	Generic	2
Amphetamine Salts	Generic	1
Amphetamine Salts (Adderall)	Brand	2
Antihemophilic factor VIII (recombinant) (Recombinate)	Specialty	1
Antihistamines	Generic	1
Apixaban	Generic	2
Apixaban (Eliquis)	Brand	9
Apremilast (Otezla)	Specialty	1
Aripiprazole (Abilify)	Specialty	1
Aspirin	Generic	2
Atogepant (Qulipta)	Brand	6
Atorvastatin	Generic	4
Atorvastatin (Lipitor)	Brand	1
Azathioprine	Generic	6

DRUG LIST (CONT'D)

Drug Name	Type	n
Azelastine	Generic	1
Balsalazide	Generic	1
Belimumab (Benlysta)	Specialty	4
Bictegravir / Emtricitabine / Tenofovir alafenamide (Biktarvy)	Specialty	3
Bimekizumab (Bimzelx)	Specialty	1
Brexpiprezole (Rexulti)	Specialty	1
Brimonidine / Timolol (Combigan)	Brand	1
Budesonide	Generic	1
Budesonide / Formoterol (Symbicort)	Brand	2
Budesonide / Glycopyrrolate / Formoterol (Breztri)	Brand	1
Buprenorphine	Generic	1
Buprenorphine / Naloxone (Suboxone)	Brand	2
Bupropion (Wellbutrin)	Brand	1
Calcipotriene / Betamethasone (Enstilar)	Brand	1

Drug Name	Type	n
Canakinumab (Ilaris)	Specialty	1
Cariprazine (Vraylar)	Brand	1
Celecoxib (Celebrex)	Brand	1
Cetirizine	Generic	1
Cevimeline (Evoxac)	Brand	1
Ciclesonide (Alvesco)	Brand	1
Clonidine	Generic	1
Clopidogrel (Plavix)	Brand	1
Corticosteroid	Generic	1
Crizotinib (Xalkori)	Specialty	1
Cyclobenzaprine	Generic	1
Dapsone	Generic	1
Darolutamide (Nubeqa)	Specialty	1
Denosumab (Prolia)	Specialty	2
Dexlansoprazole (Dexilant)	Brand	1
Diazepam (Valium)	Brand	1
Diclofenac (Voltaren)	Brand	1
Dimethyl fumarate (Tecfidera)	Specialty	1

DRUG LIST (CONT'D)

Drug Name	Type	n
Diphenhydramine	Generic	1
Divalproex Sodium (Depakote)	Brand	1
Dolutegravir / Abacavir / Lamivudine (Triumeq)	Specialty	1
Dolutegravir / Lamivudine (Dovato)	Specialty	1
Doxazosin	Generic	1
Dulaglutide (Trulicity)	Specialty, GLP-1	3
Duloxetine (Cymbalta)	Brand	1
Duloxetine HCL	Generic	1
Dupilumab (Dupixent)	Specialty	2
Efanesoctocog alfa (Altuviiio)	Specialty	1
Eletriptan (Relpax)	Brand	1
Emicizumab (Hemlibra)	Specialty	2
Empagliflozin (Jardiance)	Brand	3
Empagliflozin (Jardiance)	Specialty	2
Enalapril	Generic	1
Epinephrine	Generic	1

Drug Name	Type	n
Epinephrine (Epipen)	Brand	1
Erenumab-aooe (Aimovig)	Specialty	3
Escitalopram	Generic	1
Esketamine nasal spray	Specialty	1
Esomeprazole	Generic	1
Etanercept (Enbrel)	Specialty	8
Evolocumab (Repatha)	Specialty	1
Exemestane (Aromasin)	Brand	1
Famotidine	Generic	1
Fexofenadine	Generic	1
Fexofenadine (Allegra)	Generic	2
Fluoxetine (Prozac)	Brand	1
Fluticasone	Generic	3
Fluticasone (Flonase)	Generic	1
Fluticasone / Salmeterol (Advair)	Brand	1
Fluticasone / Umeclidinium / Vilanterol (Trelegy)	Brand	2

DRUG LIST (CONT'D)

Drug Name	Type	n
Fluticasone furoate / Umeclidinium / Vilanterol (Trelegy Ellipta)	Brand	1
Fortamet	Generic	1
Fremanezumab (Ajovy)	Specialty	3
Gabapentin	Generic	5
Gabapentin enacarbil (Horizant)	Specialty	1
Galcanezumab (Emgality)	Specialty	6
Glipizide	Generic	2
Glucophage (Metformin)	Brand	34
Golimumab (Simponi Aria)	Specialty	1
Golimumab (Simponi)	Specialty	2
Guselkumab (Tremfya)	Specialty	1
Hydrocodone	Generic	1
Hydroxychloroquine	Generic	4
Hydroxychloroquine (Plaquenil)	Brand	3
IVIG (GammaGard)	Specialty	2
Immune globulin, intravenous (human) (Octagam)	Specialty	1
Immune globulin, subcutaneous (human) (Hizentra)	Specialty	1

Drug Name	Type	n
Infliximab (Remicade)	Specialty	5
Infliximab-abda (Renflexis)	Specialty	1
Insulin	Generic	4
Insulin Lispro	Generic	2
Insulin degludec (Tresiba)	Specialty	1
Insulin glargine (Lantus)	Brand	4
Insulin glargine U-300 (Toujeo)	Specialty	1
Insulin human (Humulin)	Brand	1
Isoniazid	Generic	1
Ivabradine	Generic	1
Ixekizumab (Taltz)	Specialty	2
Keppra	Generic	2
Ketotifen (Zaditor, Alaway)	Brand	2
Lamotrigine	Generic	2
Lanadelumab	Specialty	1
Lasmidatan (Reyvow)	Brand	1
Leflunomide (Arava)	Brand	3

DRUG LIST (CONT'D)

Drug Name	Type	n
Lenalidomide (Revlimid)	Specialty	1
Levalbuterol (Xopenex)	Brand	1
Levothyroxine	Generic	6
Levothyroxine (Synthroid)	Brand	2
Levothyroxine (Tirosint)	Brand	2
Levothyroxine (Tirosint-Sol)	Brand	1
Levothyroxine (Unithroid)	Brand	1
Linaclotide (Linzess)	Brand	1
Lisdexamfetamine (Vyvanse)	Brand	2
Lisinopril	Generic	2
Lithium	Generic	1
Losartan	Generic	3
Loteprednol Etabonate (Eysuvis)	Brand	1
Lurasidone (Latuda)	Brand	1
Macitentan (Opsumit)	Specialty	2
Meloxicam	Generic	1

Drug Name	Type	n
Mesalamine	Generic	1
Methimazole	Generic	4
Methotrexate	Uncategorized	13
Methylphenidate (Concerta)	Brand	1
Metoprolol Succinate	Generic	2
Minoxidil	Generic	1
Mometasone Furoate (Asmanex)	Brand	1
Montelukast	Generic	1
Morphine Sulfate ER	Generic	1
Motrin	Generic	1
Mycophenolate mofetil (CellCept)	Specialty	2
Mycophenolic acid (Myfortic)	Specialty	1
Naltrexone	Generic	2
Naproxen	Generic	1
Naproxen Sodium (Aleve)	Generic	1
Naratriptan	Generic	1
Nerivio	Brand	2

DRUG LIST (CONT'D)

Drug Name	Type	n
Nirmatrelvir / Ritonavir (Paxlovid)	Generic	1
Ocrelizumab (Ocrevus)	Specialty	3
Ofatumumab (Kesimpta)	Specialty	3
Omalizumab (Xolair)	Specialty	1
Onabotulinum Toxin A (Botox)	Specialty	2
Oxycodone	Generic	2
Oxycodone ER (Oxycontin)	Brand	1
Oxycodone/Acetaminophen (Percocet)	Brand	1
Oxycodone/Aspirin (Percodan)	Brand	1
Pancrelipase (Creon)	Brand	1
Pantoprazole	Specialty	1
Pantoprazole (Protonix)	Brand	1
Peginterferon beta-1a (Plegridy)	Specialty	1
Perindopril (Vectoryl)	Brand	1
Phentermine	Generic	1
Pilocarpine HCL	Generic	1

Drug Name	Type	n
Prednisone	Generic	8
Pregabalin	Generic	1
Propranolol	Generic	1
Pyridostigmine (Mestinon)	Brand	1
Ranitidine (Zantac)	Generic	1
Rimegepant (Nurtec ODT)	Specialty	4
Risankizumab-rzaa (Skyrizi)	Specialty	5
Rituximab (Rituxan)	Specialty	7
Rizatriptan	Generic	3
Ruxolitinib, topical (Opzelura)	Specialty	1
Sacubitril / Valsartan (Entresto)	Brand	1
Secukinumab (Cosentyx)	Specialty	3
Semaglutide (No Brand Listed)	Specialty, GLP-1	2
Semaglutide (Ozempic)	Specialty, GLP-1	14

DRUG LIST (CONT'D)

Drug Name	Type	n
Semaglutide (Wegovy)	Specialty, GLP-1	1
Sertraline (Zoloft)	Brand	2
Simvastatin	Generic	1
Sirolimus (Rapamune)	Specialty	1
Sitagliptin (Januvia)	Brand	1
Sulfasalazine	Generic	1
Sulfonylurea	Generic	1
Sumatriptan	Generic	4
Sumatriptan (Imitrex)	Brand	5
Sumatriptan / Naproxen (Treximet)	Brand	1
Suvorexant (Belsomra)	Brand	1
Tadalafil	Generic	2
Tapentadol (Nucynta)	Brand	1
Tenofovir disoproxil fumarate (Viread)	Specialty	2
Tiotropium (Spiriva)	Brand	1
Tirzepatide (Mounjaro)	Specialty, GLP-1	8
Tirzepatide (No Brand Listed)	Specialty, GLP-1	1

Drug Name	Type	n
Tirzepatide (Zepbound)	Specialty, GLP-1	6
Tizanidine (Zanaflex)	Brand	1
Tocilizumab (Actemra)	Specialty	7
Tofacitinib (Xeljanz)	Specialty	5
Topiramate	Generic	2
Topiramate (Topamax)	Brand	2
Triptan	Uncategorized	2
Ublituximab-xiiy (Briumvi)	Specialty	2
Ubrogepant (Ubrovelvy)	Specialty	3
Ubrogepant (Ubrovelvy)	Specialty	2
Upadacitinib (Rinvoq)	Specialty	8
Ustekinumab (Stelara)	Specialty	4
Valsartan	Generic	2
Vancomycin	Generic	1
Vedolizumab (Entyvio)	Specialty	1

SURVEY DETAILS: RATIONALE, METHODS, ENDPOINTS

RATIONALE

In 2024, patients identified a significant disconnect between their real-world experiences and the findings of short, overly simplified surveys commonly used by affordability boards. These instruments often force patient experiences into pre-determined categories and policy frameworks, limiting patients' ability to explain their circumstances and constraining how affordability challenges are understood.

In response, patients with extensive experience in research and with help from a data scientist, developed [a pilot survey](#) designed to more accurately capture the complexity of affordability experiences. To confirm the pilot's findings and better understand the underlying drivers of patient-reported affordability challenges, the PIC expanded this effort to a broader and more diverse audience. Results from this expanded survey reinforced a central conclusion: without directly listening to patients and capturing the “why” behind affordability challenges, policy and programmatic solutions may focus on the state and healthcare system benefits, rather than helping patients afford the prescriptions they need.

Changes to the Pilot Survey.

Drawing on lessons learned in the pilot and in preparation for a broader audience, representatives from the PIC, Ensuring Access through Collaborative Health (EACH) patient organization participants, patient research partners, and a research consultant developed a shorter, more focused survey instrument. The goals were to reduce completion time, lower respondent burden, and increase participation while preserving analytic depth.

The original 51 question survey was streamlined to create the updated instrument, which asks up to 20 questions depending on respondent pathways (i.e., insurance type, prescription use status). Skip logic was based on whether a participant currently takes, previously took, or (new this round) was prescribed a medication, but unable to access it.

While the pilot questions focused heavily on how patients experience their disease and disease management, patients' answers told a larger story about the nuance of affordability. In refining the instrument, we reduced length while maintaining conceptual richness by eliminating questions that:

- Failed to yield responses consistent with patients' other answers (e.g., questions about copay assistance utilization, questions about method of drug administration);
- Were frequently left blank or could not be answered accurately (e.g. exact treatment start and end dates, other treatment history details);
- Focused on the indirect cost of disease; or
- Were sufficiently answered in the pilot survey (e.g. 72% of respondents said setting up copay assistance was easy, or 75% cited insurance delays as a cause of stretched or skipped doses).

The updated survey focused more intently on patients' prescription affordability-related experiences, as well as demographic factors that influence or correlate with these areas (e.g. household size, employment status, etc.). For example, the revised instrument:

- Explored whether (*and why*) respondents paid multiple prices for the same drug;
- Added the option to report why a prescription drug was prescribed but never taken;
- Allowed respondents to assess the affordability of *each price point they reported paying during any time they used the drug*; and,
- Asked patients to define affordability in their own words, including identifying an affordability ‘threshold’.

To minimize survey length, while maximizing insight into patients' financial experiences, we leveraged four open-ended questions derived from themes found in the pilot survey:

- “Explain in detail why you reported the out of pocket cost(s) of *this medication* affordable or unaffordable. Details may involve: your insurance coverage, access to a manufacturer copay assistance plan or other financial assistance plan, personal feeling that this out of pocket cost is unreasonable for most people, household income, job loss, cumulative cost of all medications or medical services, other situations, feelings, or attitudes.”
- “How valuable do you feel *this medication* is to you and/or to others diagnosed with *your disease*? Is there something about this medication that you feel makes it better or worse than other options to treat *your disease* or your individual needs?”
- “Have you tried other prescription drugs to treat *your disease*? If yes, please describe why you are no longer on the other medication(s) in the space provided.”
- “How does, did, or could having access to *this medication* impact *your disease*? Have you ever lost access to *this medication* or worried about losing access to it? If so, please share your experiences with or feelings about losing access.”

STUDY ENDPOINTS

Taken together, the survey captures the following study endpoints, which largely reflect those established in the initial pilot:

- Diagnosis and Comorbidities
- Prescription Drug Usage (current, past, never used) and reasons for discontinuation
- Out-of-pocket costs (1 prescription per survey)
- Patient-reported “affordability” assessment (“the why” a drug is affordable or unaffordable)*
 - Barriers: insurance coverage, cost, financial assistance, lifestyle circumstances, hardships*
 - **Definition of affordability and associated patient-identified affordability threshold**
- **Prescription Drug Value**
 - **Impact/value of this drug**
 - **Therapeutic Alternatives (if there are multiple drug options, does this drug have more value to you than others? If so, why?)**

*Captured in open-ended responses.

Endpoints that were added to the original pilot endpoints are bolded.

Distribution and Targeted Participation. Like the original survey, the update was distributed through advocacy networks and word-of-mouth. For this iteration, we focused on soliciting responses from individuals with conditions that were likely to be treated by specialty and high-cost medications and who resided in states with active PDABs or considering establishing one (Colorado, Maryland, Minnesota, New Jersey, and Washington, Virginia).

To ensure a sufficiently large and analytically robust sample, we:

- Enlisted Health Union to connect us to patient advocates to promote the survey (patient advocates were paid \$15 for each referred patient that completed the survey).
- Solicited paid responses through SurveyMonkey Audience to ensure responses from five states with active PDABs (Colorado, Maryland, Minnesota, New Jersey, and Washington) and one state strongly considering the establishment of a PDAB in 2026 (Virginia). We paid for more respondents in Maryland because of their efforts to look for true patient affordability challenge drivers (“Non-UPL Track”).

Paid respondents were required to have respondent profiles that identified one or more medical conditions. They were further qualified using survey questions about their condition(s) and prescription use. Finally, all responses were screened for inconsistent and nonsense answers, and excluded if either were found.

The inclusion of paid respondents yielded unanticipated benefits that strengthened the dataset's generalizability. While the primary goal was increased volume, the paid cohort contributed important demographic balance, including:

- Improved gender balance
- Enhanced racial representation
- Greater socioeconomic detail, particularly across working class families
- The ability to offer robust insight in several key states.

METHODOLOGICAL CONSIDERATIONS

The streamlined design aimed to reduce respondent burden while preserving the nuance necessary to understand why affordability challenges occur and how they affect patient decision-making. However, relying on respondents to explain “their (un)affordability why” in open-ended comment boxes - rather than providing multiple choice questions (i.e., “Did you use financial assistance and, if so, which type(s)?” - we were unable to obtain “the why” from those who chose not to share qualitatively. While this percentage of respondents was small, and thus did not impact our findings, it highlighted the importance of having context; without it, narratives are left for interpretation.

The survey was conducted between August and October 2025.

See Appendix for survey questions, pilot study endpoints, and initial Patient Research Partner CO PDAB survey design analysis and recommendations that, after being dismissed, ultimately led to our studies.

SURVEY DETAILS: ENDPOINTS, QUESTIONS, NEEDS ASSESSMENT

SURVEY ENDPOINTS

Endpoints that were added to the original pilot endpoints are **bolded**.

- Diagnosis and Comorbidities
- Prescription Drug Usage (current, past, **never used**); Reasons for discontinuation
- Out-of-pocket costs
- Patient-reported “affordability” assessment (“the why”)*
 - Barriers: insurance coverage, cost, financial assistance, lifestyle circumstances, hardships*
 - **Patient-defined affordability and patient-identified affordability threshold**
- Prescription Drug Value
 - Impact/value of this drug
 - **Therapeutic Alternatives (if there are multiple drug options, does this drug have more value to you than others? If so, why?)**

*Captured in open-ended responses.

NEEDS ASSESSMENT

View letters submitted by AiArthritis to the Colorado Prescription Drug Affordability Board (PDAB) expressing concern regarding patient-facing data collection and analysis:

<https://bit.ly/PICSurveyNeedsAssessment>

SURVEY QUESTIONS

[View the survey questions.](#)



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.

WWW.EACHPIC.ORG



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**ENSURING ACCESS THROUGH
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