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August 18, 2025

Oregon Prescription Drug Affordability Board
Department of Consumer and Business Services
350 Winter Street NE
Salem, OR 97309-0405

Patient Experience Survey Findings and Opportunities for Collaboration

Dear Members and Staff of the Oregon Prescription Drug Affordability Board:

The Ensuring Access through Collaborative Health (EACH) and Patient Inclusion Council (PIC) is a two-part coalition that unites patient organizations and allied groups (EACH), as well as patients and caregivers (PIC), to advocate for drug affordability policies that truly benefit patients.

We are pleased to share the results of our *Patient Experience Survey: Prescription Drug Affordability and Unaffordability*, a national, patient-led initiative designed to address gaps in how affordability is currently measured by policymakers. The survey was created by patients and research partners after recognizing that the simplified surveys often used by boards and lawmakers fail to capture the deeper context behind patient affordability challenges.

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

Why We Conducted This Survey

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

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

What We Learned

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

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

2. **“Unaffordable” often means inaccessible.** When patients labeled drugs unaffordable, they were often describing access issues, not cost alone. One hundred percent of patients who stopped taking a drug “due to affordability reasons” actually cited insurance barriers in the open-ended comments, like denials, step therapy, or being forced to switch off assistance. Seventy-five percent of those who skipped or stretched doses pointed to insurance-related delays.

3. **Insurance and copay assistance—not drug type or price—were the strongest predictors of affordability.** Among those taking specialty drugs, seventy-one percent with financial assistance said their medication was affordable, and eighty-eight percent of patients who reported paying $0–$10 per month used financial assistance. *No individual drug emerged as singularly creating hardship.*

Implications for PDAB Processes

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

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

We recommend that the board:

- **Enhance patient engagement:** Incorporate in-depth, patient-led data collection, pairing quantitative data with qualitative narratives before and during affordability reviews to better direct board efforts, including which, if any, medications are posing affordability issues for patients.

- **Broaden definitions of affordability:** Include cumulative health-related costs, insurance barriers, and personal financial context in addition to drug price.

- **Co-design engagement with patient organizations:** Use patient-led listening sessions, focus groups, and surveys to capture unfiltered experiences, ensuring diverse participation and adequate representation of vulnerable populations to address patient-identified issues.

- **Assess downstream impacts of policies before implementation:** Engage insurers, PBMs, providers, and patients to anticipate how affordability policies may affect coverage, access, and continuity of care.

Invitation to Partner

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

We would welcome the opportunity to:

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

Thank you for your ongoing work to improve drug affordability. We look forward to the opportunity to work alongside you to ensure that affordability reviews translate into meaningful improvements in patient access, equity, and health outcomes.

Sincerely,

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Attachments:

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

PATIENT
INCLUSION COUNCIL

PATIENT EXPERIENCE SURVEY: PRESCRIPTION DRUG AFFORDABILITY AND UNAFFORDABILITY

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PUTTING PATIENT VOICES FRONT AND CENTER

Background. Across the country, efforts to lower prescription drug costs through price-setting policies, by state Prescription Drug Affordability Boards (PDABs) and federal actions like the Inflation Reduction Act (IRA), are gaining momentum. Yet these efforts often fail to include meaningful input from the patients most affected.

The Patient Inclusion Council (PIC), led by patients and patient organizations, supports drug affordability but is concerned that these efforts overlook key patient realities and miss the deeper context behind why patients consider drugs affordable or not.

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.

Rationale. This survey was developed after patients recognized a serious disconnect between their real-world experiences and the results of short and overly simplified surveys used by affordability boards. These surveys often rely on yes/no questions and lack space for patients to explain their individual situations.

Methods. In response, PIC partnered with patient research partners (PRPs), Ensuring Access through Collaborative Health (EACH) patient organization participants, and a research consultant to create the *Patient Experience Survey: Prescription Drug Affordability and Unaffordability*. This 51-question tool, based on 8 endpoints, captures quantitative data (multiple-choice and short fill-in-the-blank questions) and qualitative data (addition of comment boxes to collect patient experience data). The survey was conducted between August and December 2024.

Study endpoints included:

- Diagnoses, treatment history, and medication impact
- Out-of-pocket costs and financial strain
- Perceptions of affordability
- Barriers to medication adherence
- Insurance navigation and access to financial assistance programs

Distributed through advocacy networks and word-of-mouth, and analyzed by a data scientist and PRP, this survey and its results offer policymakers actionable insights rooted in patient experience.

See Appendix for endpoints, survey questions, and initial PRP CO PDAB survey design analysis and recommendations.

PATIENT EXPERIENCE SURVEY: PRESCRIPTION DRUG AFFORDABILITY AND UNAFFORDABILITY

FINDINGS AND POLICY RECOMMENDATIONS

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KEY FINDINGS

By focusing on the affordability of a single prescription drug, decision-makers miss critical context about patients' broader challenges. Across all price points, patients may struggle with out-of-pocket (OOP) costs due to insurance barriers, the cumulative cost of multiple medications, evolving life situations, and expenses related to non-drug disease management.

Our preliminary data shows that while patients with higher OOP costs are more likely to report a drug as unaffordable, affordability does not strictly correlate with patient costs. Instead, it reflects complex personal experiences, evolving circumstances, and differing interpretations of what "affordability" means.

1. Affordability Is Deeply Personal and Often Subjective

The survey underscores that affordability does not neatly correlate with income level or OOP drug costs. **Instead, affordability hinges on each individual's unique life circumstances, health burdens, and financial responsibilities.**

- **20% of patients paying $0-$10 per month still reported their medications as unaffordable.** Some reasons included insurance transitions, accumulators, low income levels, or high list prices.
- Across responses, some individuals reported low costs as significant, and some individuals reported high costs as manageable.
- One patient described affordability not as a dollar amount, but as whether a cost could be managed "even after shifting around your budget."

"Affordability" is not a fixed metric; it is filtered through personal financial pressure, health status, and available support systems.

2. Perceived Affordability Often Reflects Broader Financial Anxiety, Not Just OOP Costs

Many patients labeled their medication as unaffordable even when reporting low monthly OOP costs, often due to factors beyond what they directly paid.

- Across various OOP cost levels, including those paying $0-$10 a month, several cited their cost **'unaffordable' based on list prices and not true OOP costs**.
- 77% of participants reported additional OOP medical costs for doctor visits, labs, imaging, or assistive devices—expenses that compound financial strain and influence perceptions of affordability.

Many affordability judgments are made in the context of systemic costs, current life situations, additional health costs, or anticipated future hardship, not just current medication costs.

KEY FINDINGS (CONT)

3. Affordability and Access Are Often Intertwined

When patients say a drug is “unaffordable,” they may be describing access problems caused by insurance barriers, not just financial strain.

- **100%** of patients who said they stopped taking a drug due to affordability cited insurance-related reasons: denials, prior authorizations, step therapy, or exclusion of copay assistance on Medicare.
- **75%** of patients who skipped or stretched doses also reported at least one instance of care disruption due to insurance delays, not price.
- **Only 14%** cited OOP drug cost alone as the reason for missed doses, and even these patients often had low costs.

Access delays and insurance rules, not cost alone, are often the real barriers hidden behind “affordability” labels.

4. Insurance and Financial Assistance Programs Shape Patient Perceptions of Affordability

The strongest predictors of whether a patient found their medication affordable were the type of insurance they had and whether they had access to financial assistance programs.

- Among those taking specialty drugs:
    - **71%** with financial assistance said their medication was affordable.
    - **Only 38%** without financial assistance felt the same.
- Medicare patients were more likely to report unaffordability, in part because they are often ineligible for manufacturer copay assistance programs.
- **Of those paying $0–$10 per month, 88% used financial assistance.**
- Patients on Medicare were disproportionately represented among those who paid $250+ per month.
- Other types of financial assistance appear to help with affordability, but patients struggled to distinguish program differences, making it difficult for us to speak to the value of other types of programs.

Insurance status and assistance program eligibility—not income or drug type—were often the decisive factors in whether patients felt they could afford their medications.

WHAT PATIENTS NEED: NEXT STEPS 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, evolving life situations, and the cumulative burden of managing chronic illness. The following recommendations reflect the needs and priorities that patients identified through the survey:

Improve Patient Support Programs

Expand Access to Financial Assistance Programs: Expand and protect state and federal Patient Assistance Programs (PAPs) for individuals with low incomes, disabilities, or those who lack insurance coverage. Increase awareness and enrollment in manufacturer copay assistance.

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

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

Reform Patient-Identified Barriers

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

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

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

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

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. The Patient Inclusion Council (PIC) launched this survey to bring forward that missing context. In future phases, PIC will build on these findings by expanding the survey sample, increasing the diversity of participants, further exploring and expanding our endpoints, and offering flexible and varied formats to make participation more accessible and inclusive.

These insights will be continuously shared with policymakers, researchers, and affordability review boards to support smarter, more equitable solutions. We call on state and federal agencies to improve their own engagement practices and data collection methods.

Improve Patient Engagement

Build Better Surveys: Traditional surveys rely heavily on yes/no or multiple-choice questions, missing the depth behind a patient's answer. The PIC survey 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."

Capture the Full Patient Experience: Effective engagement must reflect the full patient journey. Future data collection efforts should include questions on diagnosis and treatment history, full out-of-pocket spending, financial trade-offs and perceptions of affordability, barriers to adherence (e.g., delays, switching, denials), and navigation of insurance and assistance programs.

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.

Improve Data Collection

Better Define Affordability: Develop standardized, patient-informed definitions of affordability that account for individual financial circumstances, cumulative health-related expenses, and changing life events. Definitions should distinguish between retail price, OOP costs, and perceived burden.

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, 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

SURVEY RESULTS

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POPULATION SNAPSHOT

Of our initial 143 responses, **43 (30%) were excluded** for not listing a drug, listing a fake or non-prescription drug, or residing outside of the U.S.

100
PATIENTS

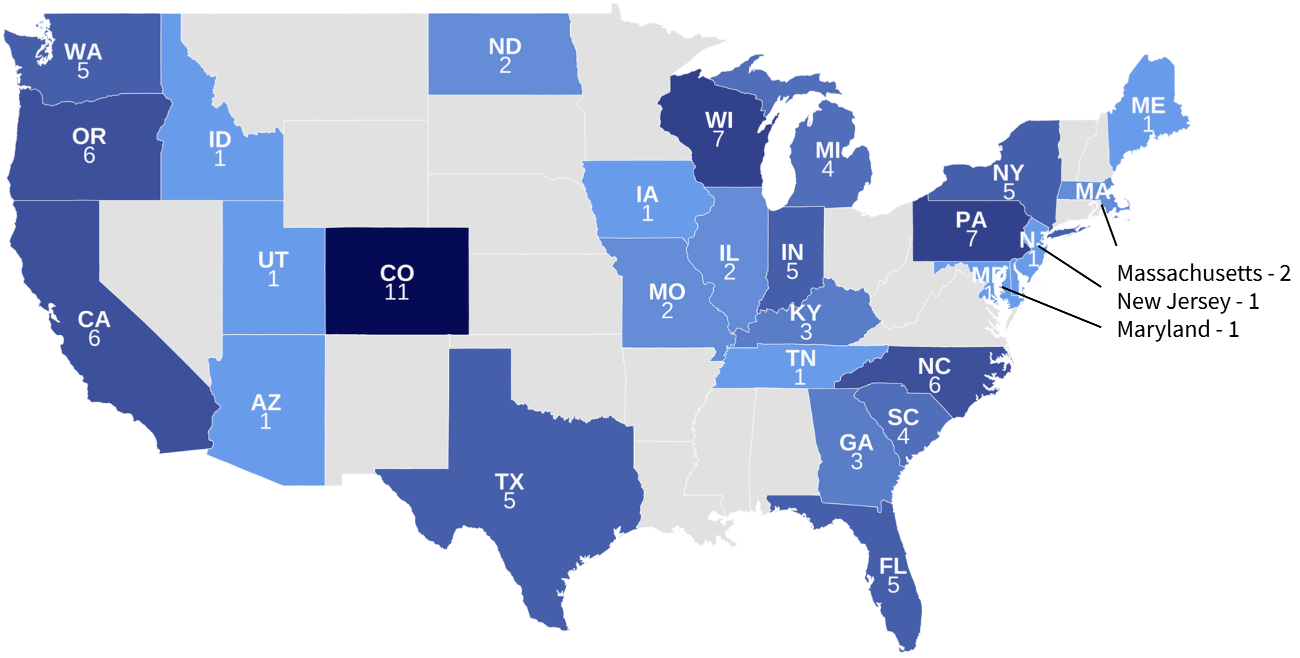
70
DRUGS

40
DIAGNOSES

77%
COMORBIDITIES

77 of the 100 participants reported being diagnosed with one or more additional conditions (comorbidity)

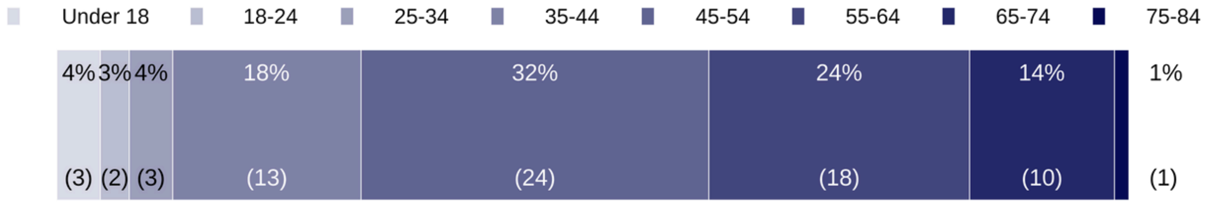
RESPONDENTS' GEOGRAPHIC LOCATION



Total Responses: 100

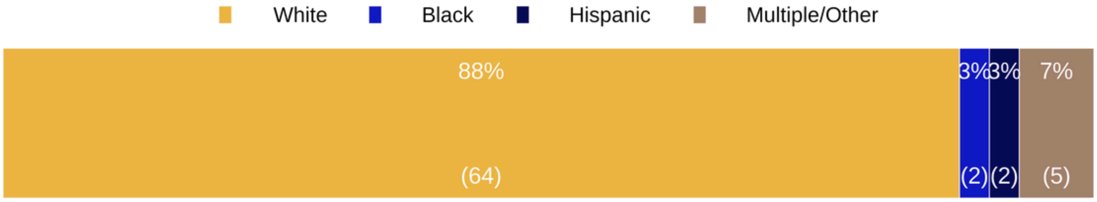
DEMOGRAPHIC BREAKDOWN

DISTRIBUTION OF PATIENTS' AGE



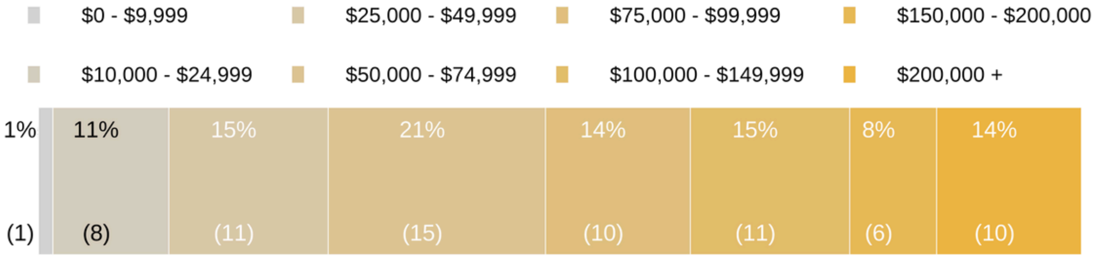
Total Responses: 74

DISTRIBUTION OF PATIENTS' RACIAL AND ETHNIC IDENTITIES



Total Responses: 73

DISTRIBUTION OF PATIENTS' HOUSEHOLD INCOME



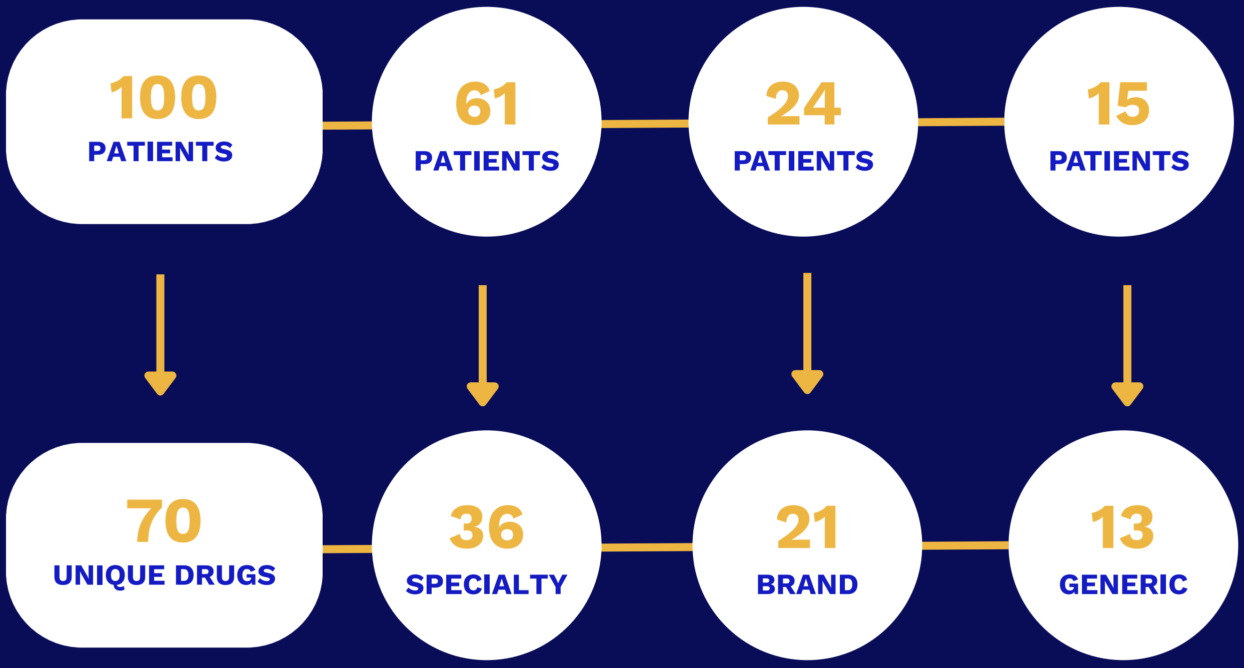
Total Responses: 72

PATIENTS’ PRESCRIPTIONS

We classified patients drugs into three types--Specialty, Brand, and Generic. Specialty drugs include biologic and biosimilar medications, GLP-1s, as well as other high-cost therapies that typically require special handling, administration, or ongoing monitoring.

Of the 100 patients in our study, 61 took specialty drugs. Several patients reported on the same specialty drugs. In total, 14 specialty drugs were reported on by two or more patients. Five of the six most commonly reported drugs were specialty medications--Enbrel (6), Creon (6), Humira (3), Rinvoq (3), and Remicade (3).

Multiple patients reported on two brand named drugs--Keppra (3) and Qulipta (2). Multiple respondents reported on two generic drugs--Levothyroxine (2) and Lacosamide (2).



100 PATIENTS → **70** UNIQUE DRUGS

61 PATIENTS → **36** SPECIALTY

24 PATIENTS → **21** BRAND

15 PATIENTS → **13** GENERIC

A complete list of drugs can be found in the appendix.

CURRENT SURVEYS ARE MISSING THE “WHY”

Current patient-facing surveys that assess prescription drug affordability often miss context in the analysis. **We sought to understand patient-reported reasons for saying drugs were affordable or unaffordable so we can steer efforts to address these challenges based on what patients say they need us to address most.**

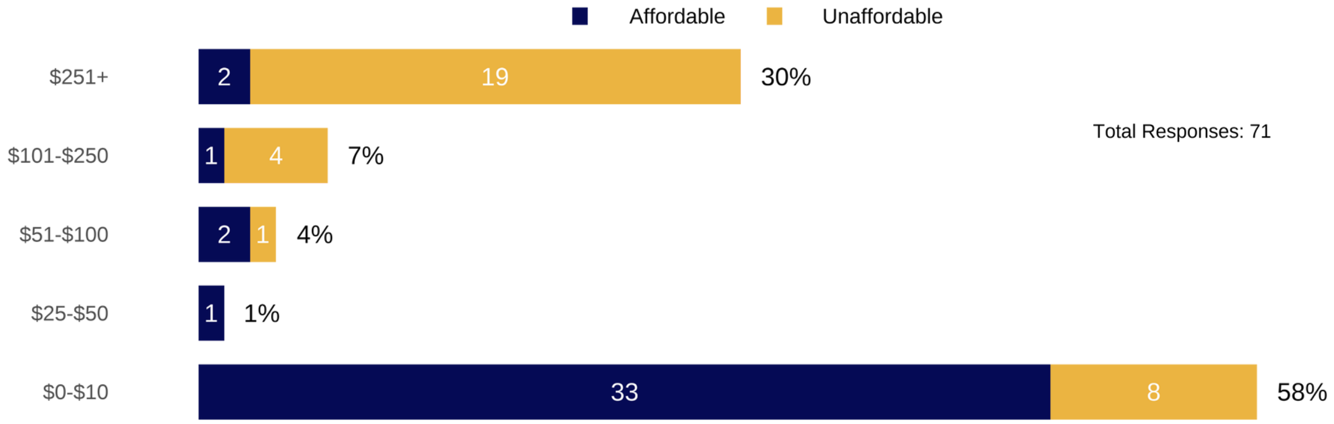
57% AFFORDABLE **43% UNAFFORDABLE**

57% OF PATIENTS REPORTED THEIR MEDICATION AS AFFORDABLE, WHILE **43%** REPORTED THEIR MEDICATIONS AS UNAFFORDABLE.

BUT *WHY*?

AFFORDABILITY BY MONTHLY DRUG COST

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



In only asking about affordability of one prescription drug, decision-makers may overlook information that is critical to understanding patients’ struggles. At all price points, some patients struggle with access due to **insurance barriers, high cumulative medication costs, and non-pharmaceutical disease management.**

Our preliminary data indicated 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.*** Instead, it is largely based on **dynamic personal experiences and opinions, evolving life situations, and perspectives related to the term “affordability.”**

INDIVIDUALS REPORTING PAYING $0-$10 PER MONTH

58% (41 people) of respondents (71 people) reported they paid $0-$10 in out of pocket costs per month.

80% (33 people) reported this amount was affordable.
20% (8 people) reported this OOP drug cost was unaffordable.

WHY DID PATIENTS REPORT THIS AMOUNT AS UNAFFORDABLE?

- **Insurance changes.** 38% (3 of the 8 people reporting this price point as unaffordable) considered <$10 reasonable, but reported the medication unaffordable ***because they were forced to stop taking the drug due to insurance changes that increased cost****;* Two patients cited switching to Medicare.
- **Accumulator-related costs.** 12% (1 person) of patients were comfortable with current costs, but struggled with overall costs due to an accumulator program, where the insurance company does not apply copay assistance programs to the deductible.
- **Low Income.** 12% (1 person) reported an income below $25,000 per year and also reported a $0 -$10 OOP cost per month unaffordable.

OPINIONS ON DRUG COSTS

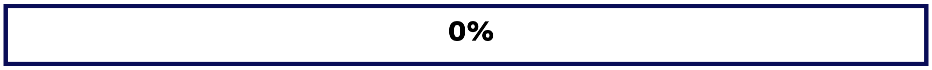
38% (3 people) of the individuals reporting drugs unaffordable gave reasons unrelated to their own out of pocket costs:

“Without copay assistance, I couldn’t afford the $1735 monthly [out-of-pocket cost].”

“State Medicaid plan pays for my copay and private insurance covers the drug. Out of pocket it costs more than $350,000 per year. That is entirely unaffordable.”

INDIVIDUALS REPORTING PAYING $11 - $25 PER MONTH

No respondents reporting paying between $11 - $25 per month for their prescription.



INDIVIDUALS REPORTING PAYING $26 - $50 PER MONTH

1% (1 person) of survey respondents (71 people) reported they paid between $26-$50 in out of pocket costs per month.

100% (1 person) reported this amount was affordable.

Financial assistance available. This person reported this amount was affordable due to a manufacturer copay assistance plan.

OPINIONS ON DRUG COSTS

“$50/month is way more affordable than continuous reconstructive surgeries, multiple ER visits, and loss of income from disability. It also keeps me from taking 9 other prescriptions that are just as pricey.”

INDIVIDUALS REPORTING PAYING $51-$100 PER MONTH

4% (3 people) of survey respondents (71 people) reported they paid between $51-$100 in out of pocket costs per month.

67% (2 people) reported this amount was affordable.
33% (1 person) reported this amount was unaffordable.

WHY DID PATIENTS REPORT THIS AMOUNT AS UNAFFORDABLE?

- **No financial assistance available.** This person stated there was no manufacturer copay assistance program available for this brand name drug.
- **Highest out-of-pocket cost of all prescription drugs.** This brand name prescription was the highest out-of-pocket cost of the multiple medications they took. They reported occasions when medication took precedence over their basic needs.

OPINIONS ON DRUG COSTS

Opinions about retail cost and diagnoses with disabilities shaped affordability response. *This person shared that the retail cost at the time ($1,200) was unreasonable and that they believed everyone with “cognitive” diagnoses should have $0 copays.*

INDIVIDUALS REPORTING PAYING $101-$250 PER MONTH

7% (5 people) of survey respondents (71 people) reported they paid between $101-$250 in out of pocket costs per month.

20% (1 person) reported this amount was affordable.
80% (4 people) reported this OOP drug cost was unaffordable.

WHY DID PATIENTS REPORT THIS AMOUNT AS UNAFFORDABLE?

- **Insurance changes.** 25% (1 person) noted their GLP-1 for obesity was affordable when they had employer insurance, but not once they lost their job and became uninsured.
- **No financial assistance available.** 25% (1 person) could not access manufacturer copay assistance due to Medicare limitations. *"This is a tier 4 drug on my prescription plan so I paid 50% of the cost which was usually around $130-170 for a 25 day supply. In addition I pay a monthly premium of approximately $80 for prescription drug coverage."*
- **Reliant on brand drug.** 25% (1 person) faced higher costs for a brand name drug. They did not indicate why they could not take the generic version of this medication, but did note stretching or skipping doses to manage affordability.
- **Out of pocket cost did not cause financial hardships.** Of the 3 people who completed the section on hardships caused by this drug or other drugs and reported this OOP amount unaffordable, **100% reported no financial hardships.**

OPINIONS ON DRUG COSTS

One person was thinking broadly about cost, not about current costs. A parent reporting for their young adult son identifies the cost as unaffordable, but has not experienced hardship, and notes having "very good" insurance. Her concern seems to center on her son's ability to afford the medication saying, *"If my son wasn't on my insurance there is no way he could afford [his medication]."*

BREAKDOWN: $251-$500, $501-$1000, $1000+

30% (21 people) of survey respondents (71 people) reported they paid $251+ in out of pocket costs per month.

10% (2 people) reported this amount was affordable.
90% (19 people) reported this OOP drug cost was unaffordable.

DEEP DIVE - EXPLORING THE ‘WHY’ BEHIND $251+ COSTS

Current processes are failing to understand the ‘why’ behind patient affordability and unaffordability. Current government prescription drug affordability reviews are trial-and-error processes where prescription drugs are chosen for investigation based largely on retail price and potential cost to the healthcare system as a whole. Since they are not chosen based on what patients say they can or cannot afford, patient testimony is collected after drug selection; yet the methods of collecting that information from patients is not robust enough, leaving decision makers to make affordability determinations based on what may benefit the larger healthcare system (including insurance companies and pharmacy benefit managers/PBMs).

The purpose of doing this survey and in-depth analysis was to show why it is essential to *listen to what patients say* are the reasons they *are or are not* struggling with prescription affordability - and then *guided by those insights*, determine what approaches and solutions will help patients most. The results show the majority of patients on specialty drugs who are insured privately or through their employer pay $0-$10 OOP a month due to manufacturer copay assistance programs. ***So why did a significant amount of respondents report paying $251+ a month for the same type of drug?***

This break out analysis into the highest reported OOP costs for prescription drugs provided insights that will help us drive solutions based on where we feel we can help patients most:

- **Medicare.** Those reporting $251+ OOP a month were largely on Medicare.
- **OOP costs are determined by the insurance plan.** Once deductibles are met, OOP costs are more affordable. Also, patients unable to take doctor prescribed medications due to insurance barriers pay more to access them.
- **Access to financial assistance and knowledge about them.** Those unable to access financial assistance are largely those on government plans, but some do not qualify to to high income. Yet still others are unaware financial assistance may be possible.

INDIVIDUALS REPORTING PAYING $251-$500 PER MONTH

17% (12 people) of respondents (71 people) reported they paid $251-$500 in out of pocket costs per month.

17% (2 people) reported this amount was affordable.
83% (10 people) reported this out of pocket drug cost was unaffordable.

WHY DID PATIENTS REPORT THIS AMOUNT AS UNAFFORDABLE?

- **Cost reported for generic drug (Tylenol/Codine)** - Employer insurance did not approve other medications. A ***$300 drug test is required, which was included in the amount paid out of pocket per month***
- One with employer insurance and on a specialty drug used a **copay assistance program that did not cover enough.**
- One person used individual insurance coverage for their brand name drug and reported that this **drug costs more at the start of the year before deductibles have been met.** This person reported that this medication was covered by individual insurance. However, they also reported the manufacturer stopped providing copay assistance and added in the open-ended comments: *“If you are on Medicare most copay assistance programs from drugs go away. It's ridiculous.”*
- **50% (5 of 10 people) were on Medicare and reported this out-of-pocket amount unaffordable.**
  - 1 person on a specialty drug mentioned the **Patient Assistance Program (PAP) annual income maximum was too low for them to qualify**. This person also reported, *“Drug plans on Medicare have* ***huge deductibles and co pays/coinsurance****.”*
  - 1 person on a specialty drug mentioned this was the **highest out of pocket amount during the start of the year due to deductible** and that this was *“equal to a car payment, which stretched beyond [their] budget.”*
  - 1 person was prescribed a brand name prescription for migraines, however, did not provide information about applying for financial assistance. *“I have to choose between food and [this drug]. I am very grateful for the local food banks. Without them I would not be able to afford it.”*
  - **Low income.** 1 person prescribed a brand drug was concerned about the cost compared to their annual household income. *“I'm retired with one income in this household. I now have limited income compared to my working years.”*

INDIVIDUALS REPORTING PAYING $501-$1000 PER MONTH

8% (6 people) of all respondents (71 people) reported they paid $501-$1000 in out of pocket costs per month.

8% (6 people) reported this out of pocket drug cost was unaffordable.

WHY DID PATIENTS REPORT THIS AMOUNT AS UNAFFORDABLE?

Insurance barriers

- **Financial assistance limited** Of the 4 people (67%) on Medicare, 2 using specialty drugs and 1 using a brand name medication, reported they did not have access to manufacturer copay assistance programs. One person on a specialty medication reported using financial assistance from an organization that was not the drug manufacturer.
- **Reliant on brand drug.** One respondent on employer insurance had to pay a higher out of pocket amount to access the brand version since insurance would only cover the generic.
- **Cost higher early in the year.** The other respondent on employer insurance reported their brand name drug costs $0 once the deductible was met.
    - They were **unsure if financial assistance was available**. *We found significant discounts on GoodRx and sent information to the participant.*

INDIVIDUALS REPORTING PAYING $1000+ PER MONTH

4% (3 people) of respondents (71 people) reported they paid $1000 in out of pocket costs per month.

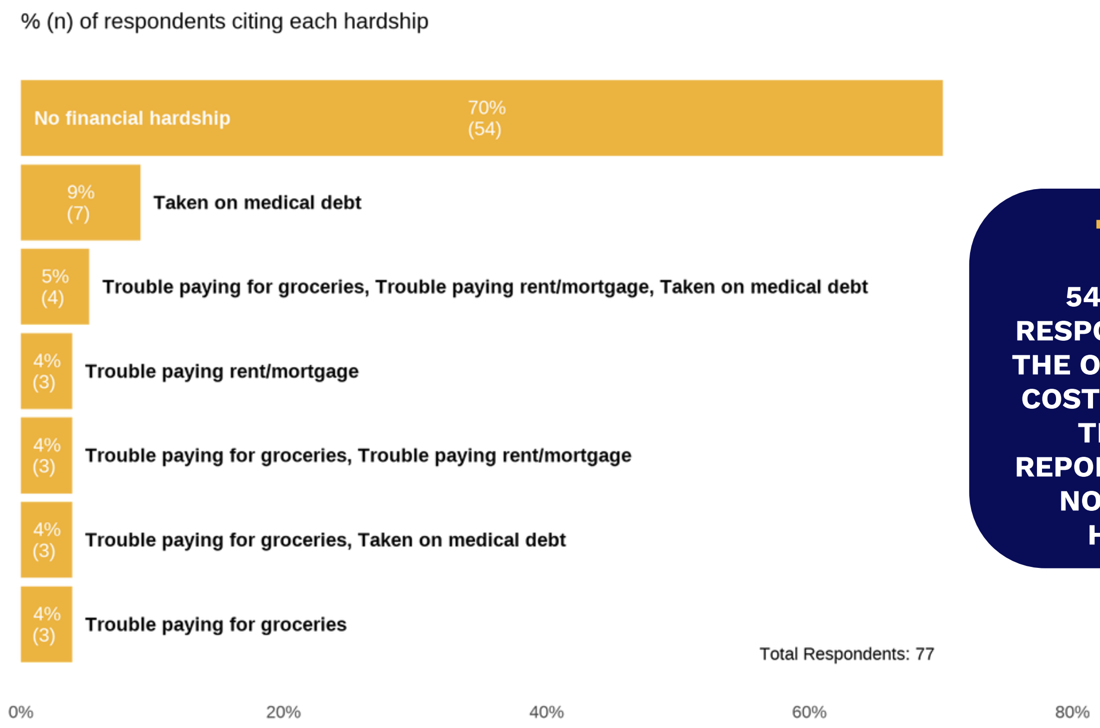
4% (3 people) reported this OOP drug cost was unaffordable.

WHY DID PATIENTS REPORT THIS AMOUNT AS UNAFFORDABLE?

- **Insurance barriers**
    - One respondent was on Medicare, tried all alternative therapies and could not tolerate them. **This drug was not covered by their insurance plan, so they had to pay the out of pocket cost.**
    - Two people reported their **insurance did not cover the medication**. One (who did not list the type of insurance they have) was waiting for a doctor appeal or "alternate funding." The other, who had individual insurance and Medicaid, stated their copay assistance program ended, forcing them to stop taking the drug. **While neither actually paid $1000+, this would be unaffordable.**

FINANCIAL HARDSHIPS

While the majority of respondents did not feel the OOP cost of this drug caused financial hardships, factors such as personal definition of affordability and total costs of all prescriptions mattered. Even some who reported the OOP cost for this medication affordable reported hardships.



70%

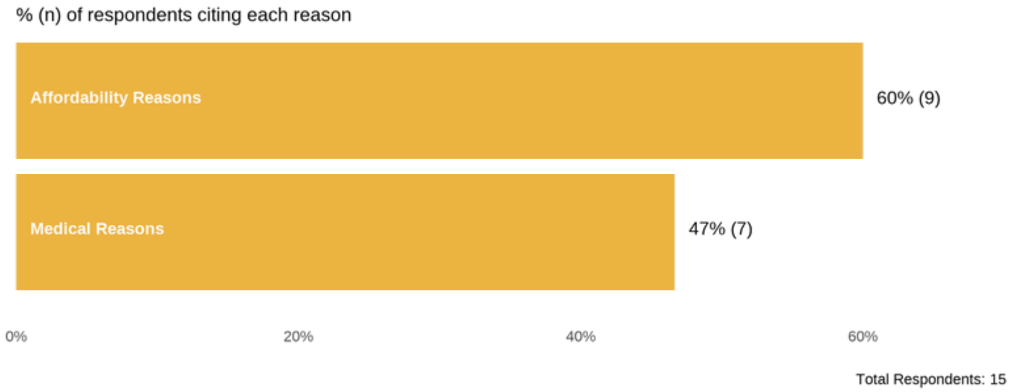
54 OUT OF 77 RESPONDENTS SAID THE OUT OF POCKET COST OF THE DRUG THEY WERE REPORTING CAUSED NO FINANCIAL HARDSHIP

70% (54 people) said the OOP cost of the drug they were reporting caused no financial hardship. Of those reporting financial hardship:

- 18% (14 people) reported taking on medical debt due to the ***total out of pocket cost of all their prescriptions.*** All but 2 patients had comorbid conditions.
- 10% of patients paying **$0-$10** (4 people of 39 respondents) reported one or more hardships.
- Of the 3 people who reported paying $151-$250 OOP, said this was unaffordable, and who completed the section on hardships caused by this drug or other drugs **100% reported no financial hardships.**
- **Affordability concerns were significantly higher when out of pocket costs reached $251+. Of those respondents:**
  - 79% (15 people of 19 respondents) reported financial hardship ***due to this drug.***
  - 85% (17 of 20 respondents) reported hardship from the ***total out of pocket cost of all their prescriptions.***

INSURANCE CHALLENGES UNDERLY UNAFFORDABILITY AND ADHERENCE

WHY PATIENTS STOPPED TAKING MEDICATIONS



We asked the question, “Why did you stop taking this medication? Select all that apply.” Answer options ranged from medical reasons to cost to insurance requirements.

- Of the 15 patients who reported this is a medication they no longer use, **47% (7 patients) stopped for medical reasons** (i.e., side effects, biologic stopped working, remission).
- **60% (9 patients) chose the option “I could not afford the out of pocket cost of the drug.”** ***But why couldn’t they afford it?***

WHAT IS BEHIND THE ANSWER, “I COULD NOT AFFORD THE OUT OF POCKET COST OF THE DRUG”?

By providing comment boxes after each question, respondents were able to provide details about their answer. **This context is missing in current surveys associated with government drug affordability initiatives, lending to misinterpretation of prescription drug “affordability”.** In reality, affordability often goes beyond just “cost.”

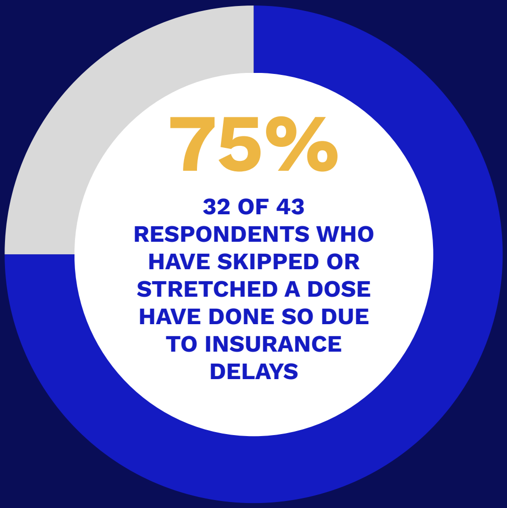
100%

of the 9 patients who chose “I could not afford the out of pocket cost of the drug” as an answer, **in the open ended comments sections that followed 100% of them described doing so due to insurance-related challenges.** These included insurance denials, step therapy, “buy-and-bill” requirements, and Medicare not permitting copay assistance. ***For transparency, we have provided the non-identifying, raw data with open ended responses below.***

REFERENCE: Raw data, Q22 “Why did you stop taking this medication?” https://bit.ly/PICSurveyStopPrescriptionWhy

INSURANCE DELAYS ARE TOP DRIVER OF SKIPPED DOSES

- **52%** (43 people of the 83 people who responded to this question) of patients **have skipped or stretched a dose** of the prescription on which they were reporting.
  - Of these people, **75% (32 people) reported *at least one instance of care disruption due to insurance issues*.**
- **14%** (12 people) reported the **out of pocket cost of this prescription as the reason.** Of these:
  - **25%** (3 people) reported paying **$0-$10** a month
  - **25%** (3 people) reported paying **$101-$250** a month
  - **42%** (5 people) reported paying **$251+** a month for this prescription.
  - One person did not report any OOP cost.



- **6%** (5 people) reported they stretched or skipped a dose of this prescription drug because ***the total combined cost to fill all their prescriptions*** *was too expensive.*

- **48% of respondents** (40 people of 83 responses) reported they have never skipped or stretched a dose of this prescription.

"At one point the insurance company said I had to switch [medications]. It took so long to find a drug to stabilize me so we fought this. ***In the process I developed neuropathy...I still...cannot feel my feet.*** *Finally, after I had a site reaction to the...[new medication]...they let me switch back."*
- Patient in MO with Private Insurance through the exchange

"When the insurance company ***delays my refill due to CONSTANT reauthorizations,*** *this makes my symptoms flare up. I was stable and then they wreck it.* ***The insurance company...techniques (prior auth, other delay tactics) are the ONLY obstacle to my accessing the medicine I need."***
-Patient in MI with Private Insurance through an employer

"My insurance company has a limit on [the number of pills they cover] per month*...It's nowhere near enough to treat a life of neurological pressure headaches. I suffer a lot."*
-Patient in PA with insurance through their spouse.

FINANCIAL ASSISTANCE IMPACT

While there are different types of payment assistance plans (i.e., manufacturer copay assistance programs, Patient Assistance Programs/PAPs, nonprofit assistance), most patients referred to any type of assistance as "copay assistance." Unless it was clear all respondents were referring to manufacturer copay assistance, the term "financial assistance" is used.

PAYMENT ASSISTANCE OFTEN EQUATES TO AFFORDABILITY

- **61% of patients** (61 people of the 100 responding) reported taking **specialty drugs.** However, only 48 of them provided cost and affordability data. Of these 48 people:
    - **64%** (31 people) reported **paying $0-$10 out of pocket a month** for their medication.
    - **56%** (27 people) benefited from **manufacturer copay assistance.**

- Of the **37 respondents with financial assistance** who also reported on drug affordability, **65%** (24 people) said their **drug was affordable.**
    - Of the **18 respondents taking specialty drugs without financial assistance** who also reported on drug affordability, **44%** (8 people) said their **drug was affordable.**
    - **9 people** on specialty drugs who reported they do not have financial assistance pay $0-$10 out of pocket a month.
    - Of the **28 respondents on brand or generic drugs without copay assistance** who also reported on drug affordability, **57%** (16 people) said their **drug was affordable.**

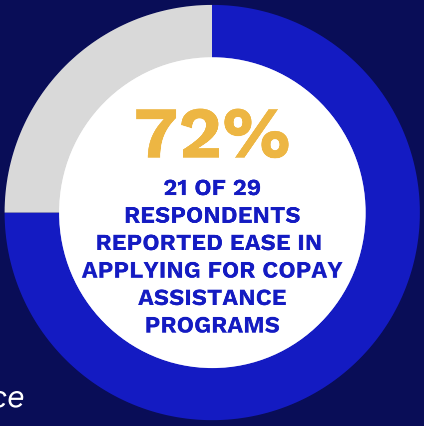
- **50%** (9 people) of the 18 patients taking a **biologic/specialty drug without financial assistance** who reported on their insurance type **were on Medicare.**

- Of the **41 respondents** who reported **paying $0-$10** for any type of medication where financial assistance was available (specialty or brand), **88% (36 people) had financial assistance.**

EASE IN SETTING UP COPAY ASSISTANCE INCREASES ACCESS

72% (21 of the 29 people) who were eligible for manufacturer copay assistance programs and who responded to this question ***reported no issues applying for the manufacturer copay assistance program. However, they did report issues communicating with their insurance company or specialty pharmacy:***

"While I did not have any issues applying for assistance, my insurance company does require I call and get the approval monthly for my copay assistance which takes anywhere from 20 minutes to 3 hours every month."

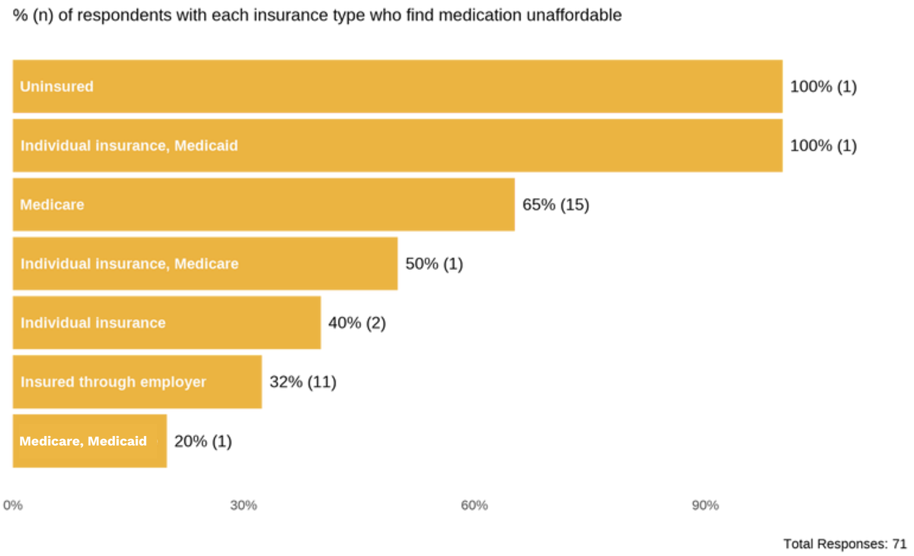


AFFORDABILITY CHALLENGES WITH MEDICARE

Of participants **with insurance coverage,** most who cited their prescriptions as unaffordable had **Medicare.**

UNAFFORDABILITY BY INSURANCE TYPE

Several respondents reported multiple types of coverage.



65%

15 OF 32 RESPONDENTS WHO REPORTED THEIR MEDICATION UNAFFORDABLE WERE ON MEDICARE

“I reached the catastrophic stage of Medicare drug coverage because I took Oxervate for dry eyes that cost about $200,000 for the 8 week treatment cycle. This made all my covered drugs paid at 1000% for the remainder of 2024.”

“Pharmaceutical company stopped providing copay assistance when I had to go on Medicare due to disability...Medicare has a gap in coverage.”

“Once I switched [to Medicare] I could no longer afford this drug.”

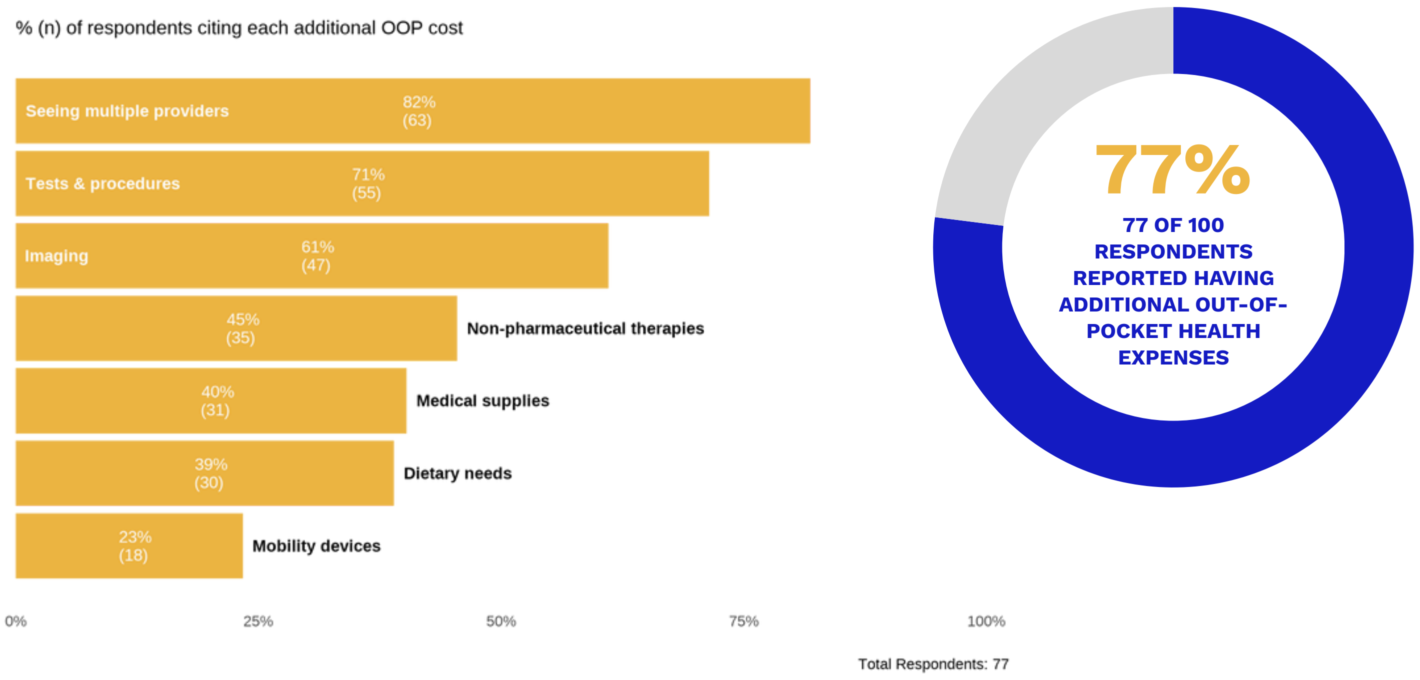
“This drug is only affordable while I am employed full time with company assisted medical benefits. However, I am retirement age but cannot retire at this time because my monthly payments would not be affordable going to several thousands of dollars in copays.”

ADDITIONAL OUT-OF-POCKET COSTS

Disease management is rarely straightforward or simple, **often involving many aspects of care simultaneously to receive diagnosis, treatment, or to improve quality of life.**

Of the **77%** (77 people of 100 respondents) who reported additional out-of-pocket costs, the majority deal with multiple cost factors outside of their medications. By far, the most common costs include **doctor and specialist visits (81%), medical procedures and testing (71%), and imaging services such as MRIs and CT scans (60%).**

CONTRIBUTING COSTS OUTSIDE OF PRESCRIPTIONS



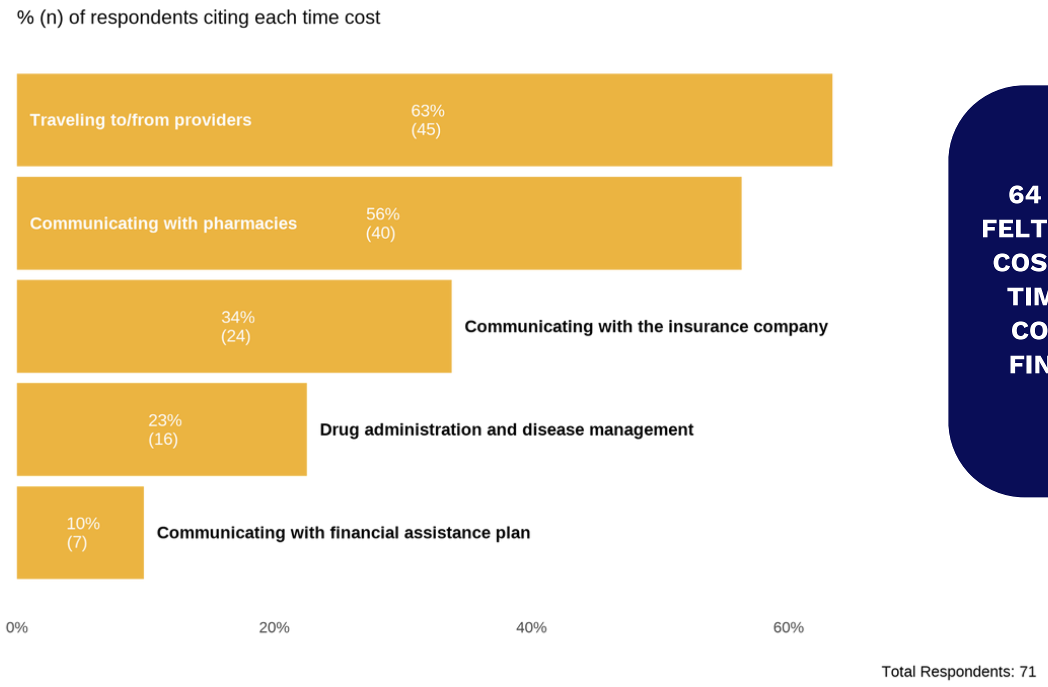
> ***“The costs of managing this condition are astronomical.*** *A CT scan is $500 out of pocket, surgeries are thousands, required blood work is only partially covered, and* ***I’ve paid out of pocket for all my mobility aids, bracing, and PT/OT.”***

TIME COSTS ASSOCIATED WITH DISEASE MANAGEMENT

The time lost to travel, phone calls, and appointments contribute to the overall costs and reflect the systemic burdens associated with managing chronic illness. **Patients reported frustrating inefficiencies and miscommunications between providers, pharmacies, and insurance companies, resulting in many hours lost trying to investigate and resolve these conflicts.**

The least time costs reported involved setting up manufacturer copay assistance programs, but those who apply for Patient Assistance Programs (potentially available to the uninsured and those with government insurance), report more time to complete applications.

COMMON SITUATIONS CONTRIBUTING TO TIME COSTS



90%

64 OF 71 RESPONDENTS FELT OTHER COMMON TIME COSTS WERE MUCH MORE TIME CONSUMING THAN COMMUNICATING WITH FINANCIAL ASSISTANCE PLANS

“I am enrolled in a patient assistance program and ***every time I need a prescription filled it seems like there is a problem with the insurance company and the drug company talking to one another,*** *and so I have to get involved in* ***multiple phone calls to straighten it out.”*** *- Patient in CA with Private Insurance and through an employer*

“Due to insurance company requirements, I have to call and order my prescription medication monthly rather that order online as in the past. ***These calls can take anywhere from 20 minutes to 3 hours.” -*** *Patient in MA with Private Insurance through an employer*

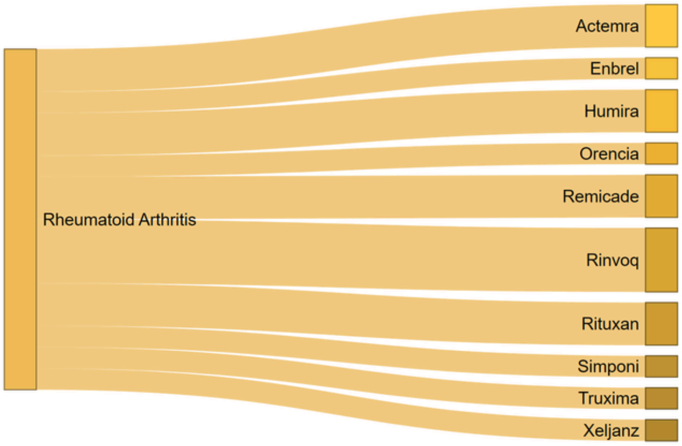
THE IMPORTANCE OF PREFERRED THERAPIES

Many patients, especially those with chronic conditions and comorbidities, rely on specific therapies that work best for them. Maintaining access to preferred treatments is critical.

THERAPEUTIC ALTERNATIVES SHOULD NOT BE CONSIDERED INTERCHANGABLE

Cost reviews often include comparing drugs with the same therapeutic class; however, treating these drugs interchangeably overlooks patient needs. Additionally, price controls could impact insurance coverage policies and put patients at risk of increased utilization management and potential non-medical switching of their medications. These policies could impede patient access to their required therapies or result in complications and harmful side effects.

PATIENTS WITH THE SAME CONDITION OFTEN REQUIRE DIFFERENT DRUGS



PATIENTS WITH RHEUMATOID ARTHRITIS HAD THE GREATEST VARIABILITY IN DRUGS TAKEN WITH 10 DIFFERENT DRUGS BEING USED ACROSS 16 PATIENTS

THERAPEUTIC ALTERNATIVES ARE NOT THERAPEUTIC EQUIVALENTS

58%

OF PATIENTS ON SPECIALTY DRUGS AND 43% OF ALL PATIENTS CYCLED THROUGH MEDICATIONS TO FIND WHAT WORKED

63%

OF PATIENTS WHO IDENTIFIED THEIR CURRENT DRUG AS THEIR MIRACLE DRUG NOTED THEY'D TRIED OTHER DRUGS

77%

HAVE COMORBIDITIES THAT MAY IMPACT WHICH TREATMENTS WOULD BE BEST FOR THEM, EVEN WITHIN THE SAME CLASS

NEXT STEPS AND ACKNOWLEDGEMENTS

EACH PIC
COALITION

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 rely on retail price and system-wide impact, selecting drugs for review without first understanding what patients actually struggle to afford. Gathering limited patient input after selection and failing to investigate discrepancies of patient cost burden fails to uncover the real reasons behind affordability challenges.

Our survey findings and analysis demonstrate a need to rethink the process, which must start with and end with the people who rely on these medications to live their best lives.

The findings make it clear. Many patients taking specialty drugs report paying $0–$10/month due to manufacturer copay assistance programs. Yet, some pay $50, some pay $150, and some pay $251+ *for the same drug or class of drugs.* *But why?*

The “why. Throughout our analysis, no individual drug emerged as singularly creating hardship; instead, affordability and access were more directly impacted by insurance coverage and personal life circumstances. Therefore, policy interventions that focus on individual drugs in an attempt to improve patient affordability are misguided.

Challenges and Limitations

Financial assistance appeared to help with affordability, but patients struggled to distinguish program differences, making it difficult for us to speak to the value of programs other than manufacturer copay assistance programs available to most people commercially insured.

Additionally, respondents lacked diversity, and vulnerable populations impacted by systemic health equity challenges were underrepresented.

Finally, this survey was conducted in 2024, prior to the implementation of changes to the Medicare Part D benefit passed in the Inflation Reduction Act, including the $2,000 cap in OOP and the prescription payment plan.

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. **To do this, we will launch a broader patient experience data collection campaign to further investigate "the why" behind patient-reported affordability challenges.**

Efforts will be led by patients from the PIC, with a focus on promoting broader participation. This dynamic, multi-layered approach to data collection will include a shorter, but largely open-ended question survey and alternate data collection opportunities (i.e., social media, discussion groups, written story submissions, peer-to-peer conversations). Our continued efforts will focus on:

- Revisiting endpoints based on lessons learned and consideration of evolving affordability narratives in current prescription drug affordability efforts.
- Increasing participation among diverse populations, particularly those who may experience the most challenges with affordability, but whose voices are not always counted.
- Investigating availability and patient usage of assistance programs offered by governments, organizations, and industry stakeholders to better assess their differences and impact on patient affordability.
- Exploring the impact, positive or negative, of affordability reviews among uninsured and/or vulnerable populations impacted by systemic health equity challenges.

To include as many patient voices as possible, we will invite any and all groups representing patient voices to help identify participants for this initiative, regardless of any political or issue divides. Together we are stronger, and together we can work towards solutions that truly benefit patients.

ACKNOWLEDGEMENTS

Survey contributors. The following groups and individuals who participated in the design of the survey: AiArthritis (International Foundation for Autoimmune & Autoinflammatory Arthritis), Arthritis Foundation, Caring Ambassadors, Pacific Northwest Bleeding Disorders, Partnership to Improve Patient Care (PIPC); Patient Research Partners (PRPs) Tiffany Westrich-Robertson and Deb Constien. Misty Knight-Finley, PhD (Senior Managing Partner and Director at Inform Analytics) led the analysis in extensive collaboration with PRPs.

This project was made possible through support from AiArthritis.

PATIENT EXPERIENCE SURVEY: PRESCRIPTION DRUG AFFORDABILITY AND UNAFFORDABILITY

APPENDIX

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COALITION

DRUG LIST

Drug Name	Type	n
Actemra	Specialty	2
Adderall	Generic	1
Ajovy	Specialty	2
Altuviiio	Specialty	1
Amitriptyline	Generic	1
Apixaban	Generic	1
Aricept	Brand	1
Azathioprine	Generic	1
Botox	Brand	1
Butalbital	Generic	1
Carbamazepine	Generic	1
Codeine	Generic	1
Cosentyx	Specialty	2
Creon	Specialty	6
Diazoxide	Brand	1
Eliquis	Brand	1
Elyxyb	Brand	1
Enbrel	Specialty	6
Epidiolex	Specialty	1
Fiasp	Brand	1

Drug Name	Type	n
Fintepla	Specialty	1
Fycompa	Brand	1
Hizentra	Specialty	1
Humate-P	Specialty	1
Humira	Specialty	3
Hyrimoz	Specialty	1
Ilaris	Specialty	2
Insulin	Generic	1
Januvia	Brand	1
Keppra	Brand	3
Lacosamide	Generic	2
Leucovorin Calcium	Generic	1
Levothyroxin	Generic	2
Migranal	Brand	1
Monjauro	Specialty	1
Naltrexone	Generic	1
Nucynta	Brand	1
Nurtec	Brand	1
Ocrevus	Specialty	2
Octagam	Specialty	1

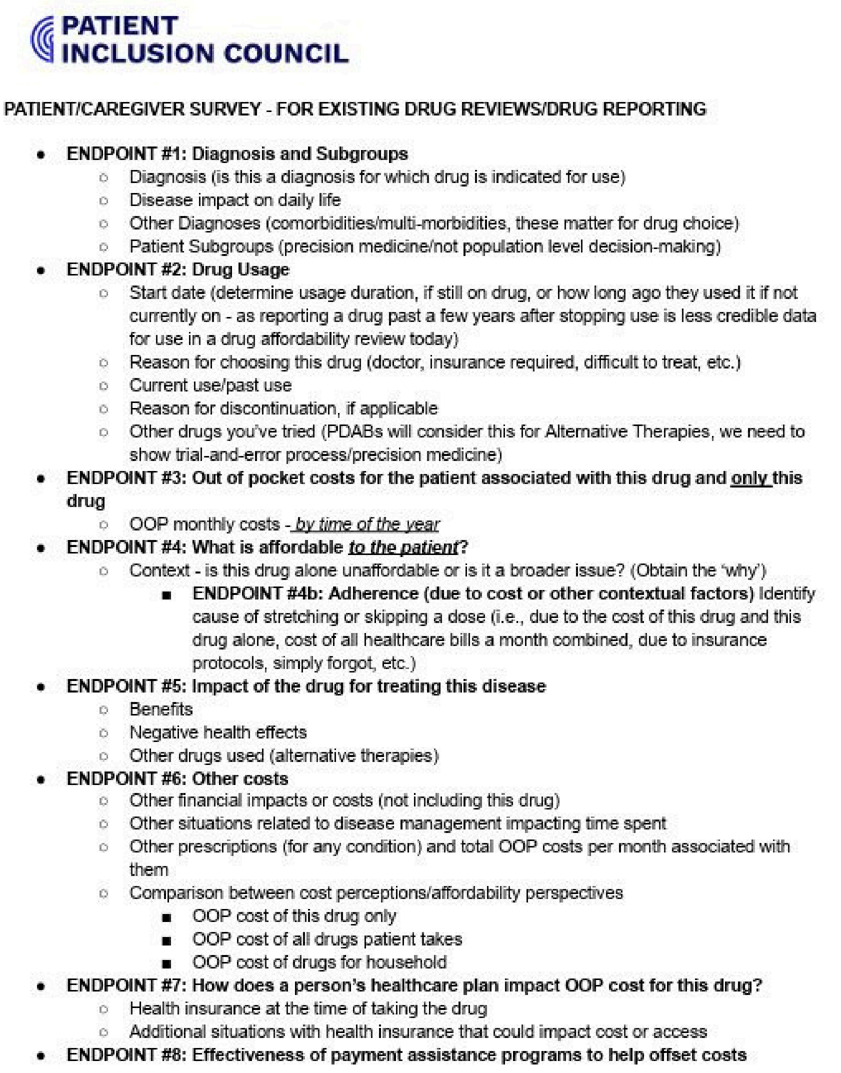
DRUG LIST (CONT)

Drug Name	Type	n
Orencia	Specialty	1
Pertzye	Brand	1
Plegridy	Specialty	1
Privigen	Specialty	2
Prozac	Brand	1
Pyridostigmine Bromide	Generic	1
Qulipta	Brand	2
Rapatha	Specialty	1
Recombinate	Specialty	1
Remicade	Specialty	3
Renflexis	Specialty	1
Rhopressa	Brand	1
Rinvoq	Specialty	3
Rituxan	Specialty	2
Savella	Brand	1
Simponi	Specialty	1
Skyrizi	Specialty	1
Slynd	Brand	1
Symdeko	Specialty	1
Synthroid	Brand	1

Drug Name	Type	n
Tagrisso	Specialty	1
Taltz	Specialty	1
Tirzepatide	Specialty	1
Trikafta	Specialty	2
Truxima	Specialty	1
Tylenol	Brand	1
Valtoco	Brand	1
Wegovy	Specialty	1
Xeljanz	Specialty	2
Zarxio	Specialty	1

SURVEY DETAILS: END POINTS, QUESTIONS, NEEDS ASSESSMENT

Survey Endpoints



PATIENT INCLUSION COUNCIL

PATIENT/CAREGIVER SURVEY - FOR EXISTING DRUG REVIEWS/DRUG REPORTING

- **ENDPOINT #1: Diagnosis and Subgroups**
  - Diagnosis (is this a diagnosis for which drug is indicated for use)
  - Disease impact on daily life
  - Other Diagnoses (comorbidities/multi-morbidities, these matter for drug choice)
  - Patient Subgroups (precision medicine/not population level decision-making)
- **ENDPOINT #2: Drug Usage**
  - Start date (determine usage duration, if still on drug, or how long ago they used it if not currently on - as reporting a drug past a few years after stopping use is less credible data for use in a drug affordability review today)
  - Reason for choosing this drug (doctor, insurance required, difficult to treat, etc.)
  - Current use/past use
  - Reason for discontinuation, if applicable
  - Other drugs you've tried (PDABs will consider this for Alternative Therapies, we need to show trial-and-error process/precision medicine)
- **ENDPOINT #3: Out of pocket costs for the patient associated with this drug and only this drug**
  - OOP monthly costs - *by time of the year*
- **ENDPOINT #4: What is affordable *to the patient*?**
  - Context - is this drug alone unaffordable or is it a broader issue? (Obtain the 'why')
    - **ENDPOINT #4b: Adherence (due to cost or other contextual factors)** Identify cause of stretching or skipping a dose (i.e., due to the cost of this drug and this drug alone, cost of all healthcare bills a month combined, due to insurance protocols, simply forgot, etc.)
- **ENDPOINT #5: Impact of the drug for treating this disease**
  - Benefits
  - Negative health effects
  - Other drugs used (alternative therapies)
- **ENDPOINT #6: Other costs**
  - Other financial impacts or costs (not including this drug)
  - Other situations related to disease management impacting time spent
  - Other prescriptions (for any condition) and total OOP costs per month associated with them
  - Comparison between cost perceptions/affordability perspectives
    - OOP cost of this drug only
    - OOP cost of all drugs patient takes
    - OOP cost of drugs for household
- **ENDPOINT #7: How does a person's healthcare plan impact OOP cost for this drug?**
  - Health insurance at the time of taking the drug
  - Additional situations with health insurance that could impact cost or access
- **ENDPOINT #8: Effectiveness of payment assistance programs to help offset costs**

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 pilot survey questions: https://bit.ly/PilotPatientSurvey

EACH PIC
COALITION

The **Ensuring Access through Collaborative Health (EACH)** and **Patient Inclusion Council (PIC)** is a two-part coalition that unites patient organizations and allied groups (EACH), as well as patients and caregivers (PIC), to advocate for drug affordability policies that benefit patients.

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

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ENSURING ACCESS THROUGH
COLLABORATIVE HEALTH

PATIENT
INCLUSION COUNCIL

ENSURING ACCESS THROUGH COLLABORATIVE HEALTH

POLICY BRIEF

PATIENT EXPERIENCE SURVEY: PRESCRIPTION DRUG AFFORDABILITY AND UNAFFORDABILITY

EACH PIC COALITION

DETERMINANTS OF AFFORDABILITY: WHAT PATIENTS SAY MATTERS MOST

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

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

Insurance Design and Disruptions Shape Affordability

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

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

Financial Assistance Programs Make the Difference

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

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

Total Health Costs Matter, Not Just an Individual Drug

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

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

WHAT PATIENTS NEED: NEXT STEPS FOR POLICYMAKERS

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

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

Improve Patient Support Programs

Expand Access to Financial Assistance Programs: Expand and protect state and federal Patient Assistance Programs (PAPs) for individuals with low incomes, disabilities, or those who lack insurance coverage. Increase awareness and enrollment in manufacturer copay assistance.

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

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

Reform Patient-Identified Barriers

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

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

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

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

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COALITION

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ENSURING ACCESS THROUGH
COLLABORATIVE HEALTH

PATIENT
INCLUSION COUNCIL

AIMEDALLIANCE

August 18, 2025

Shelley Bailey, Chair
Oregon Prescription Drug Affordability Board
350 Winter St. NE
Salem, OR
<u>Via Electronic Correspondence</u>

RE: Drug Affordability Review Process

Dear Chair Bailey:

Aimed Alliance is a not-for-profit health policy organization that seeks to protect and enhance the rights of healthcare consumers and providers. We appreciate the Oregon Prescription Drug Affordability Board's ("PDAB" or "Board") previous recognition that meaningful drug affordability reforms require careful development and thoughtful implementation, as demonstrated in its decisions last year to temporarily pause its affordability reviews to refine its criteria and methodologies.

As the Board moves forward, we strongly urge it to maintain this same level of care and ensure that patient and stakeholder feedback is meaningfully prioritized, incorporated, and reconciled throughout the process.

I. Ensure the Drug Review Timeline Allows for Meaningful Data Review and Discussion

Aimed Alliance appreciates the inherent challenges and complexity of conducting affordability reviews. As such, we are concerned by the Board's accelerated timeline and the concerns expressed by Board members. The volume of material being considered in the review packs, with six drugs reviewed in each meeting, makes meaningful deliberation difficult. Rushing through these reviews' risks undermining both the quality of the Board's decisions and public confidence in its work. Our concern was further emphasized during the July meeting in which one Board Member stated, ***"I'm super concerned about process and the volume of drugs here."*** Similarly, another Board Member asked whether there would be an additional meeting to ensure enough time to ***"actually… have a good conversation about each one of them"***.[1]

Aimed Alliance recognizes that Board Members have unique and unparalleled insights into the Board's process and decision-making. Thus, Aimed Alliance finds these comments particularly concerning and indicative of the need to adopt a slower review process to ensure comprehensive review and consideration of each selected drug.

The difficulties associated with prescription drug reviews are not exclusive to Oregon. For example, in the April 2025 meeting of the Colorado PDAB, board members acknowledged that

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[1] Oregon Division of Financial Regulation, *Oregon PDAB Meeting of July 16, 2025*, https://www.youtube.com/watch?v=wAl1u10eAM4.

data submitted by a pharmacy benefit manager (PBM) had been mischaracterized, creating confusion between Medicare and commercial data sets. Although the Colorado Board stated this error would not affect its affordability reviews, it remained unclear to advocates and consumers how this mischaracterized data would not negatively influence the review processes.

Aimed Alliance does not intend for a slower process to halt, change, or alter the intent of the Oregon Board to develop upper-payment limits for selected prescription drugs. However, considering the approach adopted and implemented by the Board for these six drugs will be replicated by the Board in future reviews, and potentially by other state PDABs, we urge the Board to develop a timeline and process that reflects the complexity and intricacies of these reviews, ultimately ensuring a credible, meaningful, replicable, and sustainable process that promotes public trust and engagement.

II. Prioritize the Patient Voice During the Affordability Review Process

Aimed Alliance appreciates the Board's commitment to incorporating the patient voice into the cost review process. Patients are the individuals most directly impacted by affordability determinations, yet their perspectives are far too often underrepresented in healthcare decision-making.

For example, a recent patient-led study found that prescription drug affordability was complex and varied between individuals.[2] Importantly, the survey found that access and affordability are often conflated, with 75% of respondents stating they skipped or stretched doses at least once due to insurance delays, not price. While less than 15% reported skipping or missing doses solely due to price.[3] As such, Aimed Alliance urges the Board to not only engage with patients through information surveys and public comment periods, but to also meaningfully integrate and reconcile patient-reported feedback and data with its final affordability determinations. Reconciling decisions with feedback informs consumers on how their information was helpful and encourages consumers to continually engage with these processes.

Moreover, reconciliation of feedback and decision-making can provide greater clarity to regulators, policymakers, and legislators on the types of supplemental reforms that may be necessary to better and more directly address consumer affordability. For example, if a primary reason consumers report a drug as unaffordable is out-of-pocket costs resulting from delays in prior authorization—rather than the actual price of the drug—it is important to reconcile why the Board would pursue a UPL for a drug whose unaffordability is not driven by its cost. However, insights like this may not be adequately derived from survey questions that are not designed with patients, caregivers, and healthcare consumers in mind. Therefore, Aimed Alliance urges the Board to center patient experience throughout its affordability reviews to adequately understand the factors that make a prescription drug "unaffordable."

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[2] *EACH/PIC Releases Results from Patient-Led Survey on Drug Affordability,* https://eachpic.org/each-pic-releases-results-from-patient-led-survey-on-drug-affordability/.

[3] *Id.*

III. Conclusion

In conclusion, Aimed Alliance urges the Board to maintain a thoughtful, evidence-based approach to drug affordability reviews that centers on patient experience and utilizes robust patient data. Aimed Alliance looks forward to continuing to engage with the Board as it conducts its affordability reviews. If you have any questions, please contact us at policy@aimedalliance.org.

Sincerely,

Ashira Vantrees
Director of Legal Strategy & Advocacy

Allergy & Asthma NETWORK

10304 Eaton Place, Suite 100, Fairfax, VA 22030 • 800-878-4403

August 28, 2025

Oregon Prescription Drug Affordability Board
PO Box 14480
Salem, OR 97309

Re: August Oregon Prescription Drug Affordability Board Meeting

Dear Oregon Prescription Drug Affordability Board (PDAB) Members,

On behalf of the Allergy and Asthma Network (AAN), I am writing to submit comments to the Oregon Prescription Drug Affordability Board (PDAB) regarding prescription drugs under review that impact treatment access for patients with asthma and related respiratory conditions. We appreciate the opportunity to highlight barriers to affordability and access to these vital treatments

AAN is the leading national organization advocating on behalf of the 33 million Americans with allergies and 28 million with asthma. We are encouraged by the Oregon PDAB's consideration of patient affordability for the current medications up for review that are used to treat asthma and related conditions. We are hopeful that this affordability review may lead to increased access to asthma treatments, mitigating onset of asthma-related morbidity and improved health outcomes for Oregonians.

For forty years, AAN has empowered patients living with respiratory illnesses, such as asthma and chronic obstructive pulmonary diseases (COPD, through our patient education programming, such as the Trusted Messengers Program. Trusted Messengers Program is an asthma coaching program that educates patients on proper self-management of their breathing conditions. The program helps AAN Asthma Coaches gather qualitative data from patients regarding their treatment goals.

From a patient perspective, the goals are clear: to breathe more easily, to reduce the fear and disruption of exacerbations, such as asthma attacks or COPD flare-ups, and to maintain an active and fulfilling life. Patients gauge their improvement by their overall sense of empowerment and confidence in managing their symptoms.

We acknowledge that treatment choices hinge on a few key factors: access, efficacy, and ease of use. Our role at AAN is to guide patients through these choices with unbiased information and encourage informed discussions with their doctors. A once-daily option like Trelegy Ellipta, a medication currently under review, can significantly improve adherence. However, the high cost of this medication is a major barrier. At an average of $600 to $800 per device, Trelegy Ellipta's price tag could jeopardize consistent use. Additionally, while the 2025 Medicare Part D out-of-pocket cap will limit expenses for those beneficiaries to $2,000, the financial impact on people without Medicare remains a serious and unaddressed concern.

Patients unable to afford treatment options such as Trelegy Ellipta often opt to get two separate inhalers (one Flovent and one long-acting bronchodilator) that are generic. While this is generally a cheaper alternative, it is not ideal, as inhaler adherence is typically poor and this option prompts the patient to use the medicine twice daily for the same effect.

Trelegy Ellipta is a once-a-day dry powder inhaler (DPI), consisting of three separate long-acting medicines in one inhaler, providing 24 hours of better breathing. It is an option that has better odds for adherence than a twice a day inhaler. If patients are forced to switch from a DPI inhaler to a standard puffer inhaler due to cost, they will need to use twice a day dosing and learn how to use a metered dose inhaler (MDI) properly. This will compromise adherence, as individuals are not typically familiar with correct technique for MDI usage, and this impedes efficacy as the medication does not enter the lungs as effectively as with a DPI inhaler.

Furthermore, many of these dual inhalers have an Inhaled Corticosteroid (ICS) and a Long-Acting Beta Agonist (LABA). These options vary in their specific medications, mechanisms, and dosages. Trelegy Ellipta has Fluticasone (flovent), Vilanterol (used for COPD), and Umeclidinium. Even though these devices are available, and some providers will switch, or a formulary will include an ICS with a LABA, does not mean that these two drugs are the “same” and that dosages are comparable to one another. These differences mean they are not interchangeable, and switching could impact adherence, especially if different devices are involved.

We urge Oregon PDAB to establish an Upper Payment Limit (UPL) for Trelegy Ellipta costs across all applicable health coverage types. This request extends to the Affordable Care Act and Commercial health insurance marketplaces. Due to the lack of direct equivalents to Trelegy Ellipta, and the non-interchangeability in medication, device, and dosage of dual inhaler options, a UPL will help ensure greater affordability and access to the medication, further encouraging adherence. Furthermore, by leading the charge in facilitating affordability in other coverage types across Oregon, the state can provide a real-world model to help influence similar decisions at the Federal level to help bring costs down in Medicare Part D plans.

We urge Oregon PDAB to prioritize patient lived experience in drug affordability reviews. To accomplish this, we request the Oregon PDAB to support measures to ensure equitable access to Trelegy Ellipta and similar therapies. This includes conducting evaluations with an emphasis on affordability, accessibility, and equitable access to treatments that have improved outcomes, slow disease progression, and have fewer side effects.

We urge the Oregon PDAB to collaborate with existing state partners, such as the Oregon Asthma Program, to support patient education on proper inhaler techniques. Proper inhaler technique is a critical component of effective asthma management. If a patient is unable to use their inhaler correctly, the medication's efficacy is compromised, and the money spent on the drug is wasted. AAN stands as a ready partner to assist the state with capacity for this effort through our virtual asthma self-management coaching program, Trusted Messengers.

AAN greatly appreciates your consideration of our comments. We welcome an opportunity to provide further patient insights to help inform the Oregon PDAB’s review. Please contact me or our Director of Advocacy, Nissa Shaffi, at 571-395-8912. If you have any questions and to learn more about the Allergy and Asthma Network, visit AllergyAsthmaNetwork.org.

Sincerely,

Lynda Mitchell

Lynda A. Mitchell CEO
Allergy and Asthma Network