EACH PIC COALITION

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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Patient Inclusion Council (PIC) Coalition Lead

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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TABLE OF CONTENTS

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

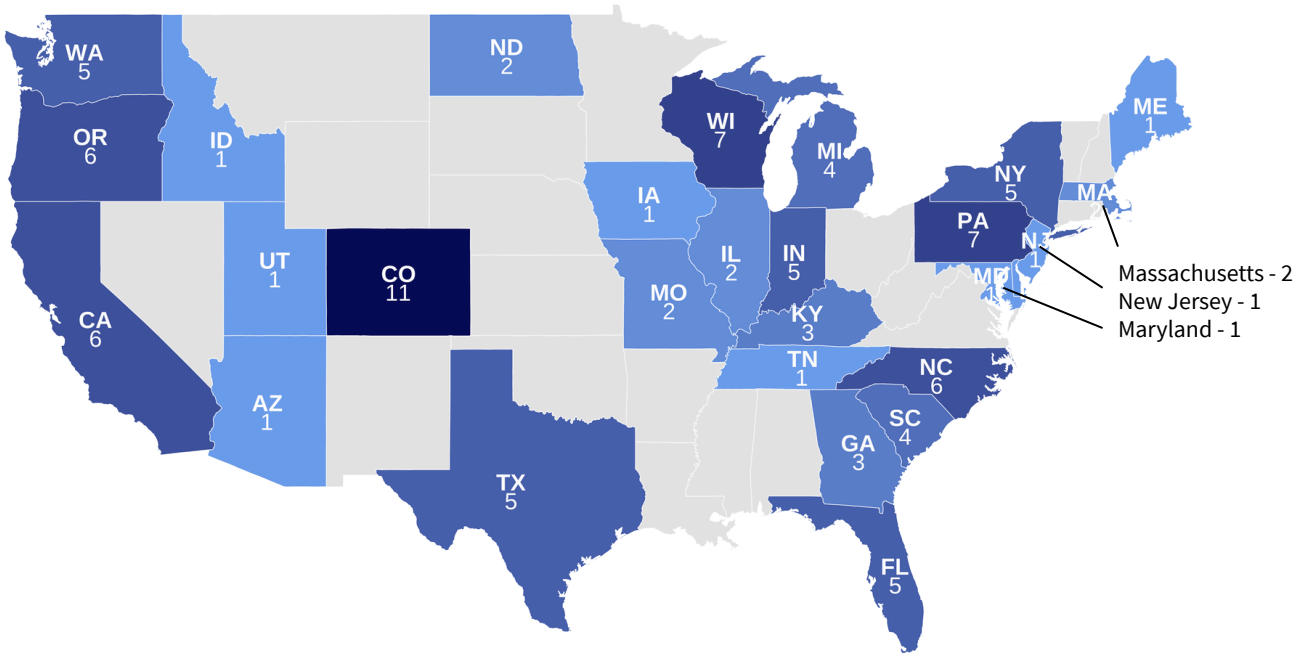
70 DRUGS

40 DIAGNOSES

77% COMORBIDITIES

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

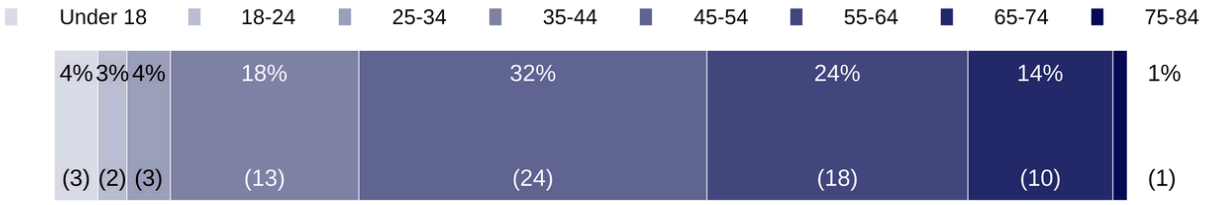
RESPONDENTS' GEOGRAPHIC LOCATION



Total Responses: 100

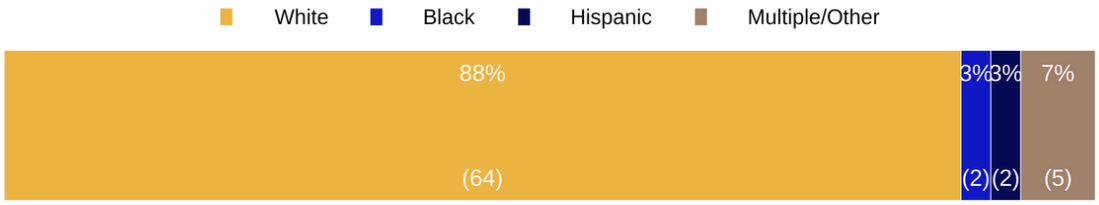
DEMOGRAPHIC BREAKDOWN

DISTRIBUTION OF PATIENTS' AGE



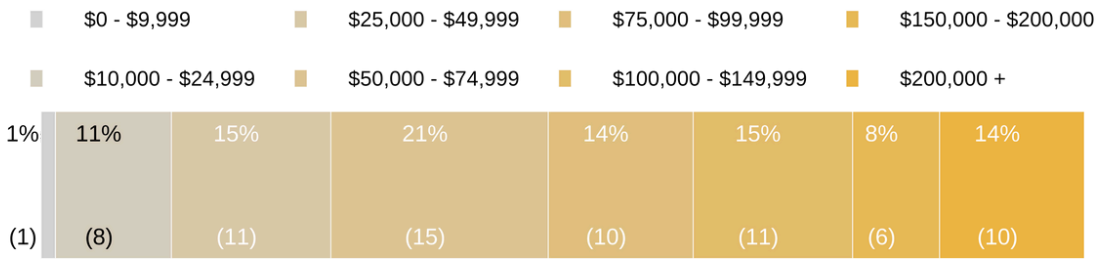
Total Responses: 74

DISTRIBUTION OF PATIENTS' RACIAL AND ETHNIC IDENTITIES



Total Responses: 73

DISTRIBUTION OF PATIENTS' HOUSEHOLD INCOME



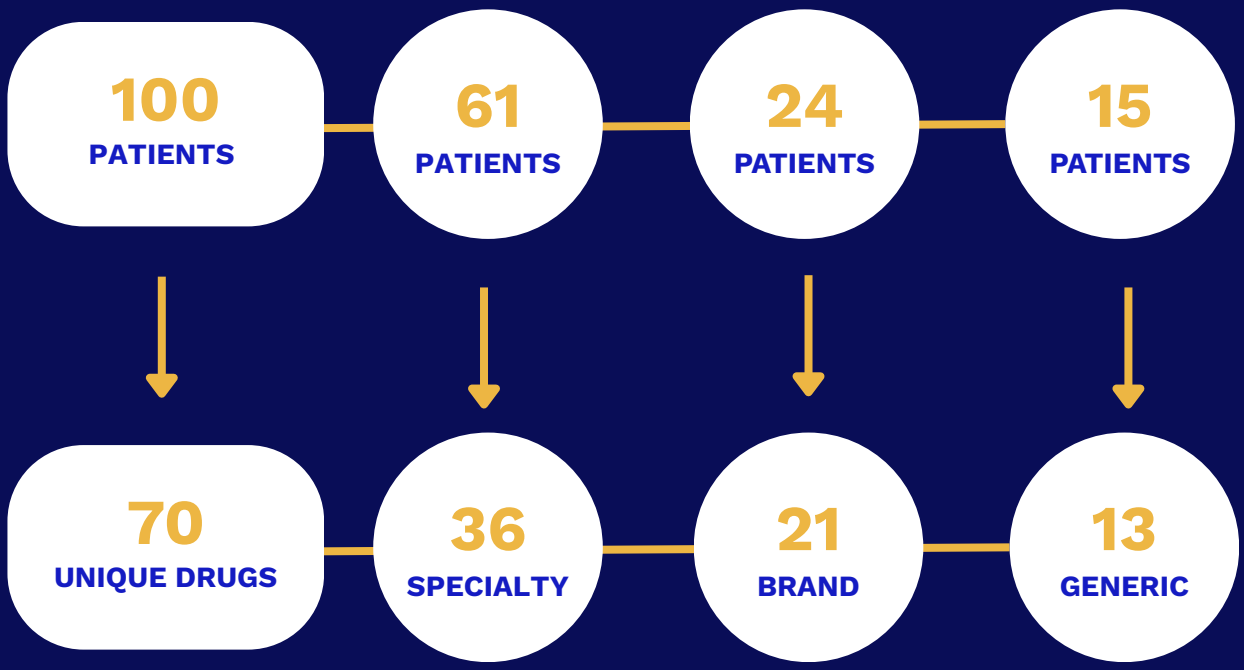
Total Responses: 72

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).



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

CURRENT SURVEYS ARE MISSING THE "WHY"

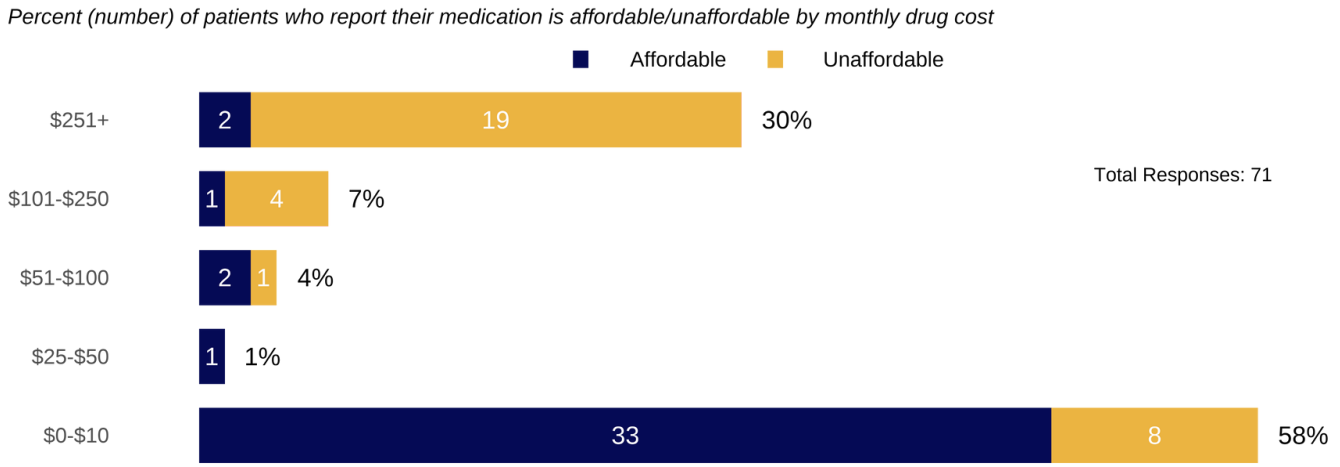
Current patient-facing surveys that assess prescription drug affordability often miss context in the analysis. **We sought to understand patient-reported reasons for saying drugs were affordable or unaffordable so we can steer efforts to address these challenges based on what patients say they need us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



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.

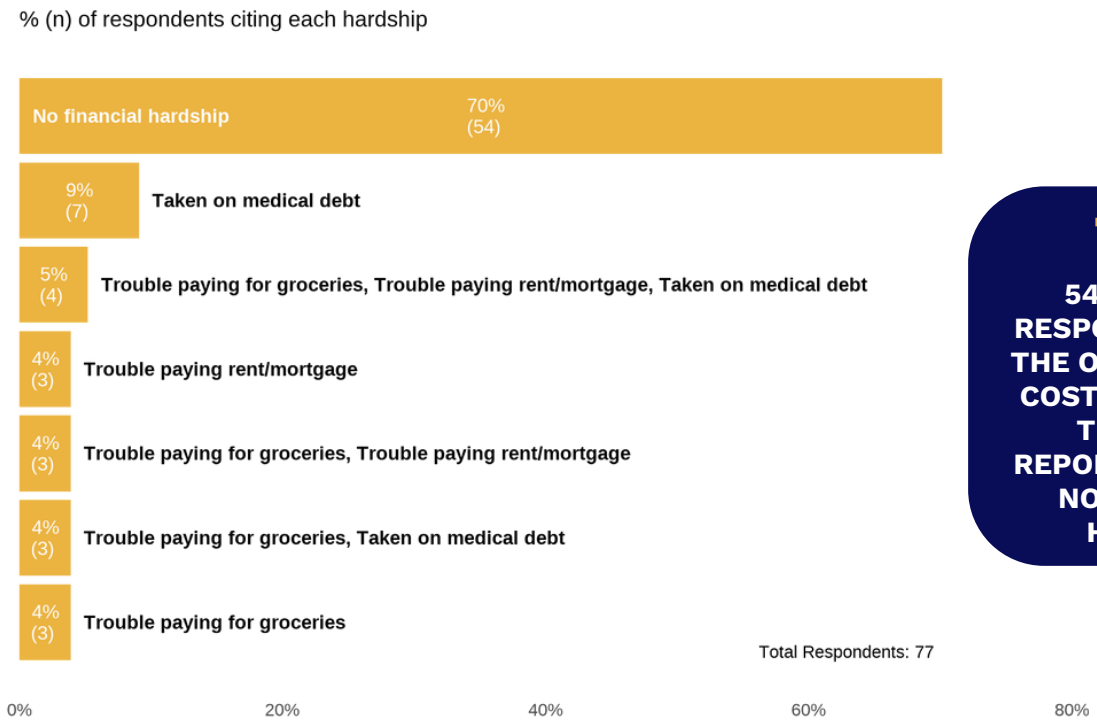
4% (3 people) reported this OOP drug cost was unaffordable.

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%

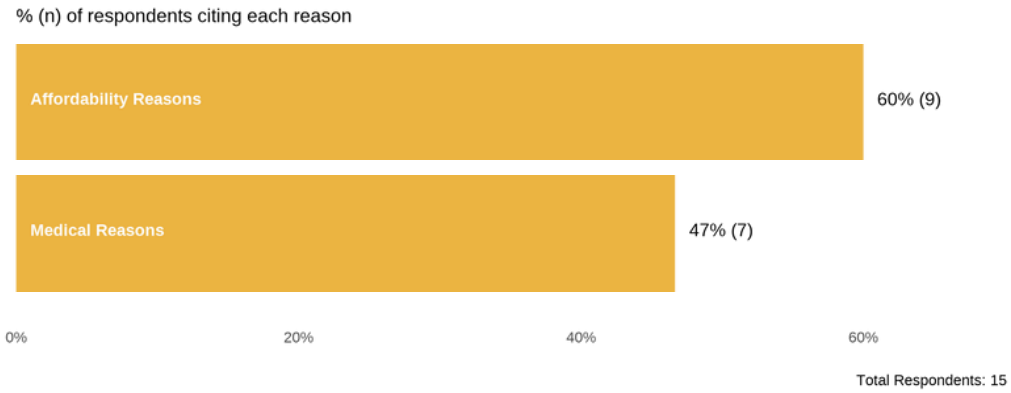
54 OUT OF 77 RESPONDENTS SAID THE OUT OF POCKET COST OF THE DRUG THEY WERE REPORTING CAUSED NO FINANCIAL HARDSHIP

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?***

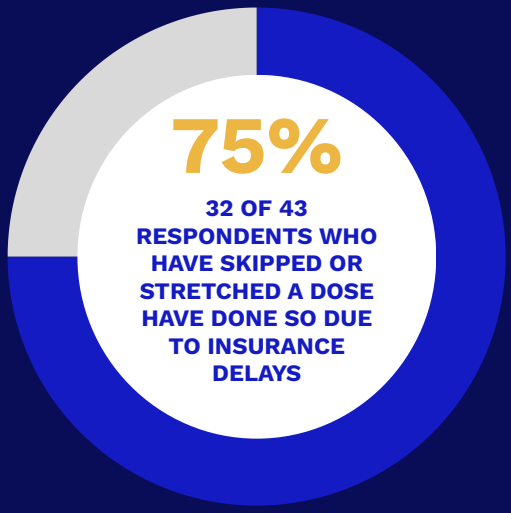
WHAT IS BEHIND THE ANSWER, "I COULD NOT AFFORD THE OUT OF POCKET COST OF THE DRUG"?

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.**

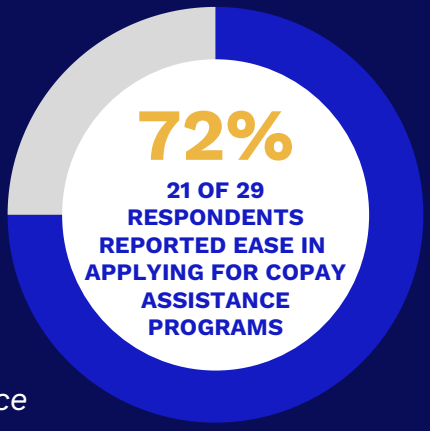
- **50%** (9 people) of the 18 patients taking a **biologic/specialty drug without financial assistance** who reported on their insurance type **were on Medicare.**

- 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."

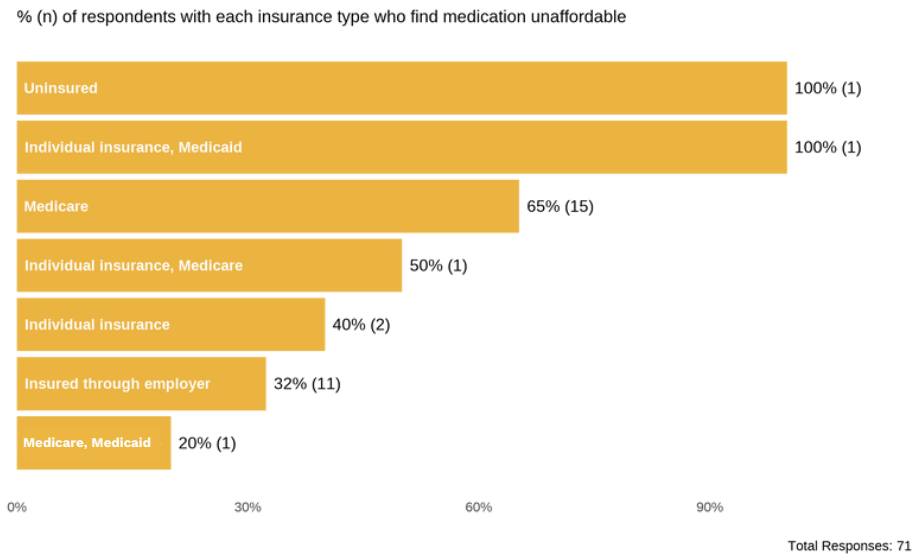


AFFORDABILITY CHALLENGES WITH MEDICARE

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."

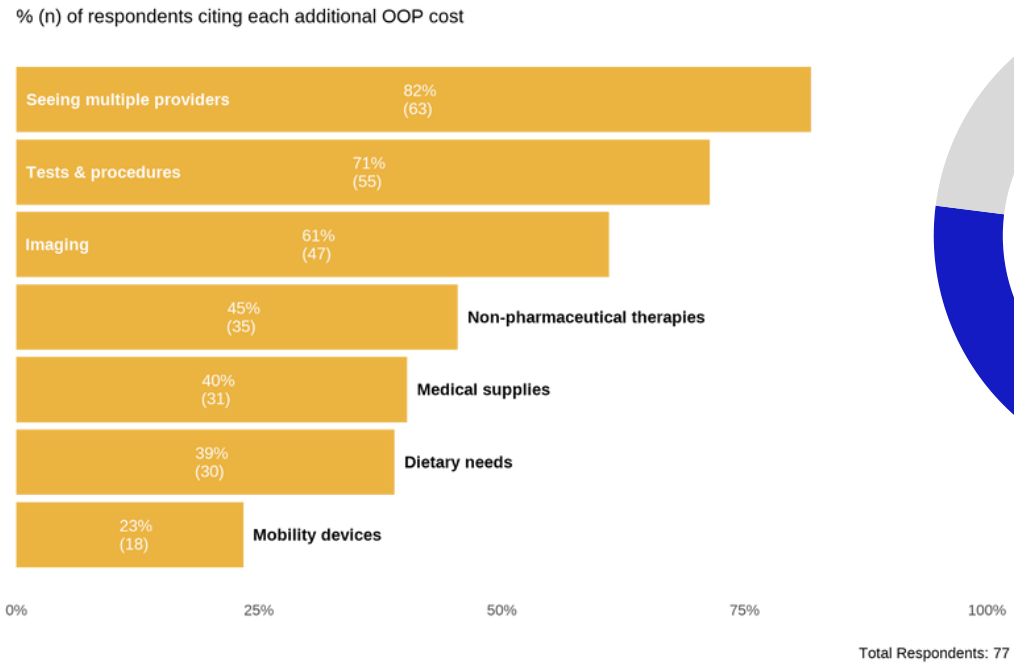
"This drug is only affordable while I am employed full time with company assisted medical benefits. However, I am retirement age but cannot retire at this time because my monthly payments would not be affordable going to several thousands of dollars in copays."

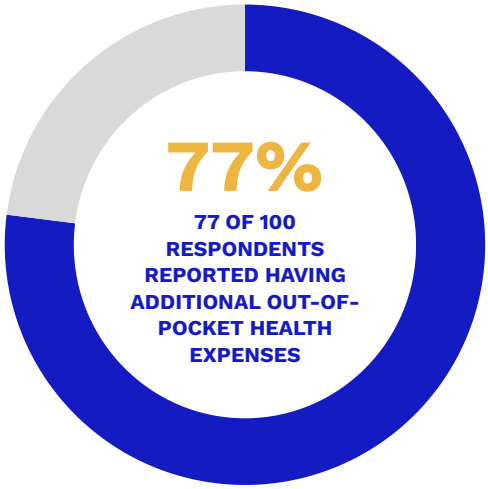
ADDITIONAL OUT-OF-POCKET COSTS

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





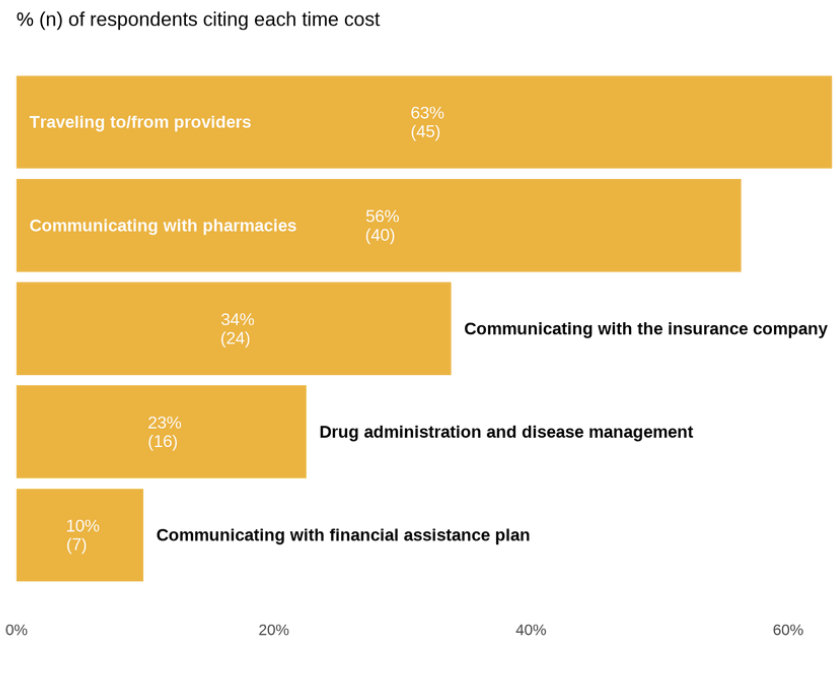
"The costs of managing this condition are astronomical. *A CT scan is $500 out of pocket, surgeries are thousands, required blood work is only partially covered, and* ***I've paid out of pocket for all my mobility aids, bracing, and PT/OT."***

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*

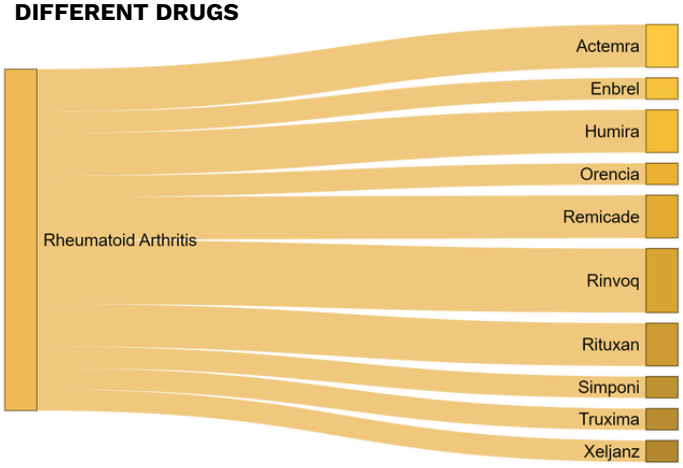
THE IMPORTANCE OF PREFERRED THERAPIES

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

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

EACHPIC 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

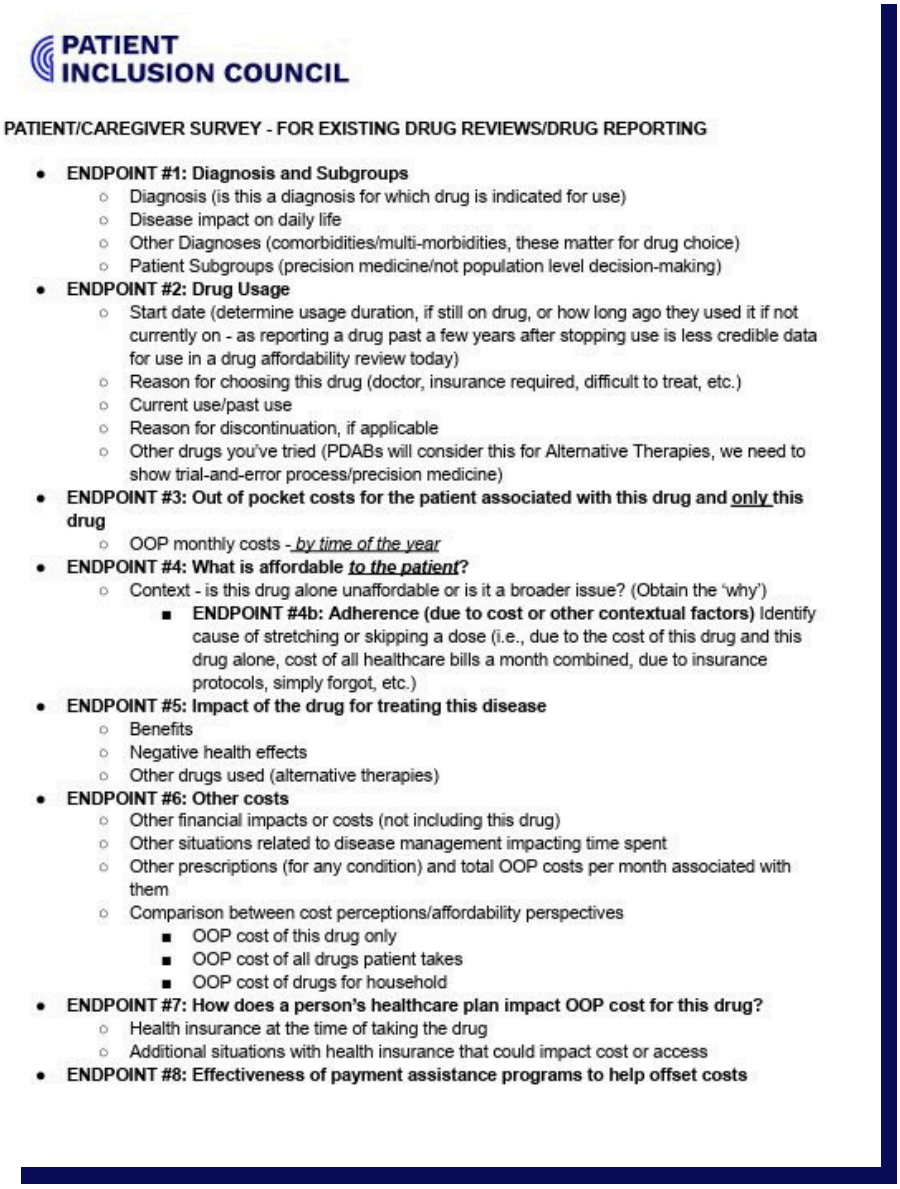
DRUG LIST (CONT)

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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INCLUSION COUNCIL

AIMEDALLIANCE

August 18, 2025

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

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

[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.

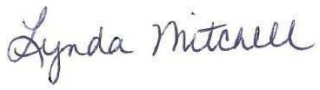
Allergy & Asthma NETWORK

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

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 A. Mitchell CEO
Allergy and Asthma Network

September 15, 2025

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

TO: Members of Oregon Prescription Drug Affordability Board

I write to express my concerns regarding the drug reviews you are conducting for the selected antidiabetic drugs. The Board's opportunities to receive input, information, and opinions from stakeholders to address affordability challenges are excellent. Yet I remain troubled at the Board's focus on drug list prices and rather than the total health costs to patients, as this limited inquiry risks inhibiting access to essential medications and creating longer-term negative health outcomes

I am a board-certified pediatrician and pediatric rheumatologist with decades of experience in office, hospital and policy environments. My primary focus is always ensuring the well-being of patients, but as a result of your legislative charges, I fear that the Board's analyses and decisions cannot reflect this same mandate.

Clinicians view the Board's search for "therapeutic alternatives" as inherently misguided and potentially dangerous to patients for whom substitution is not clinically appropriate due to their unique medical situations, genetics and/or treatment needs. As a result, the complexities of personalized patient care cannot be considered as these so-called "alternatives" may not be able to address the breadth of a patient's individual circumstances. Further, unilaterally designating certain medications as "therapeutic alternatives" fundamentally disrupts the clinician's ability to exercise their medical expertise in concert with their patient.

While I applaud the Board for conducting more its extensive analysis and medication comparisons within the same therapeutic classes, these drugs still have differing approved indications. Unless the Board considers interventions that directly address the full range of approved FDA indications and conditions impacted by these medications, the comparisons are incomplete. Given the varying overlaps in therapeutic indications, an easily foreseeable result of the current approach would be a patient requiring a combination of drugs to control their multiple medical issues that were previously successfully controlled by one. It is also important to note that ICER is revising their cost-effective recommendations for these medications, and that new data should be included within your deliberations.

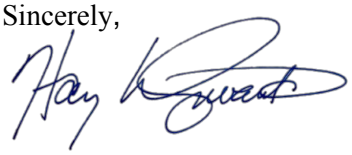
Everyone shares the Board's goal to lower prescription drug costs, but the current myopic process that only focuses on a drug's list price and not the total cost to patients risks limiting access to essential medications while creating longer term negative health outcomes and increased costs. Since the Board is unable to address the roles of all participants within the drug pricing and supply ecosystem, I fear your many efforts will be for naught. I am encouraged to see that the your agenda includes recommendations for legislative actions that would address these systemic issues, such as price concession passthroughs, no spread pricing, and single PBM requirements. These broader reforms are excellent first steps to creating meaningful affordability improvements and emphasize the difficulties the Board faces in its mission.

All clinicians and patients are eager to collaborate with the Board to ensure affordability decisions reflect real-world patient needs with a more thoughtful, patient-centered approach. As it stands, however, the Board's actions could inadvertently restrict access to effective cost-saving medications for those Oregon residents who need them the most. We appreciate the Board asking the legislature to address the multiple

deficiencies and restrictions placed upon it and allow it to develop methods of lowering actual drug costs, not just the list prices of drugs purchased by the State and Oregonians.

Thank you for your attention to this critical issue.

Sincerely,



Harry L. Gewanter, MD, FAAP, MACR
Board Member, Let My Doctors Decide Action Network

COMMUNITY ACCESS NATIONAL NETWORK

Mailing Address:

Attn: Jen Laws
PO Box 3009
Slidell, LA 70459

Chief Executive Officer:

Jen Laws
Phone: (313) 333-8534
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Email: jen@tiicann.org

September 14, 2025

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

RE: Ongoing Review Developments

Dear Honorable Members of the Oregon Prescription Drug Affordability Board,

The Community Access National Network (CANN) is a 501(c)(3) national nonprofit organization focusing on public policy issues relating to HIV/AIDS and viral hepatitis. CANN's mission is to define, promote, and improve access to healthcare services and support for people living with HIV/AIDS and/or viral hepatitis through advocacy, education, and networking.

While CANN is primarily focused on policy matters affecting access to care for people living with and affected by HIV, we stand in firm support of all people living with chronic and rare diseases and recognize the very reality of those living with multiple health conditions and the necessity of timely, personalized care for every one of those health conditions. State Prescription Drug Affordability Boards are of profound importance to our community.

Continued Focus on Quality Analysis is Encouraging

The extension for the final selection of drugs deemed as causing affordability challenges is encouraging. It is an example of words translating into action regarding the desire to do what is in the best interests of Oregonians. We also understand that the new domain charts and scoring rubrics are not the sole tools to be used in making decisions, but are frameworks being developed to guide how decisions are made. However, the domains and associated key questions are very relevant points of inquiry, and we encourage you to delve into those areas as you develop the chart and rubric further. Additionally, as you do that, we hope that your discourse will provide clarity on how the information is being used to make determinations.

Policy Recommendations For the Legislature

The 2025 policy concepts listed for discussion contain many practical ideas. Several were notable. Instituting one PBM for all Medicaid and managed care patients in Oregon would not only be administratively efficient, but it would facilitate focused negotiation of operations as well as effective monitoring/oversight. Additionally, the suggestions of eliminating spread pricing in favor of fixed administrative fees, combined with the delinking of PBM fees from the list price of a drug or other fees/rebates, are worthwhile policy objectives to pursue. Reducing PBM incentives to artificially raise prices, as well as adversely manipulating formulary tiering, would positively affect patient access.

Banning PBMs from contractually requiring pharmacies to dispense medications below cost, in addition to requiring payers to provide a pharmacy dispensing fee equal to or greater than the dispensing fee used in Oregon's medical assistance programs, are also vital suggestions. Protecting pharmacies' ability to operate in a fiscally sound manner increases patient access to medications as well as other community services that many patients depend on, without having to venture far away from the communities in which they live.

Any policy suggestions that reduce some of the opacity in the system, increase access for patients regarding cost and services, and strengthen pharmacies and their access to plan networks in relation to plan network access are areas in which we encourage the development of policy recommendations.

We applaud your continued thoughtful deliberations.

Respectfully submitted,

Sincerely,
Ranier Simons
Director of State Policy, PDABs
Community Access National Network (CANN)

On behalf of
Jen Laws
President & CEO
Community Access National Network

September 17, 2025

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

Dear Chair Bailey and board members,

Thank you for the hard work you are doing to address the impact of high-cost prescription drugs on Oregonians.

I am glad to see you are addressing the issue of trade secrets, confidential, and proprietary information from manufacturers to garner the critical data points you need to address affordability. Once a process is adopted, will you update the cost information to reflect what plans and Oregonians are actually paying for their prescriptions? Will the Board have sufficient time to discuss those changes before making any decisions?

The policy recommendations from Board members are refreshing in that they reflect the Board's understanding that prescription drug costs are just a part of the supply chain that ultimately leads to higher-priced drugs. As these recommendations have pointed out, there are numerous opportunities outside of your current authority to reduce costs for both the state and patients. I hope that you will consider two additional policy recommendations;

- PDAB members are authorized and encouraged to interact and ask questions of those offering public testimony. Members shall acknowledge, review, and consider public comment received in their discussions and consider in their determinations.
- Establish a Stakeholder Advisory Board to assist the PDAB Board Members and DCBS staff.

This last recommendation is because patient and provider engagement is still lacking in your reports. Every drug under review has this same statement regarding feedback from individuals with scientific or medical training:

> *"Surveys were posted on the PDAB website to collect drug information from individuals with scientific and medical training. There were no reports for NAME THE DRUG to determine the impact of the disease, benefits or disadvantages, drug utilization, or input regarding off-label usage."*

Your meeting times and lack of specified times for each review on the agenda lead to a lack of participation by patients and providers. Given that you do not have an established advisory board and that you have some extra time, experts could present their perspectives to further educate the Board before deliberating on the numerous drugs under review.

I am pleased to see the improvements in the rubric. However, I still see no change in the therapeutic alternative scoring, so I ask again, if there are no effective/affordable alternatives, then why would it receive a severe impact score? Is this approach solely focused on saving the state money? It's crucial to consider the patient's perspective-if there is no alternative for a patient, it is not in their interest to have it scored higher. A patient-centered approach is essential in your evaluations.

In closing, our healthcare system will face challenges in the near future, and many difficult decisions will need to be made regarding resource allocation. The Board should consider requesting an expansion of its scope to encompass more than just drug costs and utilize its collective expertise to assist legislators in navigating these changes, thereby minimizing disruptions to Oregonians living with chronic diseases.

Thank you for your work and attention to these comments and concerns.

Sincerely,

Lorren Sandt, Executive Director

EACH PIC COALITION

September 15, 2025

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

RE: Public Comments on Draft Policy Proposals

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, allied groups, patients, and caregivers to advocate for drug affordability policies that put patient needs first.

We appreciate the board's decision to publish in advance of its meeting the policy proposals raised by board members for consideration to be included in the final report to the Oregon Legislature. This allows for increased time to evaluate and provide feedback, and we thank the board for the opportunity.

Support for PBM Reform

We applaud the inclusion of reform proposals that would hold pharmacy benefit managers (PBMs) accountable for their role in driving up drug costs. Specifically, we strongly endorse the elimination of spread pricing, the delinking of PBM compensation from drug prices, and requirements for increased transparency.

Our Patient Experience Survey found that affordability is often determined less by list price and more by how insurance and PBM practices shape patients' actual costs. For example, patients repeatedly cited insurance barriers such as accumulator policies, denial of copay assistance, and formulary restrictions as key drivers of unaffordability, even when their reported monthly out-of-pocket costs were low. In fact, 20% of patients paying only $0–$10 per month still reported their medications as unaffordable due to PBM-driven rules and insurance design.

Eliminating spread pricing, requiring rebates and savings to be shared with patients, and increasing transparency into PBM practices will directly address these patient-reported problems. Such reforms are essential to ensure affordability policies actually result in lower costs at the counter, not just on paper.

Broadening Networks and Ensuring Fair Reimbursement to Protect Access

We also support provisions to broaden pharmacy networks. Patients should be able to access their medications from the providers and pharmacies that best meet their needs, without being constrained by artificially narrow networks.

Equally important is ensuring that reimbursement rates and dispensing fees reflect the true costs of dispensing medications. Pharmacies and physician practices should not be forced to operate at a loss to provide care. If reimbursement is set below cost, many providers, especially smaller or independent practices, will face unsustainable financial pressure. This risks reduced access to care, particularly in rural and underserved communities, and could lead to disruptions in treatment continuity for vulnerable patients.

Ultimately, upper payment limits (UPLs) could worsen this problem by further eroding reimbursement rates for pharmacies, infusion centers, and physicians. We urge the board to holistically evaluate policy reforms to ensure that they are not making improvements in some areas, while worsening conditions for patients in others.

Concerns with Upper Payment Limits (UPLs)

Finally, while we are encouraged that the recommended policies include a range of potential solutions, we continue to emphasize that UPLs are the wrong approach. As our coalition has consistently noted, UPLs cap what insurers and the state pay, not what patients pay. Patients may see no benefit of UPLs. Worse, insurers and PBMs may respond with higher cost-sharing, formulary reshuffling, or new utilization management requirements. These responses can lead to delays, disruptions, and even non-medical switching of stable therapies, with serious consequences for patient health.

Furthermore, our own Patient Experience Survey data underscores that affordability challenges are driven more by insurance design, copay assistance, and PBM practices than by list price alone. Proceeding with UPLs without first addressing these patient-reported barriers could worsen affordability and access rather than improve them.

Conclusion

We thank you for your commitment to addressing drug affordability and for considering policies that take aim at structural drivers of cost, such as PBM practices. As the board finalizes recommendations for the legislature, we encourage you to prioritize reforms that directly address the patient-reported drivers of affordability challenges, particularly PBM reforms, over untested approaches like UPLs that risk worsening access without guaranteeing savings.

We urge you to continue centering patient experience in your deliberations, ensuring that all policy proposals safeguard access to care, and remain available as a resource to the board as these recommendations move forward.

Sincerely,

Tiffany Westrich-Robertson

Tiffany Westrich-Robertson
tiffany@aiarthritis.org
Ensuring Access through Collaborative Health (EACH) Coalition Lead

Vanessa Lathan
vanessa@aiarthritis.org
Patient Inclusion Council (PIC) Coalition Lead

Regence | 200 SW Market Street, 11th Floor
Portland, OR 97201

September 12, 2025

Prescription Drug Affordability Board
350 Winter St. NE
Room 410
Salem, OR

SUBMITTED VIA EMAIL

RE: Comments on September 17 Board Meeting

Dear Members of the Oregon Prescription Drug Affordability Board,

On behalf of Regence BlueCross BlueShield of Oregon and our members, we thank the Prescription Drug Affordability Board and Staff for the opportunity to comment on topics covered in the September 17 board meeting.

As one of the state's largest health insurers, Regence is committed to addressing persistent and emerging health needs for the nearly 1 million Oregonians we serve. In keeping with our values as a tax-paying nonprofit, 90% of every premium dollar goes to pay our members' medical claims and expenses. We comment to aid in the board's mission of making prescription drugs more affordable for Oregonians.

PDAB Policy Recommendations

We appreciate the Board's dedication to addressing affordability and access to prescription drugs for Oregonians, particularly focusing on high-cost drugs. While some of the proposed policy recommendations align with the Board's mission, we have concerns about how the numerous proposals focusing on pharmacy benefit managers, pharmacy reimbursement, and drug rebates may undermine the Board's core affordability mission. Based on our data, and the data of other carriers, we believe these recommendations are likely to increase consumer prices at the pharmacy counter, as well as in their health insurance premiums.

Regence | 200 SW Market Street, 11th Floor
Portland, OR 97201

We would encourage the Board to look at the extensive work that has been done by industry stakeholders, the pharmacy community, the Division of Financial Regulation, and the legislature to address PBM reform. In the summer and fall of 2024, a workgroup led by Rep. Nosse met and exhaustively discussed the complexities of concepts similar to those put forward by the Board. A workgroup process was also held during the 2025 Legislative Session led by Reps. McIntire and Diehl on the same swath of issues. Though legislation did not pass in 2025, Rep. Hai Pham is convening another workgroup this fall to continue towards solutions that address the challenges identified by the Board and other stakeholders in ways that do not negatively impact drug affordability and access in the state. We believe that the recommendations put forward by the Board regarding PBMs and drug pricing severely undermine the progress towards viable solutions that have been made over the past year.

PBMs partner with health plans to ensure members can access prescription drugs at the lowest cost, highest quality, and most accessible sites of care. Through formulary and network design, pharmacy benefits are structured to enhance access to low-cost drugs. PBMs negotiate with manufacturers to reduce the cost impacts of expensive brand and specialty drugs to health plans and their members – they do not set drug prices but work to mitigate for the high prices set by pharmaceutical manufacturers.

As the 2024 Prescription Drug Price Transparency Program Results and Recommendations report clearly demonstrates, PBMs only retain 0.56% of manufacturer rebates; the remainder is passed on to the health plan or to enrollees to reduce costs. It's also important to note that generic prescription drugs, which account for the vast majority of drug utilization, are not rebate-eligible in the commercial market. Only a subset of brand and specialty drugs receive rebates. At Regence, 90% of drug utilization amongst our members is generic; only a subset of the remaining 10% is eligible for manufacturer rebates. Nationally, generic utilization sits at 85%.

The workgroup processes mentioned highlighted the need for targeted, tailored solutions to ensure equitable and affordable access to prescription drugs statewide and particularly in rural and frontier communities. The policy concepts proposed by the Board do not reflect those nuanced discussions. The

importance of prioritizing consumer affordability is particularly poignant at this time, where prices continue to climb and difficulties affording medical care are worsening. In one survey of Oregon residents, 83% expressed worry about affording health care in the future; the board should be extremely cautious in supporting policies that can increase consumer costs and that would undermine their goal of making health care more affordable for Oregonians.

Once again, we appreciate the opportunity to offer comment on the Board's proposed policy recommendations to the legislature. Regence shares the Board's concerns about affordable access to prescription drugs, as well as the goal of supporting our pharmacy partners. We hope the Board will consider our comments and remove recommendations regarding PBMs, pharmacy reimbursement, and drug rebates. We encourage Board members to explore existing avenues through which this work is already occurring and are happy to discuss any additional follow-up items.

PDAB Review of Ozempic, Rybelsus, Trulicity, and Mounjaro

We believe that there are significant affordability issues with Ozempic, Rybelsus, Trulicity, and Mounjaro, four of the drugs the PDAB has selected for review, that must be addressed at the manufacturer level.

The Growing Cost Challenge

In Oregon, prescription drugs account for 20-30% of all plan spending, and GLP-1 medications represent a significant portion of this burden. Annual health plan costs per member for each of these medications are substantial, even with current evidence-based coverage:

- **Ozempic**: Roughly $12,000 per member annually
- **Rybelsus**: Roughly $11,000 per member annually
- **Trulicity**: Roughly $12,090 per member annually
- **Mounjaro**: Roughly $13,500 per member annually

These costs continue to escalate. At the start of 2024, Novo Nordisk raised the price of Ozempic by 3.5%, bringing a month's supply to roughly $1,100. A 2025 JAMA study found that the costs of GLP-1s in the U.S. increased by more than

500% from 2018 to 2023. Although rebates exist, members still struggle to afford these medications at the pharmacy, making adherence—which is essential for efficacy—more difficult.

Market Dynamics and Utilization Trends

We acknowledge the complexities surrounding these medications and GLP-1s in general. Currently, Regence covers these medications for members with type-2 diabetes and major adverse cardiovascular event (MACE) secondary prevention, after appropriate prior authorization requirements are met. Over the last two years, we have seen a dramatic increase in the use of GLP-1s, consistent with changes in standards of care for treating diabetes and, increasingly, for weight management indications. As market utilization steadily increases across multiple therapeutic areas, such as obstructive sleep apnea (OSA) and metabolic dysfunction-associated steatohepatitis (MASH), we know the annual cost of these medications will continue to rise.

Recent developments highlight significant pricing inconsistencies that demand PDAB attention. While the Institute for Clinical and Economic Review's (ICER) draft report analysis confirms these drugs provide substantial health benefits, it reveals a critical market disconnect despite their cost-effectiveness, fewer than 1% of eligible patients can be treated before crossing ICER's budget impact threshold of $880 million annually.

Even more telling is Eli Lilly's recent announcement offering direct-to-consumer pricing of $499 per month for Zepbound (tirzepatide) through their LillyDirect platform. This direct-pay option represents a significant discount from standard insurance-negotiated rates and demonstrates that these medications can be made available at substantially lower price points. The fact that a manufacturer willingly offers such dramatic price reductions for cash-paying patients highlights the artificial inflation of prices within the traditional insurance market. This creates an imbalanced dynamic where insured patients may actually face higher effective costs than uninsured cash-pay patients, ultimately placing additional financial strain on health plans and driving up premiums for all members.

Our Request for Action

Regence | 200 SW Market Street, 11th Floor
Portland, OR 97201

Costs to health plans are costs to our members. We want our members to have access to their lifesaving medications and are adamant that the cost of these medications needs to be reviewed. The collective impact of Ozempic, Rybelsus, Trulicity, and Mounjaro on our members' health care costs represents one of the most significant pharmaceutical cost challenges we face today. We urge the PDAB to carefully consider affordability measures that will ensure continued access while addressing the unsustainable cost trajectory of this entire drug class.

We will be happy to discuss any additional follow-up items. Thank you for your consideration of our feedback.

Sincerely,

Mary Anne Cooper
Director of Government Relations
Regence BlueCross BlueShield of Oregon

To: Oregon Prescription Drug Affordability Board

From: Jennifer Hazen

Date: 9/15/2025

Topic: Jardiance and Mounjaro

With the rising costs of healthcare, including premiums, deductibles and out-of-pocket costs, the costs of these drugs can be quite expensive. My out of pocket is almost 3x what it was last year…same with my deductible….and several thousand dollars. Therefore, for most of the year, these drugs to lower my A1c as a type 2 diabetic are quite expensive.

OCAP OREGON COALITION FOR AFFORDABLE PRESCRIPTIONS

September 14, 2025

Oregon Prescription Drug Affordability Board
350 Winter Street NE
Salem, OR 97309-0405
pdab@dcbs.oregon.gov

Dear Chair Bailey, Vice Chair Burns, and PDAB Members,

Thank you for the opportunity to submit public comment and for the time and effort you provide to protect Oregonians and our healthcare system from the high cost of prescription drugs. As the Oregon Coalition for Affordable Prescriptions (OCAP) we believe that prescription drugs should be affordable and accessible to all who need them. We are focused on ensuring that prescription drugs are affordable for every single Oregonian.

The cost of prescription drugs continues to rise, and Oregon patients are suffering. According to the Oregon Health Insurance Survey, **in 2024 more than 150,000 Oregonians delayed filling a prescription because of cost, and nearly 160,000 skipped or reduced medication so that a prescription would last longer.**[1]

Numerous polls in Oregon and across the country have demonstrated that Americans of all political leanings believe that more regulation is needed. Not only that, but **higher out-of-pocket costs for patients are associated with abandoned medication prescriptions and worse adherence for various chronic conditions.**[2]

After reviewing the policy concepts brought forward for discussion, we are concerned that your focus is too narrow. Pharmacy Benefit Managers are a problem in the supply chain, there's no doubt about that, and we appreciate many of your thoughtful policy concepts to regulate and hold them accountable. But **PBMs are not the only reason that so many Oregonians are struggling to afford their prescription medication** and we urge you to broaden your scope as you develop your legislative recommendations.

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[1] Oregon Health Insurance Survey Program. (2024). Cost Dashboard. Interactive display accessed 09/11/2025. Salem, OR: Oregon Health Authority. https://www.oregon.gov/oha/HPA/ANALYTICS/pages/ohis-cost.aspx

[2] Martin, M., Rome, B., Hwang, C., Hussain, Lalani, S., Raymakers, A., Rand, L., Bendicksen, L., Mooney, H., Liu, I., Avorn, J., & Kesselheim, A. (2023). Conducting drug affordability reviews executive summary. https://eadn-wc03-8290287.nxedge.io/wp-content/uploads/2024/04/Affordability-Review-White-Paper.pdf

Brand name drug prices increased by a median percentage of 4.5% this year[3], which while lower than in recent years, is still 150% of the rate of inflation, they routinely stack secondary drug patents to delay generic medication development, overuse the ORPHAN drug designation, and have spent countless dollars on advertising campaigns and lobbying to shift the blame for high drug costs solely on PBMs.

Everyone is looking for a silver bullet to end this crisis. But it's more complex than that. **A patient centered approach means addressing the problem of high prescription drug costs, from all sides: holding both pharmaceutical companies and PBMs accountable.**

As you continue through the affordability review process, we recognize the importance of ensuring that these reviews are thorough, evidence-based, and aligned with the PDAB statutory mission. **We are hopeful that the extension of the affordability report deadline will allow you to produce high-quality analyses that truly reflect the intent of the law and the needs of Oregonians.**

At the same time, it is critical to acknowledge that repeated delays in the review process have real-world consequences: they increase financial strain on vulnerable patients, force small businesses to absorb unsustainable costs, and ultimately provide cover for large pharmaceutical companies and industry groups to continue business as usual.

We urge you to make the most of this additional time by acting decisively and with urgency. In doing so, we recommend you review the White Paper *Conducting Drug Affordability Reviews*, published by Harvard Medical School and Brigham and Women's Hospital's Program on Regulation, Therapeutics, and Law (PORTAL), which outlines concrete considerations for state prescription drug affordability boards. If you have not already, this resource can help strengthen the board's process and ensure that your work delivers meaningful relief to the people of Oregon.

Thank you for the opportunity to submit these comments. Our board is available to support your work in any way we can. You can reach us at info@affordablerxnow.org or through BethAnne Darby at Strategies 360 Oregon.

Sincerely,
The Oregon Coalition for Affordable Prescriptions Board
John Mullin, Board Chair (Seanduine, and health and human service advocate)
Richard Blackwell, Board Treasurer (Pacific Source)
Marcus Mundy, (Coalition of Communities of Color)
Odalis Aguilar, (AFSCME Council 75)
Christi Marcotte, (Oregon Health Care Professional)

[3] Link, B. (2025, January 23). *Brand drug list price change box score*. 46brooklyn Research. https://www.46brooklyn.com/branddrug-boxscore

OREGON STATE PHARMACY ASSOCIATION
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(503) 582-9055 • www.oregonpharmacy.org • info@oregonpharmacy.org

September 12, 2025

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

Subject: Legislative Recommendations to Safeguard Oregon's Pharmacies and Patient Care

Dear Members of the Oregon Prescription Drug Affordability Board,

On behalf of the Oregon State Pharmacy Association, I am writing to submit our unified and urgent recommendations for the policies you should present to the legislature. The current practices of Pharmacy Benefit Managers (PBMs) are jeopardizing patient health and driving community pharmacies to the brink of collapse. These are not merely economic challenges; they are a public health crisis that demands immediate and bold legislative intervention.

Incremental reforms have proven insufficient. The data and our on-the-ground experience confirm that PBMs operate with a fundamental lack of transparency and an inherent conflict of interest that consistently prioritizes corporate profit over patient well-being.

We urge the Board to formally recommend the following legislative actions to protect Oregonians:

- **Eliminate Spread Pricing:** Ban the wasteful and costly practice of spread pricing in all Medicaid and managed care programs. All patients and taxpayers would benefit from this reform, as it would ensure that funds are directed toward healthcare, not hidden PBM profits.
- **Establish a Single, Transparent PBM for Medicaid:** Institute a single, transparent PBM for all Medicaid and managed care patients. This PBM must be selected through a bid process that emphasizes efficiency, reduced taxpayer costs, access for all Oregonians, and maximum transparency.
- **Reform Reimbursement and Fees:** Require that drug cost figures for reimbursement be based on objective, verifiable data sources, not on PBM-owned and managed lists that can be manipulated for profit. PBM fees should be delinked from the price of a drug and instituted as service fees, which would remove the incentive for PBMs to favor high-priced drugs.
- **Mandate 100% Rebate Pass-Through:** Require that PBMs pass 100% of all rebates and discounts back to the payer and patient at the point of sale. This would reduce out-of-pocket costs for patients and ensure that negotiated savings benefit the healthcare system, not PBM shareholders.
- **Establish fiduciary responsibility for PBMs to act in clients' best interests:** A fiduciary duty is a legal and ethical obligation to act in the best interest of another party. For PBMs in Oregon, this would mean they would be legally required to prioritize the financial well-being of the patients, pharmacies, and health plans they serve over their own profits. To protect patients, pharmacies, and the sustainability of Oregon’s healthcare system, a bold shift is necessary.

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- **Restrict formulary practices that prioritize PBM profit over patient care:** While generics are widely used where no alternatives exist, PBMs systematically restrict access to lower-cost alternatives within therapeutic classes in favor of drugs yielding higher rebates.USC research found that **the share of drugs restricted in non-protected classes in Medicare Part D rose from 31.9% in 2011 to 44.4% in 2020**. By 2020, Medicare plan formularies excluded an average of 44.7% of brand-name-only drugs. These restrictions compromise patient care through non-medical switching, prior authorization delays, and step therapy requirements, all designed to maximize PBM rebate revenue rather than optimize patient outcomes.

Oregonians cannot afford to wait for federal reform. We must act now to correct a broken system that is failing our patients and jeopardizing our pharmacies. The recommendations above provide a clear, actionable path to creating a more transparent, equitable, and patient-centered drug supply chain.

We thank you for your commitment to the health of our state and for your consideration of these critical recommendations.

Sincerely,

Brian Mayo
Executive Director

PCMA

September 12, 2025

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

On behalf of the Pharmaceutical Care Management Association (PCMA), I appreciate the opportunity to provide comments regarding the Board's discussion of 2025 Policy Concepts at your September 17th meeting.

As a reminder, the Board's statutory charge is *"to protect residents of this state, state and local governments, commercial health plans, health care providers, pharmacies licensed in this state and other stakeholders within the health care system in this state from the high costs of prescription drugs."* Unfortunately, the current policy concepts do not objectively advance this mandate. Instead, they appear to reflect legislative priorities advanced primarily by pharmacists and, to some extent, drug manufacturers.

Importantly, none of the concepts presented align with the law's directive to recommend "legislative changes necessary to make prescription drug products more affordable in the state." There is no evidence that the proposals under consideration would reduce costs for Oregon patients, health plans, or taxpayers.

We agree that the Board has an interest in studying and analyzing the role of pharmacy benefit managers (PBMs). However, focusing narrowly on PBMs—without fulfilling the statutory requirement to *"study the entire prescription drug distribution and payment system in the state"*—creates the perception that the Board is a single-issue body, advancing the interests of certain stakeholders rather than protecting all Oregonians. The Board has a critical opportunity to examine the full drug supply chain, evaluate the role and impact of all entities, and develop recommendations that meaningfully address affordability. To focus otherwise would miss both the spirit of the law and the Board's statutory responsibility.

Thank you for your consideration of these comments. PCMA stands ready to serve as a resource as the Board continues its important work.

Sincerely,

Bill Head
Assistant Vice President
State Affairs

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