

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



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# PUTTING PATIENT VOICES FRONT AND CENTER

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

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

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

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

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

## Study endpoints included:

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

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

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

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**FINDINGS AND POLICY  
RECOMMENDATIONS**

## KEY FINDINGS

By focusing on the affordability of a single prescription drug, decision-makers miss critical context about patients' broader challenges. 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.



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**SURVEY RESULTS**

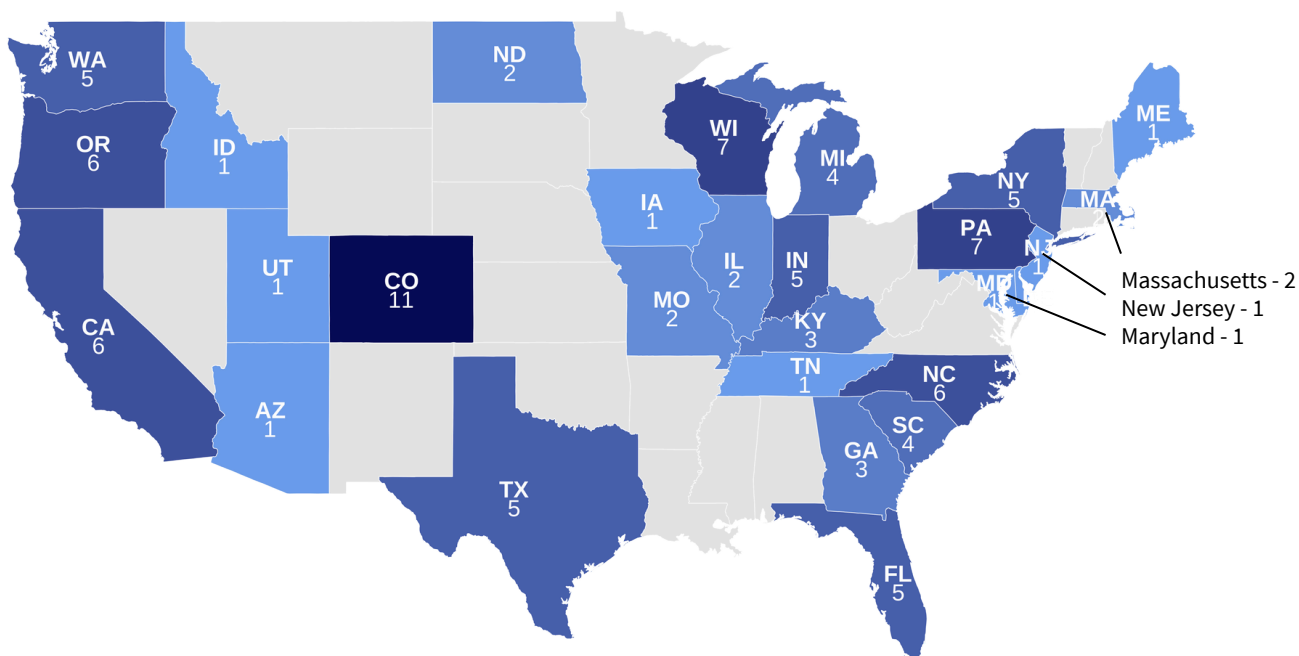
# POPULATION SNAPSHOT

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)

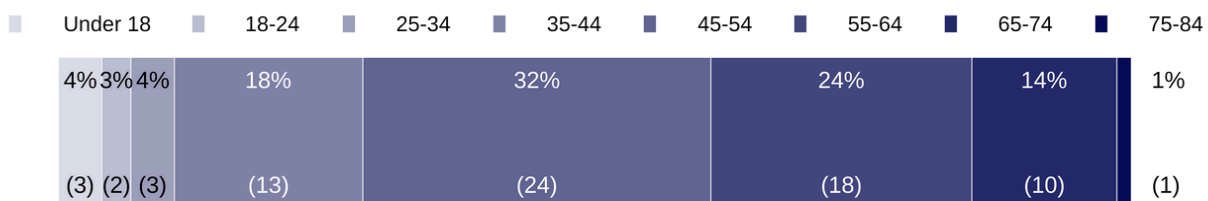
## RESPONDENTS' GEOGRAPHIC LOCATION



Total Responses: 100

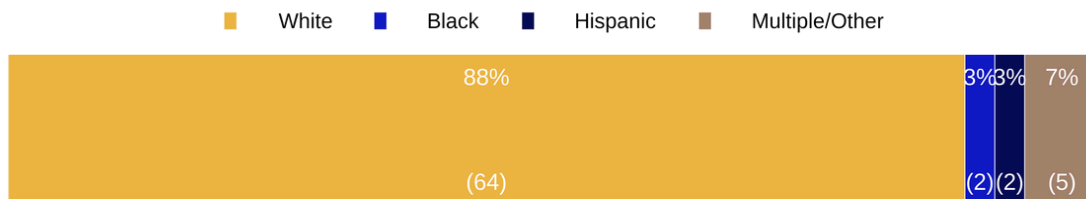
# DEMOGRAPHIC BREAKDOWN

## DISTRIBUTION OF PATIENTS' AGE



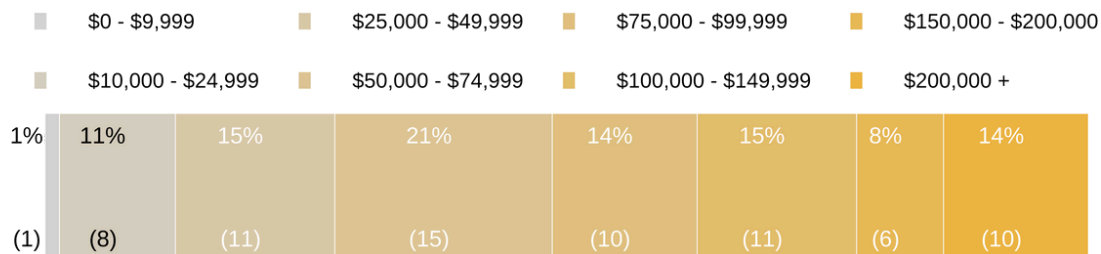
Total Responses: 74

## DISTRIBUTION OF PATIENTS' RACIAL AND ETHNIC IDENTITIES



Total Responses: 73

## DISTRIBUTION OF PATIENTS' HOUSEHOLD INCOME



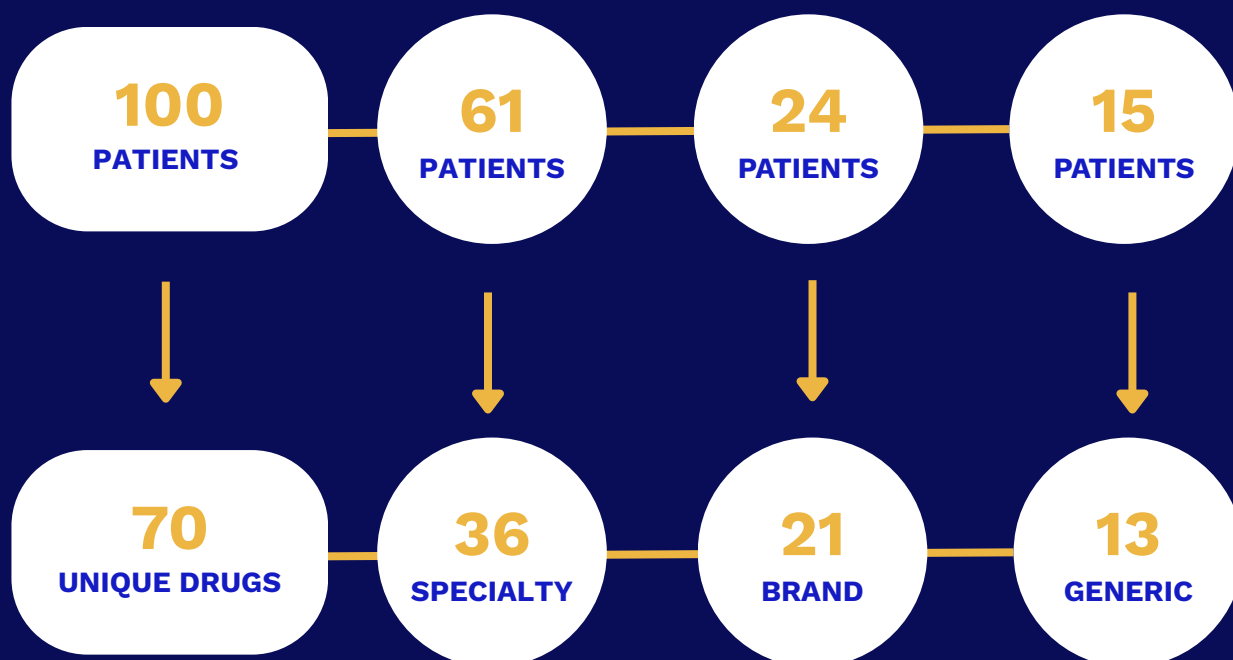
Total Responses: 72

# 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).



## CURRENT SURVEYS ARE MISSING THE “WHY”

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

**57% AFFORDABLE**

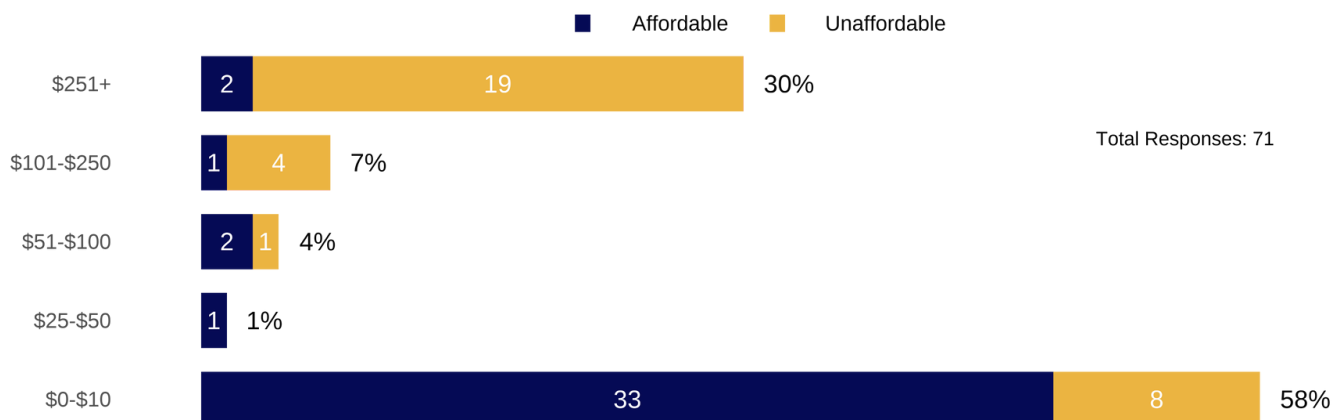
**43% UNAFFORDABLE**

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

**BUT WHY?**

### AFFORDABILITY BY MONTHLY DRUG COST

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



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

Our preliminary data indicated that while patients who pay more for their drugs are more likely to say those drugs are unaffordable, **affordability does not solely align with drug price.** Instead, it is largely based on **dynamic personal experiences and opinions, evolving life situations, and perspectives related to the term “affordability.”**

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

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

80%

20%

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.

0%

## 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%

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%

33%

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.

80%

20%

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.

90%

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%

83%

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 this **drug costs more at the start of the year before deductibles have been met.** This person reported 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.

100%

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.

100%

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

### WHY DID PATIENTS REPORT THIS AMOUNT AS UNAFFORDABLE?

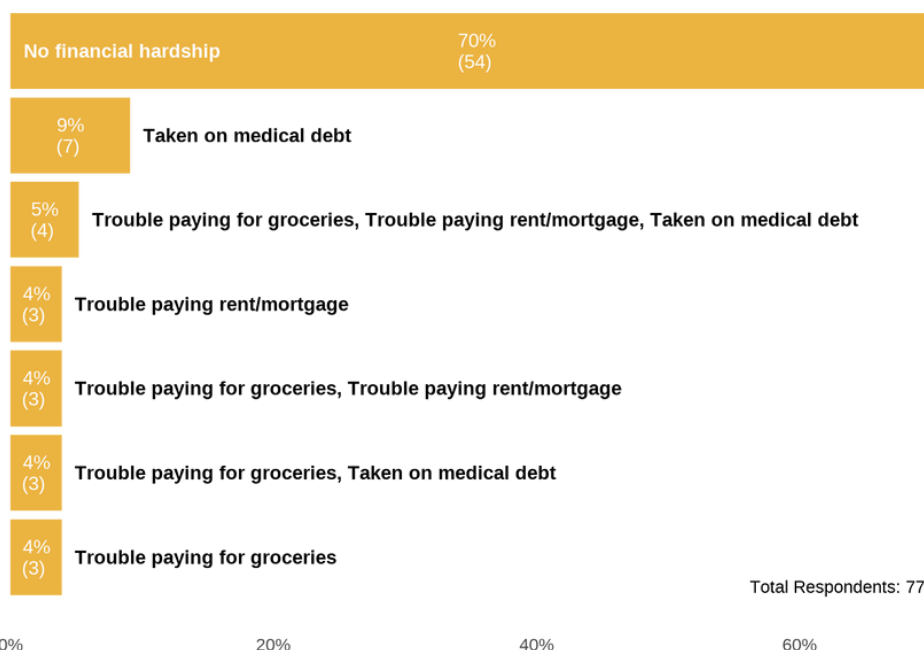
#### Insurance barriers

- 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.

% (n) of respondents citing each hardship



**70%**  
54 OUT OF 77  
RESPONDENTS SAID  
THE OUT OF POCKET  
COST OF THE DRUG  
THEY WERE  
REPORTING CAUSED  
NO FINANCIAL  
HARDSHIP

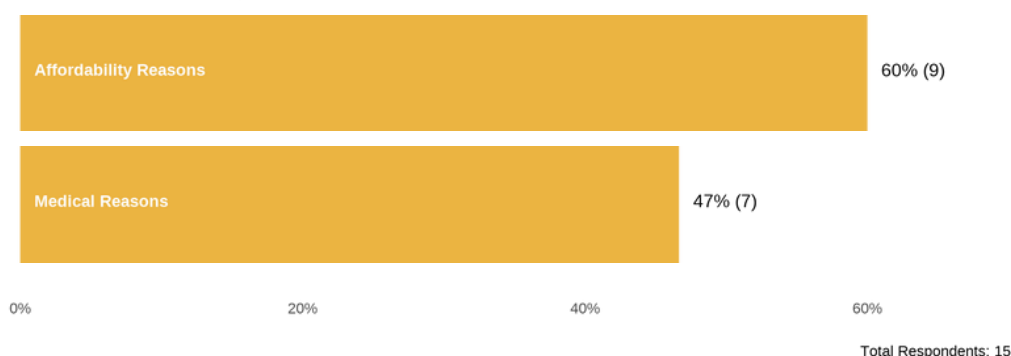
**70% (54 people) said the OOP cost of the drug they were reporting caused no financial hardship. Of those reporting financial hardship:**

- 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 completed the section on hardships caused by this drug or other drugs and reported this OOP amount unaffordable, **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

% (n) of respondents citing each reason



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”?

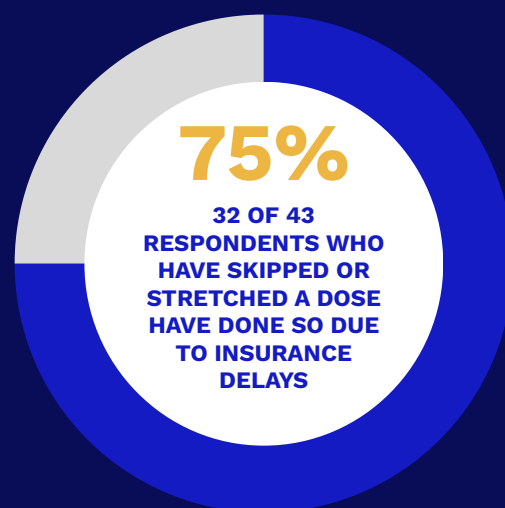
By providing comment boxes after each question, respondents were able to provide details about their answer. **This context is missing in current surveys associated with government drug affordability initiatives, leading to misinterpretation of prescription drug “affordability”.** In reality, affordability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

## 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.

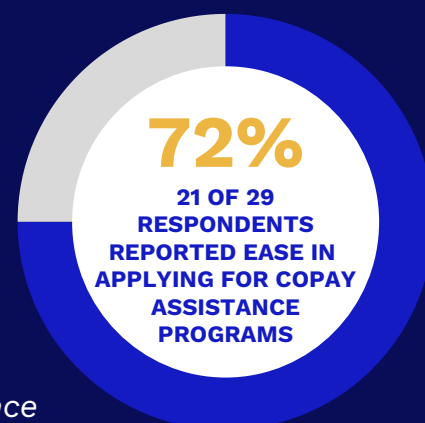
### PAYMENT ASSISTANCE OFTEN EQUATES TO AFFORDABILITY

- **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.”*





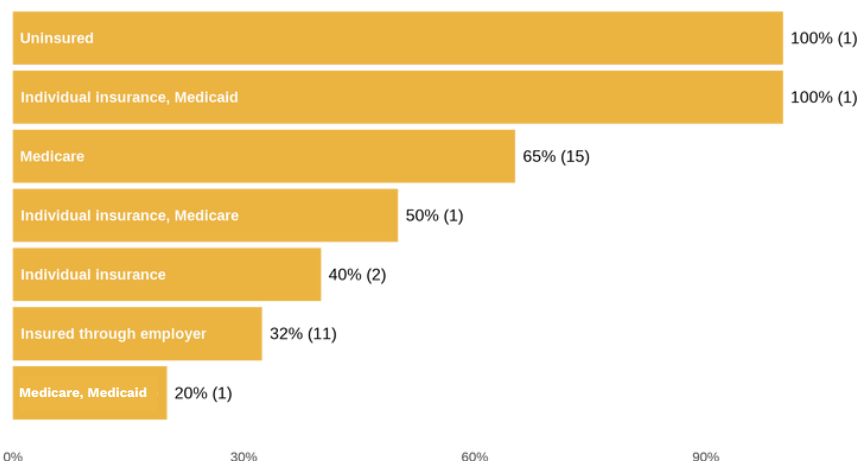
# AFFORDABILITY CHALLENGES WITH MEDICARE

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.*

% (n) of respondents with each insurance type who find medication unaffordable



Total Responses: 71

**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."*

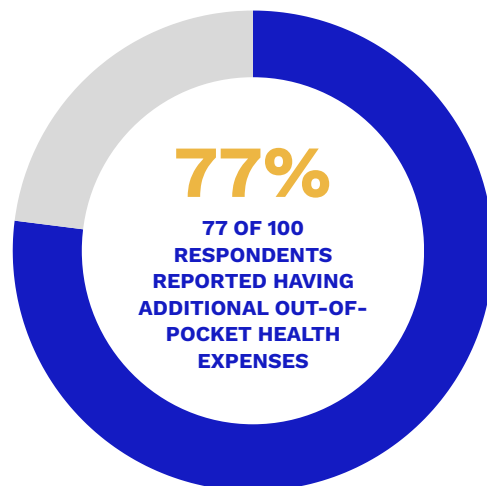
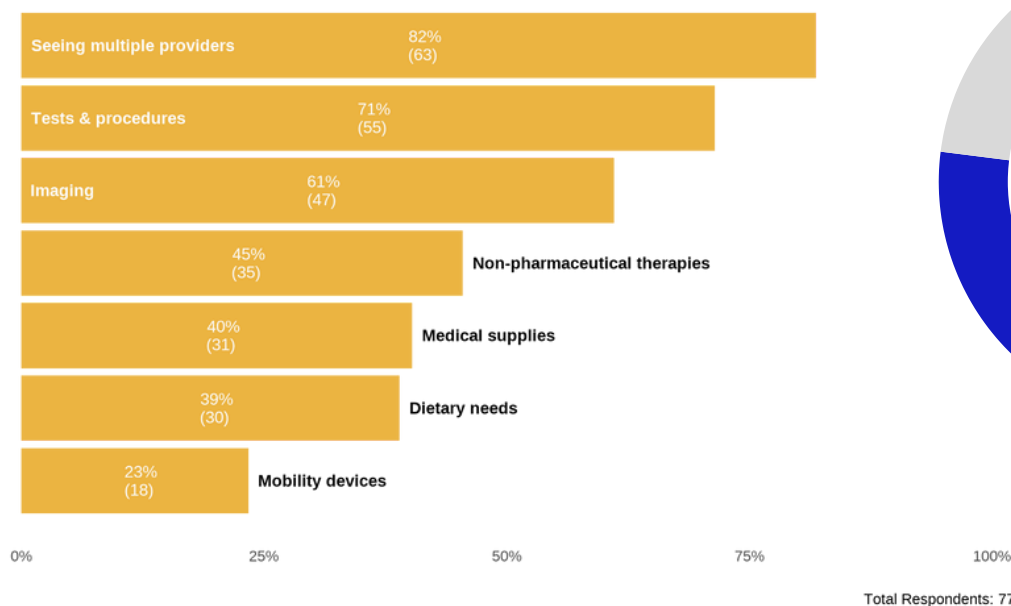
## ADDITIONAL OUT-OF-POCKET COSTS

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

% (n) of respondents citing each additional OOP cost



***“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.”***

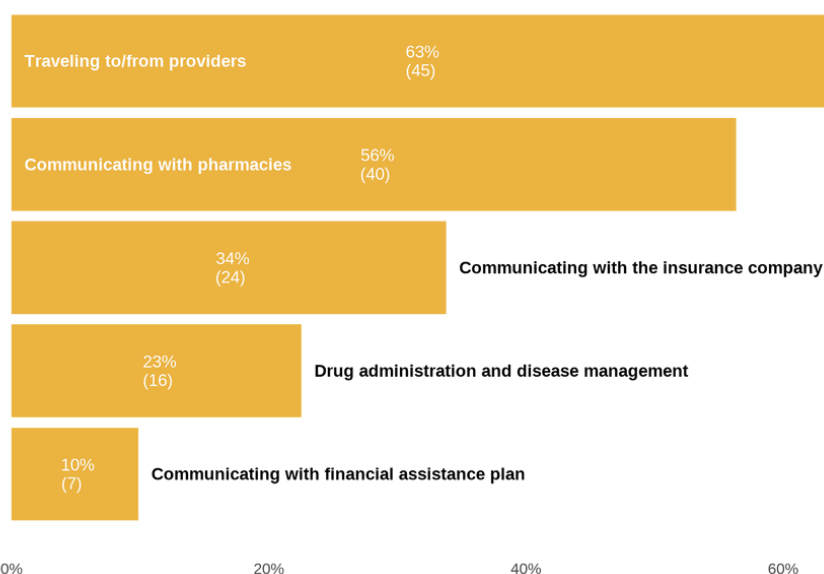
## TIME COSTS ASSOCIATED WITH DISEASE MANAGEMENT

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

% (n) of respondents citing each time cost



Total Respondents: 71

**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 than 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*

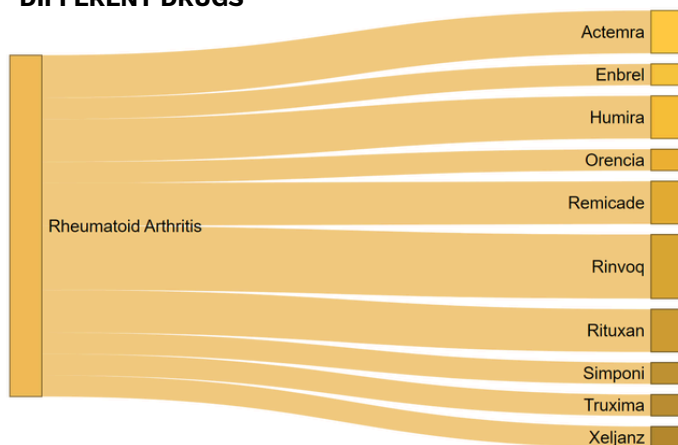
# THE IMPORTANCE OF PREFERRED THERAPIES

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

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

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**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**

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## **APPENDIX**



# 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/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>



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

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

[WWW.EACHPIC.ORG](http://WWW.EACHPIC.ORG)



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**ENSURING ACCESS THROUGH  
COLLABORATIVE HEALTH**



**PATIENT  
INCLUSION COUNCIL**