PATIENT INCLUSION COUNCIL

UNDERSTANDING PATIENT-REPORTED PRESCRIPTION DRUG AFFORDABILITY

WHY THE FULL STORY MATTERS

A Patient-Centered Analysis of Findings from the Patient Experience Project: Patient-Reported Affordability & Unaffordability Survey 2.0

EACH PIC COALITION

This study was led by the Ensuring Access through Collaborative Health (EACH) and the Patient Inclusion Council (PIC) is a two-part, disease agnostic coalition that advocates for drug affordability policies that benefit patients.

OVERVIEW

WHY DID THE PATIENT INCLUSION COUNCIL (PIC) DO THIS STUDY?

Current policies fail to address the root causes of patient issues. Across the country, healthcare policy decisions that are touted as helping patients actually only result in lowering costs for the government or even insurance companies.

Improving healthcare affordability for patients is a critical issue; however, it can't be solved without asking the right questions. Often, patient surveys ask simple yes/no questions and do not leave room for patients to share context around their answers. These surveys have led policymakers to make equally simplified and, in some cases, wrong assumptions about patient responses.

Better surveys lead to better understanding. We believe the best way to help patients is to listen to them, understand ***why*** their medicines are hard to afford, and then work to create solutions based on that information.

ACCURATE DATA = EFFECTIVE SOLUTIONS

In this 18-month, two-phase study, we demonstrated how properly worded questions and open-ended comment boxes better capture patient perspectives on the costs of their medications.

We hope this vital, patient-focused research sheds light on two things:

- Determining the true drivers of patient affordability and access challenges so that we can find real solutions to patient-identified problems.
- Establishing a model for effective patient-facing question design that can be used by policymakers to better understand how to help patients.

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DEMOGRAPHICS & AFFORDABILITY

DEMOGRAPHICS

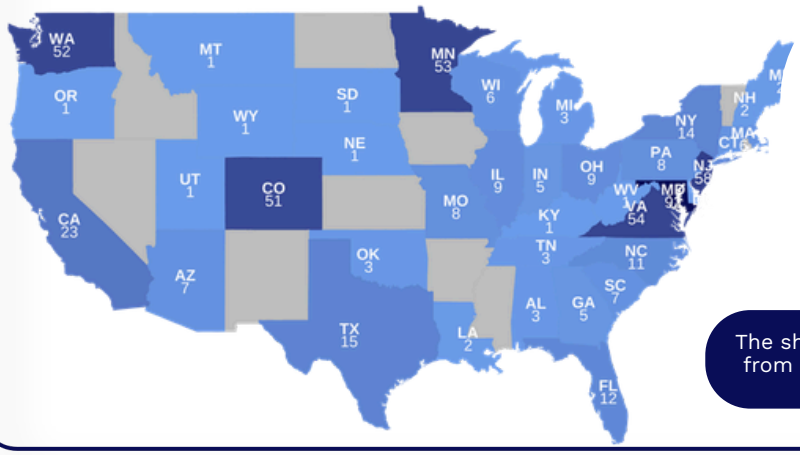
Survey responses came from paid (SurveyMonkey) and unpaid respondents (often recruited through patient advocacy organizations, patients, and word-of-mouth).

537 PATIENTS

94 DIAGNOSES

88% COMORBIDITIES (being diagnosed with one or more additional conditions

Respondents were asked to report on ***one*** prescription drug used to treat chronic conditions like autoimmune diseases/diabetes, and asthma.



225 DRUGS

174 GENERIC

208 SPECIALTY

104 BRAND

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

WHAT DOES "AFFORDABLE" MEAN TO PATIENTS?

200 patients defined affordability as "the ability to consistently obtain medications within *their essential* monthly household budget, considering income, total healthcare costs, and life circumstances."

As confirmed in our pilot survey of this research, ranking a drug "affordable" or "unaffordable" depended on:

- **Personal Income**
- **Insurance Coverage**
- **Number of Medications**
- **Life Circumstances**

> ***"This is not a one-size-fits-all-answer. [Affordability] is a moving target."***

KEY TAKEAWAYS

Until this study, patients had not been asked to define what affordability means to them, even though decisions about whether they can or cannot afford a medication are being made by people who do not take the prescriptions under review.

Affordability Did Not Solely Align with the Retail Price of the Drug
Patients consistently reported prescription affordability based on insurance design, income, cumulative costs, and evolving life situations.

Shifting Costs Often Means Shifting Affordability and Access
Many patients pay different prices for the same drug over time ("out-of-pocket cost shifting"), causing affordability to change ("affordability shifting"). This can result in losing access to the medication ("access shifting").

Stopping or Never Taking a Drug is Insurance Related
Insurance policies were the most common reason patients could not afford or access their medications.

Hardship is Common
Even some who reported paying $0-$50 for a prescription or making over $200,000 a year reported issues paying for groceries or rent/housing and accumulating medical debt.

Access to Financial Assistance Programs Matter
Financial assistance often makes medications affordable, but insurance rules or lack of knowledge that they exist can block or limit that help.

Racial Differences in Access and Affordability
Patients of color reported affordability challenges at higher rates and reported brand and generic drugs over specialty medications. This suggests access and cost burdens are not equal.

Medications Are Not Interchangeable
Medications work differently for each patient and are not interchangeable, so protecting access to the treatment that works best is as important as managing costs.

1. AFFORDABILITY DID NOT SOLELY ALIGN WITH THE RETAIL PRICE OF THE DRUG

"Respondents were asked, "Thinking of **the last time** you took [drug], what was the monthly out-of-pocket cost you paid?" Choices were $0-10, $11-25, $26-50, $51-100, $101-250, $251-500, $501-1000, $1001+.

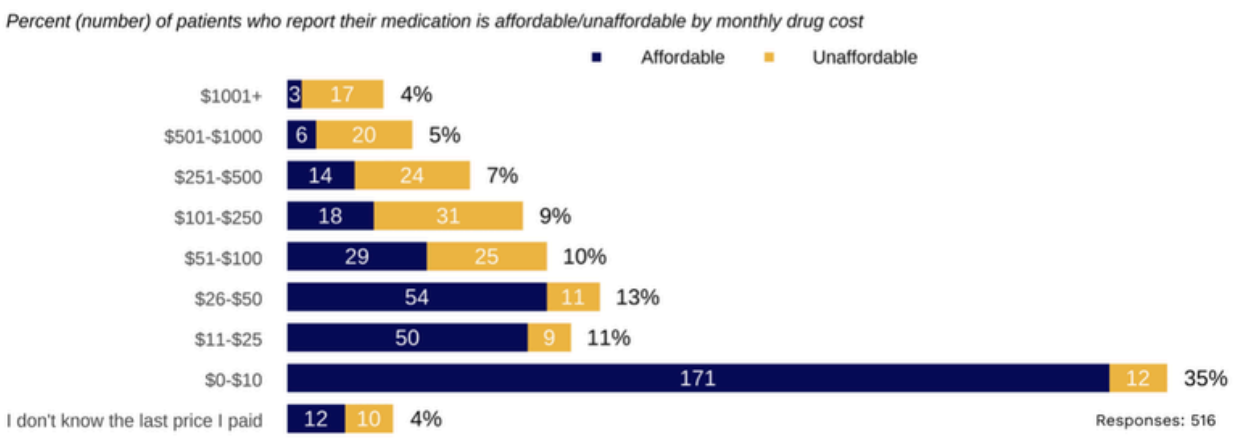
They were then asked, "Do you consider this **affordable or unaffordable? Explain why." Here is the breakdown of the last out-of-pocket cost.**

69% AFFORDABLE | **31% UNAFFORDABLE**

*But **why**?*

Patients consistently reported prescription affordability based on insurance design, income, cumulative medication or healthcare costs, and evolving life situations (like job loss). A few - including some who paid $0 - said this amount was unaffordable based of opinions about prescription drug prices, not what they actually paid.

AFFORDABILITY BY *MOST RECENT* OUT-OF-POCKET COST



But these numbers actually are only a screenshot in time. Our expanded research also showed many patients struggle with affordability at ***some times, but not at other times,*** if they have paid multiple prices for the same drug over time.

Largely due to this "affordability shifting", the research concluded that no one drug - even those reported on more than 30 times - created affordability hardships for any group of people.

2. SHIFTING COSTS OFTEN MEANS SHIFTING AFFORDABILITY AND ACCESS

While trying to figure out the tipping point when an out-of-pocket cost goes from affordable to unaffordable, researchers discovered new drivers that lead to treatment affordability and access issues.

In addition to being asked to report their last out-of-pocket cost for the drug, respondents were also asked:

- If you have paid more than one price for [drug], report **all prices** you've paid.
- For all of the prices you've paid for [drug], please note whether you considered each price **affordable or unaffordable.**
- **Explain in detail why** you reported the out-of-pocket cost(s) affordable or unaffordable.

21% of **all 537 respondents** reported they **paid more than one out-of-pocket cost for the same drug over time,** which the PIC defined as **"out-of-pocket cost shifting".**

51% of those reporting out-of-pocket cost shifting **also flip-flopped reporting the same drug as both "affordable" and "unaffordable".** The PIC defined this as **"affordability shifting."**

- 41% of those who reported their drug as "unaffordable" in this survey also reported the same drug as "affordable" at another point in time.
- 18% of those who reported their drug as "affordable" in this survey also reported the same drug as "unaffordable" at another point in time.

90% of the 92 people who explained ***why*** **affordability shifting happened** said it was **due to insurance plan barriers** (high deductibles, out-of-pocket maximums, coverage denials). For some this was made worse by **unstable financial assistance, income changes, and changing life circumstances.**

Of those who experienced affordability shifting, many said they no longer could access the drug, even if they could before. The PIC defined this as "access shifting."

> ***"I previously had Anthem and got this medication for a copay of $15 a month. I now have United Healthcare and they will not cover it. Out-of-pocket cash price is over $700 a month. I can't use a savings card because that medication must be on their formulary. I am now going without this medication and am now having daily migraines."*** *- Out-of-pocket costs for the same drug, same person from $0-$1001*

3. STOPPING OR NEVER TAKING A DRUG IS MOSTLY INSURANCE RELATED

With the exception of medical reasons, insurance policies were the most common reason patients could not afford or access their medications.

95% of patients who stopped taking their medication due to "cost," explained in open-ended comments that the high cost was due to insurance-related challenges such as coverage removal, high deductibles, step therapy requirements, or copay accumulator policies.

72% of those who never started their prescribed medication cited insurance-related barriers - like the medication was not approved by the insurance company or they had high deductible plans.

4. HARDSHIP IS COMMON

Even higher-income families reported affordability challenges due to insurance coverage changes and long-term healthcare costs. Of the 340 people who reported on hardships:

71% said the **cost of *one or more* prescription drugs caused hardships** such as difficulty affording groceries, housing, or medical debt. About half of them reported their last out-of-pocket cost was $0-$50.

56% of people reporting these hardships also reported their drug as **"affordable".**

> ***"My doctor prescribed it and since my insurance did not cover it the cost would have been over $1000!"***

> ***"If I become unable to pay for private insurance through COBRA, then I will immediately be facing massive hardship with other expenses, including house payments and groceries. The mental hardship, of course, is priceless."***

4. ACCESS TO FINANCIAL ASSISTANCE PROGRAMS MATTER

Among specialty drug users who mentioned assistance, 71% said it was the reason why their medication was affordable. But not everyone had financial assistance. Some were not aware it was available.

Over 40 respondents said **they could not afford their medications** because of high deductible insurance plans and limitations applying financial assistance to their copays.

In past research, those on Medicare reported high out-of-pocket costs because they could not qualify for copay assistance. In this study, only two reported this issue. **New $2,000 limits and pay-over-time options** may be why**.**

5. RACIAL DIFFERENCES IN ACCESS AND AFFORDABILITY

This survey highlighted known systemic differences in healthcare access among people of color.

Patients of color were more likely to report **using brand or generic medications and less likely to report using specialty drugs** compared to non-Hispanic white patients.

Patients of color **experienced affordability challenges at higher rates for specialty and generic drugs**, and at similar rates for brand-name drugs.

These findings suggest that differences in access to specialty medications—and possible gaps in awareness of financial assistance programs that often make those drugs affordable—may contribute to these disparities.

> ***"After 3 denials and a lot of paperwork I was finally approved by my insurance company and drug company program! But most people would have given up."***

> ***"My insurance didn't cover much, and my income is low, so it was unaffordable."***

6. PRESCRIPTION DRUG VALUE

Our research shows that medications do not work the same way for everyone. Even patients taking the same drug reported different results—some said it was life changing, while others said it did not work for them.

In 60 respondents with Rheumatoid Arthritis, **82% tried more than one specialty medication before finding the one that worked.** 49% of them had comorbidities (more than one health condition) that could impact treatment decisions. This means “therapeutic alternatives”, or medications in the same class, may not be right for them.

Patients also reported **harm when they were forced to switch drugs for insurance reasons, not medical reasons,** leading to flare-ups and worse health. This type of forced switch is called Non-Medical Switching.

> ***“When I dealt with a forced non-medical switch my life flipped upside down. I went from being in remission for nine years to being debilitated for almost two months, this was extremely upsetting and really messed with my life as a mom of three young kids.”***

CONCLUSION

Prescription drug affordability cannot be understood through a single question or a single month’s cost. Without first identifying the patient-reported “why” behind affordability challenges, solutions will fail to reflect the needs of those most affected.

This study offers a patient-centered model for affordability reviews, focusing on the right questions and methods to uncover the real drivers of cost challenges. Efforts to improve affordability should be grounded in this approach to ensure they truly support patients.

This research shows that solutions designed to cap costs for insurance companies will likely not resolve patient affordability challenges. In those cases, solutions to address patient prescription drug affordability should be reconsidered if the goal is to meaningfully help patients.

Learn more about the Patient Inclusion Council (PIC) and get involved today!