

Prescription Drug Affordability & Unaffordability Patient Experience Survey

Introduction and Consent

The Patient Inclusion Council (PIC) seeks to uncover factors presenting prescription drug affordability and access challenges for patients in the United States. This survey was created by research professionals, patient research partners (PRPs), and patient organizations.

The results of this project will be shared with Prescription Drug Affordability Boards (PDABs), the Centers for Medicare & Medicaid Services (CMS), and legislators to inform prescription drug affordability reviews and connected legislative efforts. Understanding patient issues, concerns, and successes related to prescription drug affordability and accessibility is a vital step towards making improvements.

Please share this survey with anyone you know prescribed a high-cost drug in the United States.

WHO SHOULD TAKE THIS SURVEY:

- **Patients living in the United States who take a prescription drug that is considered high cost (or caregivers caring for someone who meets these criteria).**
- **It doesn't matter if the drug is too expensive or if you can afford it. Understanding the "why" behind affordability is critical to identifying solutions.**
- **You can take this survey if you currently take the drug, used to take it in the last 10 years, or could have taken the drug, but didn't (e.g. your doctor prescribed the drug, but you could not access it for some reason).**

CONSENT TO PARTICIPATE:

- **Description of Activity:** We invite patients and caregivers (who meet the criteria listed above) to share their perspectives via the survey.
- **Voluntary Participation:** Your participation in this survey is entirely voluntary. You may choose to withdraw at any time without penalty or loss of benefits.
- **Confidentiality:** No identifying information will be included in any reports resulting from this study. If you choose to provide your name and contact information at the end of the survey, this will NOT be published, nor will any identifiable information be shared.
- **Risks and Benefits:** There are minimal risks associated with participating in this survey. You may benefit by contributing data to help improve prescription drug affordability and accessibility.
- **Optional Continued Participation:** You may continue sharing your experiences after this survey in patient-led discussions.
- **Duration:** The survey will take approximately 20 minutes to complete.

By starting this survey, you are consenting to participate. You may stop participating at any time.

[CLICK HERE to preview the survey questions.](#)

The Ensuring Access through Collaborative Health (EACH) and Patient Inclusion

Council (PIC) is a two-part coalition that unites national and state organizations (EACH), patients and caregivers (PIC), to advocate for drug affordability policies that benefit patients.

The Patient Inclusion Council aims to empower patients and caregivers to shape healthcare policy through peer-led education, perspective sharing, and activities to ensure patient-reported needs are incorporated into drug affordability solutions.

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Key Demographics

During this survey, we will be asking you questions about the one drug you are reporting on today. But first, let's get a little more information about you.

* 1. Are you the person who takes or took this drug (**patient**) or are you a **caregiver** submitting answers on behalf of a patient?

- Patient
 Caregiver

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Key Demographics

***Caregiver Note: Please answer all remaining questions from the perspective of the patient.**

* 2. State

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Key Demographics

* 3. Zip Code

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Diagnosis Information

***Caregiver Note: Please answer all remaining questions from the perspective of the**

patient.

In this next section, we want to hear about the diagnosis that is treated by the one drug you are reporting. If you are living with more than one condition, you can tell us more about other diagnoses in a different question. diagnosis.”

* 4. What is **the diagnosis** for which this drug is/was prescribed to treat?

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Diagnosis Information

* 5. **How long ago** were you diagnosed with {{Q4}}?

- Less than 1 year ago
- More than 1 year but less than 3 years ago
- More than 3 years but less than 5 years ago
- More than 5 years but less than 10 years ago
- More than 10 years ago

* 6. How does {{Q4}} **impact your daily life**?

Provide examples that include how {{Q4}} impacted your life prior to treatments (if applicable) as well as how it impacts your life today.

* 7. In addition to {{Q4}}, are you **diagnosed with other co-existing conditions or additional diagnoses** (defined below)?

Co-existing conditions are additional diagnoses that are directly related to this diagnosis. For example, if you are reporting a drug to treat rheumatoid arthritis, you may also have heart disease or eye disease because of uncontrolled rheumatoid arthritis. These co-existing conditions, or complications from the diagnosis for which you take this drug, might impact the medication your doctor chooses to prescribe.

Additional diagnoses are conditions you also have that are not related to this diagnosis. So in the case of a person reporting on a drug used to treat asthma, if they also had diabetes that would be an additional diagnosis. This is also important to understand because the prescription the doctor chooses may be affected by other diagnoses.

- No
- Yes (please list other conditions)

8. Is there **anything else** you would like to share about your **diagnosis** related to how it impacts your life and any need for treatment related to this diagnosis?

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Drug Information

***Caregiver Note: Please answer all remaining questions from the perspective of the patient.**

Please Focus on One Drug for This Section

We understand that many patients take multiple medications, however, for this survey please focus on submitting information about one specific drug (taken to treat {{Q4}}).

You will have an opportunity to discuss other medications and conditions later in the survey or in follow-up interviews (if interested).

* 9. **Name of drug** for which you are providing comments?

Please enter it exactly as written on your prescription, excluding dosage information.

10. **Dosage.**

Include how much you take/took per dose and how often you take/took it.

If you have taken different doses over time, please list only the current or most recent dosage.

If you were prescribed this medication but never took it, please put the dosage you were prescribed (if you know).

* 11. In **what way did you take** this prescription (i.e., pill, injection, infusion, etc.).

If you have taken the prescription in different ways over time, please only list the current or most recent way.

If you were prescribed this medication but never took it, please note the method by which you were supposed to take it.

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Drug Information

* 12. Are you reporting on **a drug that you are currently taking or have taken before?**

- Yes, I am taking or have taken {{Q9}} before.
- No. I have not taken {{Q9}}, but I have a diagnosis {{Q9}} could treat and would like to share more about that.

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Drug Information

* 13. **When** did you **start using** {{Q9}}?

If you are unsure of the exact date, get as close as possible.

Date / Time

Date

* 14. **Why did you start using {{Q9}}?** (Examples: doctor prescribed, insurance required, way it is administered, other medications had side effects, etc.)

* 15. Was there ever a time when you were taking this prescription drug that **access to it was interrupted?**

- No
- Yes (please explain)

* 16. Prior to using {{Q9}}, did you **try any similar prescription drugs** to treat your condition?

For example, if this drug is a biologic drug, this question asks if you have been on a similar type of drug - or another biologic. It is not referring to a milder type of treatment that may be used before stepping up to this prescription.

- No
- Yes (list the names of other drugs and describe your experiences, including why you stopped taking each)

* 17. Explain the **positive and/or negative affects** you experienced from using {{Q9}}.

* 18. Are you **currently taking {{Q9}}**?

- Yes
- No

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Drug Information

* 19. When did you **stop using** {{Q9}}?

If you are unsure of the exact date, get as close as possible.

Date / Time

Date

MM/DD/YYYY

* 20. **Why** did you **stop using** {{Q9}}?

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Health Coverage

***Caregiver Note: Please answer all remaining questions from the perspective of the patient.**

* 21. Thinking of the *most recent time when you were taking* {{Q9}}, what type of **health insurance** did you have?

If you have been on this drug for some time, and have switched insurance, please only report your most recent insurance coverage. You can add more about past insurance coverage and how it impacted affordability or access in a later question.

If you had more than one type of coverage, please select all that apply.

If you are/were on a spouse/partner or parent plan, please answer according to their insurance coverage at the time.

- I did not have health insurance at that time
- I had health insurance through an employer
- I had individual insurance (e.g. not through a group-sponsored plan; this includes health insurance purchased through government exchanges or directly through insurance companies or brokers)
- Medicare
- Medicaid
- Veterans Assistance/Tricare
- Other (please specify)

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Health Coverage

* 22. You said that you had Medicare during the most recent time you were taking {{Q9}}.

Which subgroup plan(s) did you have? *Select all that apply.*

Your subgroups can be found on the bottom left corner of your Medicare card.

- Part A
- Part B
- Part C (Medicare Advantage)
- Part D (Drug Coverage)
- Medicare Supplemental Plan/PartG-K/Medigap
- SSD/SSDI (Disability)
- Unsure

* 23. *Thinking of the most recent time you were taking {{Q9}}*, what was your **health insurance monthly premium cost (the out of pocket cost per month to have health insurance)**?

- Less than \$100
- \$100-\$249
- \$250-\$499
- \$500-\$749
- \$750-\$999
- \$1,000-\$1,499
- \$1,500-\$1,999
- \$2,000-\$2,499
- \$2,500-\$2,999
- \$3,000 or more
- I don't know

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Health Coverage

* 24. You said that your health insurance premiums cost you {{Q23}} per month. **Who did these premiums cover?**

- Just me
- Me and a partner/spouse
- Me and children
- Me, a partner/spouse, and children
- Other (please specify)

* 25. *Thinking of the most recent time you were taking {{Q9}}*, how much did the cost of your **health insurance premiums contribute to your overall financial burden?**

- Not at all - it was manageable within my budget
- Somewhat - it adds strain but doesn't significantly impact other expenses
- A lot - it makes it difficult to afford other necessary expenses
- Extremely - it is a major financial hardship

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Health Coverage

26. Is there **anything else** you would like to share about your **health coverage** as it relates to your {{Q4}} diagnosis and/or your {{Q9}} prescription?

Prescription Drug Affordability & Unaffordability Patient Experience Survey

Cost and Affordability

***Caregiver Note: Please answer all remaining questions from the perspective of the patient.**

* 27. *Thinking of the most recent time you were taking {{Q9}}*, which of the following **factors contributed to your out of pocket expense** for {{Q9}}?

- Copay
- Copay assistance or patient assistance plan
- Coinsurance
- Deductible
- Being uninsured
- Insurance not covering {{Q9}}
- I'm don't know

Other (please specify)

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Cost and Affordability

* 28. *Thinking of* the impact of the factors you listed above--*{{Q24}}*--what was the **most recent monthly out of pocket cost** that you paid for *{{Q9}}* *alone*?

- \$0-\$10
- \$11-\$25
- \$26-\$50
- \$51-\$100
- \$101-\$250
- \$251-\$500
- \$501-\$1000
- \$1001+
- Other (please specify)

* 29. *Thinking of your most recent monthly out of pocket cost for {{Q9}}*, do you consider this amount **affordable or unaffordable**?

Please explain your answer.

- Affordable
- Unaffordable

Explanation

* 30. *Thinking of the most recent time you were taking {{Q9}} and the preceding 12 months, did your **monthly costs for {{Q9}}** ever vary?*

- No
- I don't remember
- Yes (please explain)

* 31. *Because of the monthly out of pocket cost of {{Q9}}--and only the cost associated with {{Q9}}-- have you **experienced financial hardship**? Select all that apply.*

- Yes, because of the out of pocket cost of {{Q9}} I have/had trouble paying for groceries.
- Yes, because of the out of pocket cost of {{Q9}} I have/had trouble paying rent/making house payments.
- Yes, because of the out of pocket of {{Q9}} I have/had in medical debt.
- No, the out of pocket cost of {{Q9}} has not caused financial hardship.

Comments

* 32. Have you ever **stretched or skipped a dose** of {{Q9}}?

- No
- I don't know
- Yes (please explain).

* 33. *Thinking of the most recent time you were taking {{Q9}}*, did you **use any copay assistance programs, discount cards, or other savings plans provided by prescription drug manufacturers or other organizations** that helped lower your out of pocket cost for {{Q9}}?

Select all that apply.

- Yes, the manufacturer's copay assistance program
- Yes, a discount card (example: GoodRx)
- Yes, financial assistance from an organization that was not the drug manufacturer
- Yes, other type of savings plan
- I applied for the manufacturer's copay assistance program but I did not qualify
- No, there is no/was no drug manufacturer assistance program to help with the cost of this drug
- No, my health plan does not/did not permit payment assistance options (i.e., Medicare, Medicaid)
- I don't remember
- Other (please specify)

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Cost and Affordability

* 34. *Thinking about your experience with the copay assistance program* mentioned in the previous question, do **any of the following situations apply**?

Select all that apply.

- I found it difficult to find information about available programs.
- I found it hard to complete the initial application form.
- I had a difficult time getting the insurance company to add the assistance plan to my account.
- Even though I was approved for assistance the insurance company/specialty pharmacy still sent me a bill for the drug.
- No, I did not have any issues setting up or applying an assistance program to my insurance plan.
- I don't remember
- Other (please explain)

Cost and Affordability

35. Is there **anything else** you'd like to share about your **experience with your copay assistance program**?

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Cost and Affordability

* 36. Did you **apply for or receive any other assistance** not mentioned elsewhere to help afford {{Q9}}?

This includes asking a family member or friend, using Gofundme, crowdfunding, or taking donations for help paying for out of pocket costs for this drug.

- No
- Yes (please specify)

37. Is there **anything else** you would like to share about the **cost or affordability of {{Q9}}**?

You will have the opportunity to mention other costs associated with managing this condition in a separate question.

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Cost and Affordability - Other Costs

***Caregiver Note: Please answer all remaining questions from the perspective of the patient.**

* 38. Considering your {{Q4}} diagnosis what **additional out of pocket costs that are not covered by insurance** are associated with managing your condition? *Select all that apply.*

- I have additional costs associated with seeing doctors or specialists to treat this condition
- Procedures or tests (including blood test monitoring)
- Special diet needs
- Mobility devices (i.e., canes, braces, wheelchair, scooter, etc.)
- Medical supplies (i.e., needles, alcohol wipes, oxygen, etc.)
- Non-pharmaceutical therapies
- I have no additional out of pocket costs that are not covered by insurance
- Other

* 39. Do you experience any **other situations that cost you in time** spent managing your {{Q4}}?

- I spend a lot of time communicating with the insurance company (explain below).
- I spend a lot of time with my pharmacy/specialty pharmacy ordering my medication.
- I spend a lot of time communicating with the financial assistance plan (explain below).
- I spend a lot of time communicating with health professionals.
- It takes an hour or longer to have this drug administered (if infusion, etc.).
- Time spent traveling to and from office visits.
- Time spent in waiting rooms.
- Other (explain below).

Comments

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Drug Information Alt

* 40. Tell us your story. **Why didn't you take {{Q9}}?** What factors, if any, impacted **your access to or your ability to afford {{Q9}}?**

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Health Coverage Alt

***Caregiver Note: Please answer all remaining questions from the perspective of the patient.**

* 41. What type of **health insurance** did you have when you **could have taken {{Q9}}**?

If you had more than one type of coverage, please select all that apply.

If you are/were on a spouse/partner or parent plan, please answer according to their insurance coverage at the time.

- I did not have health insurance at that time
- I had health insurance through an employer
- I had individual insurance (e.g. not through a group-sponsored plan; this includes health insurance purchased through government exchanges or directly through insurance companies or brokers)
- Medicare
- Medicaid
- Veterans Assistance/Tricare
- Other (please specify)

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Health Coverage Alt

* 42. You said that you had Medicare when you could have taken {{Q9}}. **Which subgroup** plan(s) did you have? *Select all that apply.*

Your subgroups can be found on the bottom left corner of your Medicare card.

- Part A
- Part B
- Part C (Medicare Advantage)
- Part D (Drug Coverage)
- Medicare Supplemental Plan/Part G-K/Medigap
- SSD/SSDI (Disability)
- Unsure

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Health Coverage Alt

43. Is there **anything else** you would like to share about your **health coverage** as it relates to your {{Q4}} diagnosis and/or {{Q9}}?

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Continued Outreach (Optional)

* 44. **Where** did you hear about this survey?

- Facebook
- X (formerly known as Twitter)
- Instagram
- LinkedIn
- Newsletter
- In a clinic/health professional's office
- Email
- Event
- Word of mouth
- Other (please specify)

45. Did you hear about this survey from a **patient organization** or other group? If so, who?

46. If we have additional questions about your answers, could a member from our team reach out to you for more information? Team members are patients and representatives from patient organizations.

If so, please answer the following:

Name

Email

Phone number for texting

Phone number for calling

WhatsApp

Preferred Contact Method

47. If this prescription drug is selected for an affordability review, **would you be interested in submitting a verbal or written testimony about your experience** using this medication or challenges around affording or accessing it? (We can help connect you to this opportunity).

Yes

No

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Demographics (Optional)

***Caregiver Note: Please answer all remaining questions from the perspective of the patient.**

The following information is collected so we can better understand potential affordability or health equity issues that may impact prescription drug affordability or access to this drug.

48. What was your **annual household income** *at the most recent time you were taking {{Q9}}?*

- \$0 - \$9,999
- \$10,000 - \$24,999
- \$25,000 - \$49,999
- \$50,000 - \$74,999
- \$75,000 - \$99,999
- \$100,000 - \$149,999
- \$150,000 - \$200,000
- \$200,000 +

49. What was your **household size (including you)** at the *most recent time of taking {{Q9}}?*

- 1
- 2
- 3
- 4
- 5+

50. **How old were you** at the *most recent time of taking {{Q9}}?*

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75-84
- 85+

51. What is your gender identity?

- Man
- Woman
- Nonbinary
- Prefer to self-identify

- Prefer not to say

52. Are you of **Hispanic, Latino, Latinx, or Spanish** origin?

- Yes
- No

53. Which **race/ethnicity** best describes you? (Please choose only one.)

- American Indian or Alaskan Native
- Asian / Asian American / Pacific Islander
- Black or African American
- Hispanic (i.e., Cuban, Dominican, Mexican, Puerto Rican, etc.)
- White / Caucasian
- Multiple ethnicity / Other (please specify)

54. What best describes your **employment status** *when taking {{Q9}}*?

- Full-time employment
- Part-time employment
- Unemployed
- Self-employed
- Student
- Retired
- On disability
- Not working by choice
- Other (please specify)