

EACH PIC COALITION

Drug Affordability - Patient Survey

This survey was created by research professionals, patient research partners (PRPs), patient organizations, and affiliated groups to help Prescription Drug Affordability Boards (PDABs) and the Center for Medicare & Medicaid Services (CMS) capture patient-reported drug affordability/unaffordability information to be used for prescription drug affordability reviews.

By understanding many things about the disease, the drug under review, and the many factors that lead to affordability, unaffordability, and access to treatment issues, we can work with boards, CMS, and legislators to address the high costs of healthcare in ways most beneficial to the person using the drug.

NOTE: Some PDABs also consider costs to other stakeholder groups (state, payers, etc.) It is not our responsibility to capture any other data points other than patient perspectives.

[Click here to learn more about PDABs.](#)

NOTE: Information submitted on this form - NOT INCLUDING YOUR NAME/IDENTIFYING INFORMATION - will be used to report patient-reported information regarding prescription drug affordability.

****This survey is an effort led by the Patient Inclusion Council (PIC), in association with the broader Ensuring Access through Collaborative Health (EACH)/PIC coalition - a national, disease-agnostic (any disease) group of patient organizations, patients/caregivers, and allied groups who have united to ensure patient voices are counted fairly and equally as part of the discussions and processed related to drug affordability reviews.***

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* 1. Today's Date

Enter Date MM/DD/YYYY

Date

MM/DD/YYYY

* 2. City

* 3. State

* 4. Zip Code

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

- Patient
- Caregiver

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Drug Affordability - Patient Survey

Drug Information

The following questions will be worded as if the patient was completing, even if it is the caregiver completing this on behalf of a patient. Please complete only if you/they are currently taking this drug OR if you/they were on this drug in the past.

* 6. Name of drug for which you are providing comments:

* 7. What is/was your dosage (amount and how often)? (Example 100mg daily, 1500 mg monthly)

8. If this drug can be taken in different ways (i.e., an injection, an infusion), how do/did you take this drug? If this does apply to you, do not answer.

- Self-Injection at home
- Injection at a doctors office
- Injection at a pharmacy
- Infusion
- Pill
- Topical
- Other (Explain)
- Not applicable, there is only one way to take this medication.

Comments

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Drug Affordability - Patient Survey

Drug Delivery Method

* 9. Why did/do you take this drug this way? Select all that apply.

- This is the method the insurance company approved.
- This is the method I prefer to use.
- I don't like this method but it's what my insurance company approved.
- This is the only way it is administered.
- I did not have access to using a drug administered outside of the home (at a hospital, infusion center, doctor's office, etc.), so I chose based on home administering.
- I have a fear of needles.
- I have no one at home to administer the drug to me and I cannot do it myself, so I need to have it administered in an office/hospital/clinic.
- Other (Explain)

Comments

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Drug Affordability - Patient Survey

Diagnosis and Subgroups

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

* 11. How does this condition impact your daily life? *Provide examples that include how the disease has impacted your life prior to treatments (if applicable) as well as how it impacts your life today.*

* 12. **Co-existing conditions** are additional diagnoses that are directly related to this diagnosis. For example, a person with rheumatoid arthritis may also have heart disease or eye disease because of uncontrolled rheumatoid arthritis.

Additional diagnoses are conditions you also have that are likely not related to this diagnosis. So in the case of a person with rheumatoid arthritis, if they also had diabetes that would be an additional diagnosis.

In addition to this diagnosis, are you diagnosed with other co-existing conditions or additional diagnoses?

- Yes
- No
- I'm not sure

13. If you answered yes to the prior question, what are your co-existing conditions or additional diagnoses?

14. Certain diseases present and progress differently in individuals and for that reason not all treatments work for everyone, even within the same diagnosis. Whether the drug works well, or not, can depend on many things, like if you have mild or severe disease, if you are newly diagnosed or have had the disease for 20 years, and so on. Long delays in diagnosis can also impact how severe the disease is now and, in turn, how well one drug may work over another.

How, if at all, do you feel your unique experiences impacts/impacted your response to this drug?

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Impact of the drug for treating this disease

* 15. What beneficial health effects have you experienced from using this prescription drug, if any? *Select all that apply.*

- My quality of life is/was better because of this drug.
- I am/was able to work or attend school because of this drug.
- I feel this drug has/did prevent me from worse disease outcomes (more doctor visits, hospitalization, etc.)
- It is/was my "miracle drug" - better than any other medication I tried.
- I am/was able to perform daily functions better (cooking, cleaning, eating, etc.)
- I achieved remission.
- No positive effects.
- Other (Please explain)

Comments

* 16. What negative health effects have you experienced from using this prescription drug, if any? *Select all that apply.*

- This drug has/had serious side effects
- This drug causes/caused mild to moderate side effects
- I have/had site reactions (bruising, swelling, etc.)
- Allergic reaction
- No negative health effects
- Other (Please explain)

Comments

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Drug Affordability - Patient Survey

Prescription Drug Use and Affordability

* 17. When did you start taking the drug? (Approximately)

Month, Date, Year

Date

MM/DD/YYYY

* 18. What factors led you to start taking this drug? *Select all that apply.*

- It's the drug my doctor prescribed.
- It was the drug required by my insurance company.
- It's the only drug designated for this condition.
- The last drug I was on stopped working.
- I cycled through other medications trying to find one that works for me.
- Other medications I tried had bad side effects.
- I was on a drug that was working well for me, but the insurance company made me switch to this drug.
- The method of delivery (injection, pill, infusion) works best for me.
- Other options were too expensive.
- Other (Explain)

Comments

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Prescription Drug Use Continued

* 19. Are you currently using this drug or, if not, when did you stop using it?

- Currently on
- Past use, stopped 0 - 6 months ago
- Past use, stopped 7-12 months ago
- Past use, stopped 1-2 years ago
- Past use, stopped 3-5 years ago
- Past use, stopped 5+ years ago

If currently on skip to question 23

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Stopped Drug Information

* 20. Why did you stop using this drug? *Select all that apply.*

- Bad reaction to the drug
- Bad side effects
- I have another condition that made this drug potentially unsafe for me
- The drug stopped working
- I no longer needed the drug/achieved remission
- Insurance plan asked me to change to a different drug to save them money
- Insurance plan said they would no longer count my copay assistance towards my deductible
- Insurance plan stopped carrying my drug and sent me to a third party who could not help me
- The manufacturer of the drug discontinued their assistance plan
- I could not afford the out of pocket cost of the drug
- Other (Explain)

Comments

* 21. What was the **monthly out of pocket cost you paid** for this drug? *Select all that apply, as some months may have cost you more than others.*

- \$0-\$10
- \$11-\$24
- \$25-\$50
- \$51-\$100
- \$101-\$250
- \$251-\$500
- \$501-\$1000
- \$1001+

If you chose more than one option, please explain your answer:

22. What factors contributed to this out of pocket cost per month? Please choose from the options below.

- Copay amount before any copay assistance plan
- Copay amount after any copay assistance plan
- Coinsurance
- Deductible
- I'm not sure
- Other (Explain)

Comments

Skip to question 26

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Current Drug Information

* 23. What is your current monthly out of pocket cost that you pay *for this drug*?

- \$0-\$10
- \$11-\$25
- \$26-\$50
- \$51-\$100
- \$101-\$250
- \$251-\$500
- \$501-\$1000
- \$1001+

* 24. At any time during the past 12 months, did you pay less or more out of pocket for this drug? If you answered "yes" below, you will be asked to explain your answer in the next question.

- Yes, within the past 12 months there has been at least one time when the out of pocket cost was lower than what I currently pay
- Yes, within the past 12 months there has been at least one time when the out of pocket cost was higher than what I currently pay
- No, my drug has not changed out of pocket costs

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Out of Pocket Cost Changed

25. If you know the reason why your out of pocket costs were different at one point over the past 12 months, please explain.

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Out of Pocket Cost Affordability

* 26. Based on the monthly out of pocket cost you pay/paid for this drug , would you consider this amount affordable or unaffordable? *Please explain your answer.*

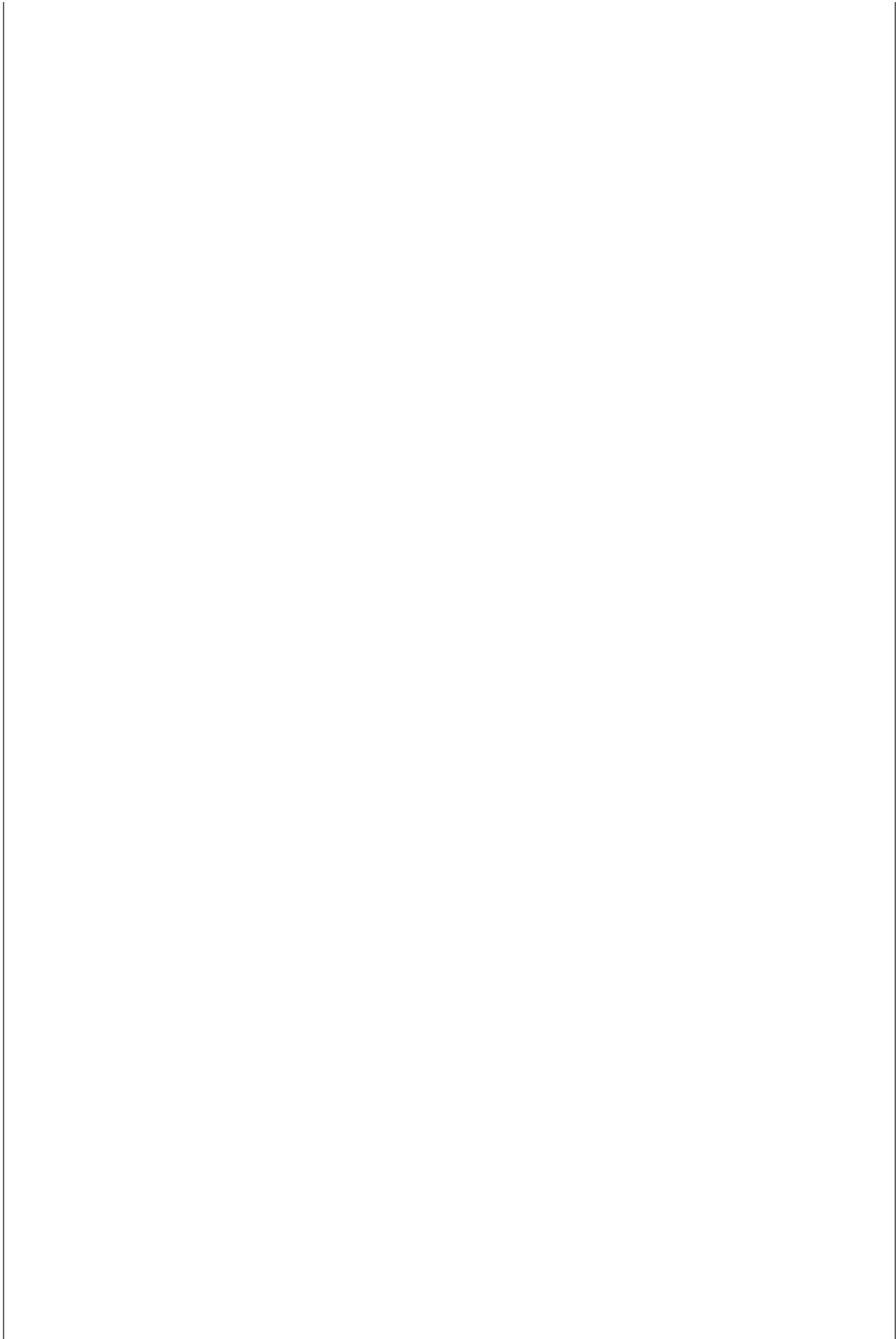
- Affordable
- Unaffordable

Would you like to share more why you answered this way?

* 27. Have you or had you ever stretched out or skipped taking doses of this prescription drug? *Please select all answers that apply:*

- Yes, I have/had stretched out or skipped a dose of this prescription drug because the insurance company delayed my order/refill.
- Yes, I have/had stretched out or skipped a dose of this prescription drug because the out of pocket cost *of this drug* was too expensive.
- Yes, I have/had stretched out or skipped a dose of this prescription drug because the *total cost to fill all my prescriptions* combined was too expensive. So I had to pick and choose which to take.
- Yes, I have/had skipped a dose of this prescription drug because I forgot to take it.
- No, I have/had never stretched out or skipped a dose of this prescription drug.
- I don't remember.
- Other (Explain)

Comments



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Other Similar Prescription Drugs Tried

* 28. Did you try any similar prescription drugs to treat your condition before using this one? *(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, this is the first.
- Yes, one other similar treatment.
- Yes, two other similar treatments.
- Yes, three other similar treatments.
- Yes, four other similar treatments.
- Yes, five or more other similar treatments.

29. If you stated you have tried other similar prescription drugs. What are the names of these drugs?

Also, which worked well and what was your experience like? Which didn't work well and why?

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Other Costs

30. Considering your diagnosis and any relevant co-existing conditions associated with this diagnosis, what additional costs, if any, are associated with managing your condition(s).

Select all that apply.

- I see several doctors or specialists to treat this condition, including any additional conditions directly related to this one
- MRI's or other imaging
- Procedures or tests (including blood test monitoring)
- Special diet needs
- Mobility devices
- Medical supplies (i.e., needles, alcohol wipes, etc.)
- Non-pharmaceutical therapies
- Other (Explain)

Comments

31. Do you experience any other situations that cost you in time spent managing your disease?

- 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).
- It takes an hour or longer to have this drug administered (if infusion, etc.).
- Time spent traveling to and from office visits.
- Other (Explain)

Comments

32. Do you take any other prescription drugs (for any condition)? If so, how many total prescriptions do you take per month? *If it varies, choose the average amount.*

- Just this drug.
- 2-5
- 6-10
- 11+

Just this drug- skip to question 35

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Drug Affordability - Patient Survey

Other Prescription Drugs

33. Considering the month where your out of pocket cost is the highest, what is your total (estimated) out of pocket cost total for all the prescription drugs you take?

* 34. Think about all of the monthly out of pocket costs you pay for all of your prescription drugs, including this drug that you are reporting. Which prescription drug costs you the most money each month?

- Of all the prescriptions I take, this drug I am reporting costs me the most out of pocket.
- Of all the prescriptions I take, they all have similar out of pocket costs.
- Of all the prescriptions I take, this drug I am reporting is not the most costly out of pocket a month.
- I'm not sure about the out of pocket costs for all the prescription drugs I take.
- Not applicable, this is the only drug I take.
- Other (please specify)

Skip to question 36

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Drug Affordability - Patient Survey

Current Prescription Continued

* 35. Because of the monthly out of pocket cost of this prescription drug that you are reporting, have you experienced financial hardship? *Select all that apply.*

- Yes, because of the out of pocket cost of this drug that I am reporting I have/had trouble paying for groceries.
- Yes, because of the out of pocket cost of this drug that I am reporting I have/had trouble paying rent/making house payments.
- Yes, because of the out of pocket of this drug that I am reporting I have/had in medical debt.
- No, the out of pocket cost of this drug that I am reporting has not caused financial hardship.

Comments

Skip to question 37

* 36. Because of the monthly out of pocket cost of all prescription drugs you are taking/were taking at the time you took this drug, does/did this cause financial hardship? *Select all that apply.*

- Yes, because of the out of pocket cost of all prescription drugs I am taking/I took at the time I have/had trouble paying for groceries.
- Yes, because of the out of pocket cost of all prescription drugs I am taking/I took at the time I have/had trouble paying rent/making house payments.
- Yes, because of the out of pocket cost of all prescription drugs I am taking/I took at the time I am/was in medical debt.
- No, the out of pocket cost of all the prescription drugs I am taking/I took at the time has not caused other financial hardships.
- Not applicable, this is the only prescription drug I take/I took.

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Drug Affordability - Patient Survey

Current Prescription Continued

* 35. Because of the monthly out of pocket cost of this prescription drug that you are reporting, have you experienced financial hardship? *Select all that apply.*

- Yes, because of the out of pocket cost of this drug that I am reporting I have/had trouble paying for groceries.
- Yes, because of the out of pocket cost of this drug that I am reporting I have/had trouble paying rent/making house payments.
- Yes, because of the out of pocket of this drug that I am reporting I have/had in medical debt.
- No, the out of pocket cost of this drug that I am reporting has not caused financial hardship.

Comments

Skip to question 37

* 36. Because of the monthly out of pocket cost of all prescription drugs you are taking/were taking at the time you took this drug, does/did this cause financial hardship? *Select all that apply.*

- Yes, because of the out of pocket cost of all prescription drugs I am taking/I took at the time I have/had trouble paying for groceries.
- Yes, because of the out of pocket cost of all prescription drugs I am taking/I took at the time I have/had trouble paying rent/making house payments.
- Yes, because of the out of pocket cost of all prescription drugs I am taking/I took at the time I am/was in medical debt.
- No, the out of pocket cost of all the prescription drugs I am taking/I took at the time has not caused other financial hardships.
- Not applicable, this is the only prescription drug I take/I took.

37. (If applicable) Considering all the people in your household, what is your estimated total OOP cost for all prescription drugs combined? How does this impact your ability to afford medications?

A large, empty rectangular box with a thin black border, intended for the respondent to provide their answer to question 37. The box is positioned below the question text and occupies a significant portion of the page's vertical space.

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Drug Affordability - Patient Survey

Health Coverage Impact on Out of Pocket Costs

* 38. What type of health insurance did you have *at the time of taking this drug*? As some people have more than one type of coverage, for example, both Medicare and Medicaid, 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 of taking this drug.

- I did not have health insurance at that time/no coverage/uninsured
- Insured through employer
- Individual (private) insurance (including the healthcare government exchange)
- Medicare
- Medicaid
- Veterans Assistance/Tricare
- I have/had one of these insurance plans but it was less expensive to get the drug a different way so I did not use it to help cover the cost of this drug
- Unsure
- Other (Explain)

Comments

Uninsured- skip to question 40

* 39. Do any of the following situations apply to you? *Select all that apply.*

- The insurance plan I had would not cover the cost of the drug, so I switched insurance plans and then I could afford this drug.
- While at first I could afford this drug, once I switched my insurance coverage I could no longer afford this drug.
- My insurance company no longer applied/applies my copay to the deductible I have to meet, so I can/could no longer afford the drug.
- My insurance company said this was no longer on their preferred drug list so I either had to switch to a therapeutic alternative of their choice or, if not, I would have to pay more out of pocket if I want to stay on it.
- My insurance company said they no longer carry this drug at all. To keep access to it at an affordable price, they referred me to a third party service.
- The manufacturer stopped offering a copay assistance plan to help offset the cost of the drug.
- None of these options apply
- Other (Explain)

Comments

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Payment Assistance

* 40. Do/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 this drug? 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'm not sure what it is called, but I used some type of assistance plan
- No, there is no/was no drug manufacturer assistance program to help with the cost of this drug
- I applied for the manufacturer's copay assistance program but I did not qualify
- I don't know if a copay assistance program is/was available for this drug
- No, my health plan does not/did not permit payment assistance options (i.e., Medicare, Medicaid)
- I don't remember
- Other (Explain)

Comments

no assistance- skip to question 43

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Drug Affordability - Patient Survey

Payment Assistance Continued

41. Did you find it difficult to apply for or set up the assistance program(s)? *Select all that apply.*

- 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 (Explain)

Comments

42. Were there any other benefits associated with the assistance program? *Select all that apply.*

- My deductible was met early in the year so my other prescriptions cost less.
- My deductible was met early in the year so I was able to afford MRIs and other expensive tests.
- My deductible was met early in the year so I did not have to worry about the cost to see more specialists.
- No, I don't think there were other benefits.
- Other (Explain)

Comments

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Optional Questions

43. Any other drug assistance you applied for or received to help afford this prescription drug that were not mentioned elsewhere? This also may include asking a family member or friend for help paying for out of pocket costs for this drug.

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Drug Affordability - Patient Survey

Continued Outreach (Optional)

44. 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

45. 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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Drug Affordability - Patient Survey

Demographics (Optional)

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.

46. Annual household income *at the time taking of this drug*:

- \$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 +

47. Age *at the time taking this drug*:

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

48. Are you of Spanish or Latino origin?

- Yes
- No

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

- American Indian or Alaskan Native
- Asian / Pacific Islander
- Black or African American
- Hispanic
- White / Caucasian
- Multiple ethnicity / Other (please specify)

50. What was your employment status *when taking this drug?*

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