



Patient Experience Survey:
Protecting Lifelines to Access
and Innovation



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Executive Summary

Patient Experience Survey: Protecting Lifelines to Access and Innovation follows lived experiences of patients navigating their health insurance, including the repercussions of insurer and pharmacy benefit manager (PBM) practices on health care costs, barriers between patients and medicines and risks to future innovative treatments. The report also reveals patients' overwhelming support for policy solutions that lower out-of-pocket costs and hold the system accountable for providing access to affordable care.

This fourth installment of the Patient Experience Survey (PES), a research initiative designed to explore the experiences and barriers patients face in accessing health care and prescription medicines, includes the perspectives of more than 5,000 Americans; the survey was conducted by Ipsos and commissioned by Pharmaceutical Research and Manufacturers of America (PhRMA).

Americans with Insurance Continue to Face Cost-Related Challenges

Although insured Americans say they overwhelmingly believe that insurance should provide affordable access to health care (93%), only a third (34%) say they believe it currently delivers. Out-of-pocket health care costs, such as copays, deductibles, coinsurance and out-of-network charges, are major concerns. In fact, insured Americans say they are more concerned about their ability to afford their health care out-of-pocket costs than they are about expenses like the costs of healthy food or transportation. Left without a financial safety net, hospital, doctor and diagnostic bills are driving medical debt. One in five (19%) insured Americans say their health care out-of-pocket costs are more than they could afford if they had a major unexpected medical event or were newly diagnosed with a chronic illness.

Insurer and PBM Practices Put Lifelines to Access at Risk

Health insurer and PBM practices threaten and restrict the ability of insured Americans to access health care. In fact, nearly three in 10 (29%) insured Americans taking prescription medicines report being subject to utilization management practices, which can restrict or delay patients' access to medicines. Moreover, these practices can lead to adherence issues, such as not filling or picking up medicine from the pharmacy, as well as uncertainty about facing future restrictions on accessing care. More than half (53%) of insured Americans say they can't anticipate what they'll pay for health care services, even if they are covered by their health insurance plan.

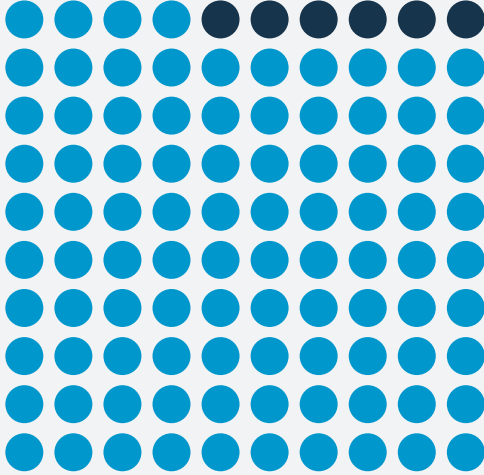
Americans Want Lower Out-of-Pocket Health Care Costs and Increased Predictability and Transparency

Insured Americans agree on reforms to address these challenges and barriers: lower out-of-pocket costs, improve transparency and limit cost-related surprises by increasing predictability. Overwhelming majorities support patient-centered policies, such as ensuring more predictability in health care costs so that people know how much they will pay and requiring health insurers to share any rebates or discounts they receive on medicines, so patients pay less at the pharmacy counter. Eighty-four percent of insured Americans agree Congress should rein in tactics by insurers and their PBMs that drive up health care costs and make it harder for people to get the medicines they need.

93%

agree

Insurance should work for everyone by providing affordable access to health care, when it's needed

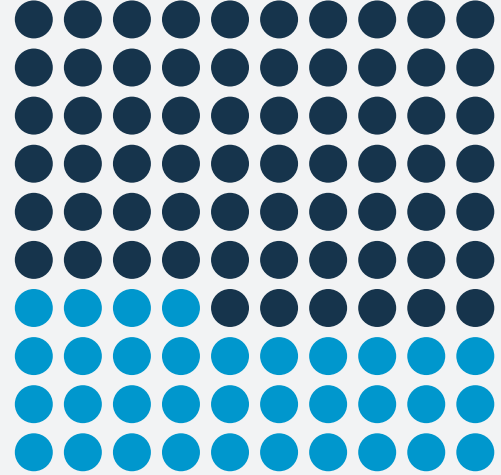


Insurance Isn't Working Like It Should

34%

agree

Insurance currently provides everyone with affordable access to health care, when it's needed



VS

Q: For each of the following statements, please indicate if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree...1) Insurance should work for everyone by providing affordable access to health care, when it's needed. 2) Insurance currently provides everyone with affordable access to health care, when it's needed.

Base: 4,823 insured Americans

Source: Patient Experience Survey, April 4 - 17, 2023

I. Americans with Insurance Continue to Face Cost-Related Challenges

For many Americans, when it comes to health insurance, there is a gap between expectations and reality. Most insured Americans (93%) think insurance should provide affordable access to health care, yet only a third (34%) think it currently does so for everyone.

Out-of-pocket health care costs are the top health care concern for Americans.

The most important health care issue for insured Americans is out-of-pocket health care costs, such as copays, deductibles, coinsurance and out-of-network charges (see figure below).

In fact, more insured Americans say they are worried about their ability to afford their health care out-of-pocket costs (57%) than about expenses like the costs of healthy food (45%) or transportation (40%).



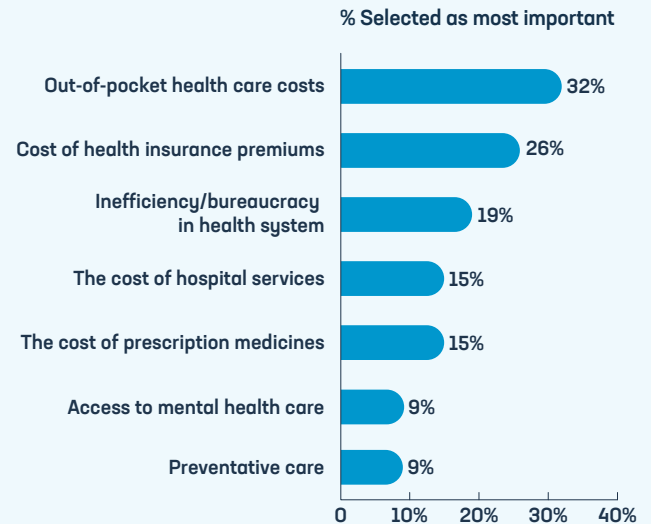
I don't understand why my insurance premiums are increasing and my out-of-pocket costs keep going up. Something is clearly wrong.

- Kevin B., Colorado

Among insured Americans who report difficulty affording their health care (15%), health insurance deductibles are the most commonly cited source of these challenges. Thirty-nine percent of insured Americans who find affording their health care out-of-pocket costs difficult say their deductible being too high is the main reason. This finding is consistent with other public polls, including a May 2022 Consumers for Quality Care poll, which also found voters' main health care concern was out-of-pocket costs, with 45% of respondents identifying deductibles as the single biggest issue people face in the health care system today.¹

Affordability is a relevant concern for Americans saddled with medical debt. A May 2023 report from the U.S. Federal Reserve System notes 16% of adults had debt from their own medical care or that of a family member.² Similarly, 17% of insured Americans in the PES self-report having medical debt; hospital bills (59%), doctor bills (57%) and diagnostic tests (42%) are the bills patients say have contributed to that debt.

OOP Health Care Costs Are #1 Health Care Issue

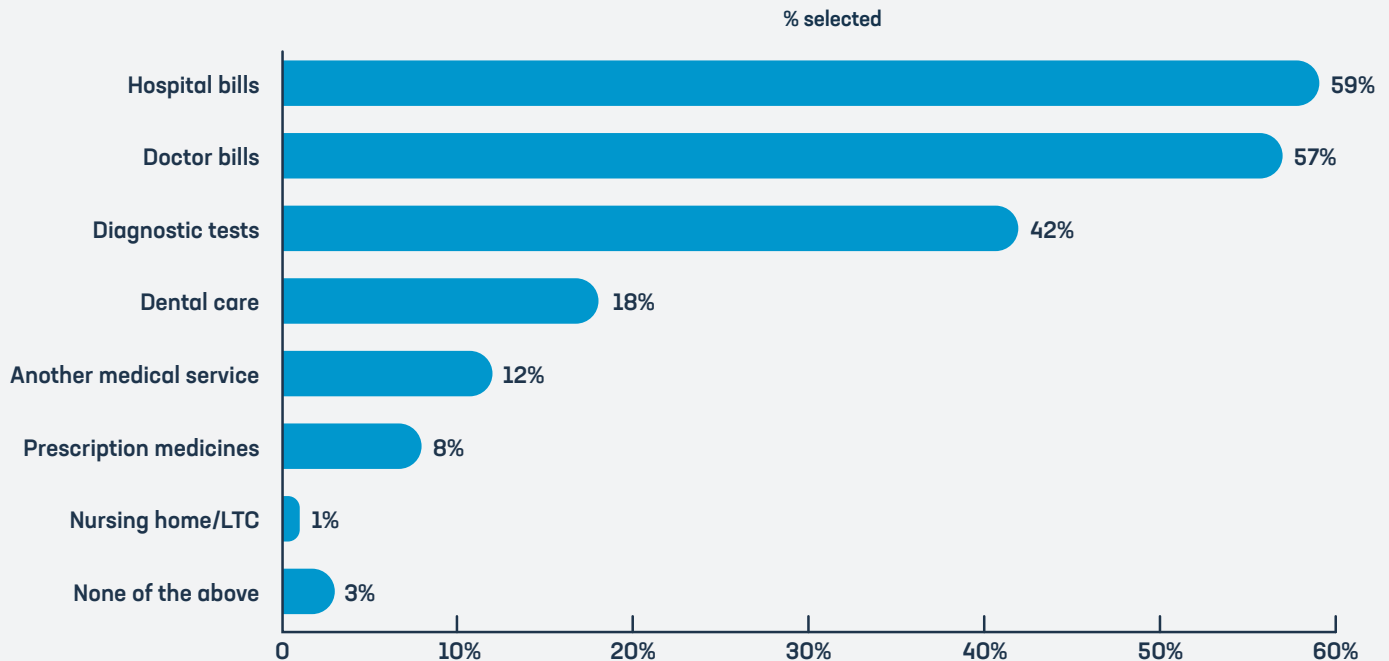


Q: From the following list, which health care issue is most important to you? (Only top items displayed.)

Base: 4,823 insured Americans

Source: Patient Experience Survey, April 4 - 17, 2023

Hospital, Doctor and Testing Bills Drive Medical Debt



Q: Which health care expenses do you owe money for as part of your total outstanding medical debt?

Base: 747 insured Americans with outstanding medical debt

Source: Patient Experience Survey, April 4 - 17, 2023

Insurance practices leave too many Americans without a financial safety net.

One in five insured Americans (19%) say their out-of-pocket costs are more than they could afford if they had a major unexpected medical event or were newly diagnosed with a chronic illness. Certain populations are particularly vulnerable. Thirty-eight percent of rural Americans, 28% of caregivers, 27% of Hispanic Americans, 26% of LGBTQ+ Americans, 23% of Black Americans and 22% of women with insurance all report being unable to afford their health care out-of-pocket costs if they faced an unexpected major medical event or new chronic illness diagnosis.



Out-of-Pocket Costs (OOPs):

The amount individuals and families pay for health care bills and expenses, in addition to their monthly premium costs, that are not paid by health insurance plans

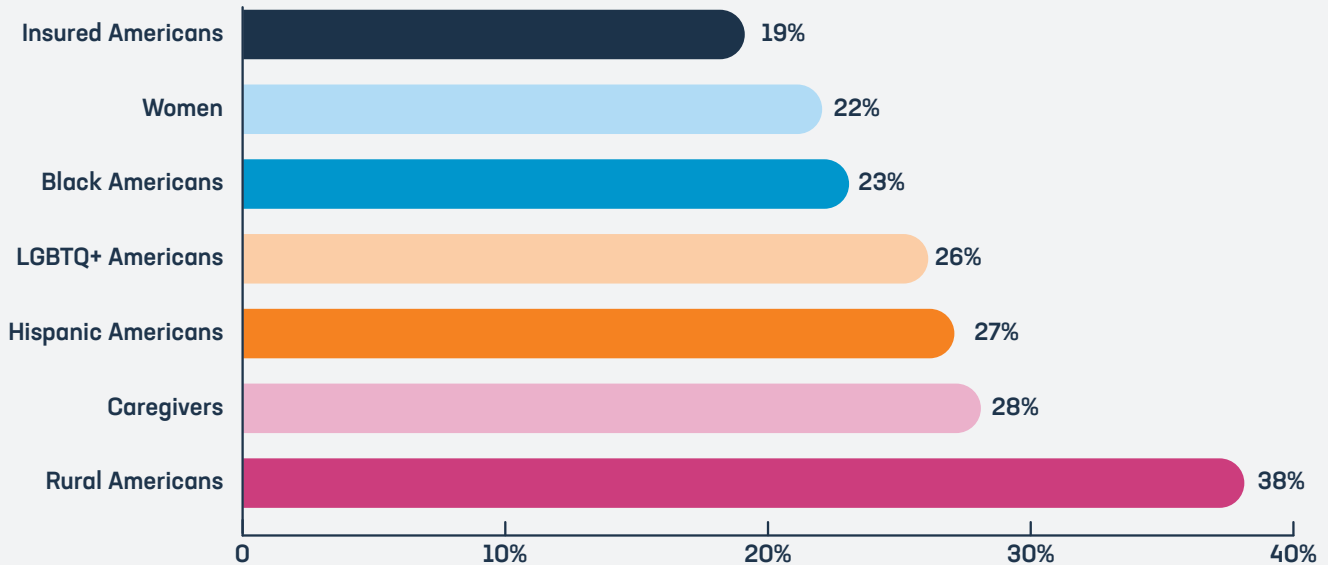


What is the point of having health insurance if they don't cover the cost of medications and care you need?

- Kati S., Georgia

Unaffordable OOP Costs Even With Insurance

% insured Americans reporting unaffordable OOP costs



Q: Which of the following comes closest to describing your situation with out-of-pocket costs? My out-of-pocket costs are more than I could afford if I had a major medical event or was diagnosed with a chronic illness today. Even though I have insurance I can't afford to get health care if I were to be seriously ill.

Base: 4,823 insured Americans

Source: Patient Experience Survey, April 4 - 17, 2023



II. Insurer and PBM Practices Put Patient Lifelines at Risk

In addition to the burden of unaffordable out-of-pocket costs, insurer and pharmacy benefit manager (PBM) practices leave many at risk of additional burdens and barriers. In reviewing the data, it appears that too many insured Americans lack a safety net for unexpected health care out-of-pocket costs and face restricted access to the medicines their doctors believe are best for them. These Americans are concerned with their access to care and medicines today, and in the future.

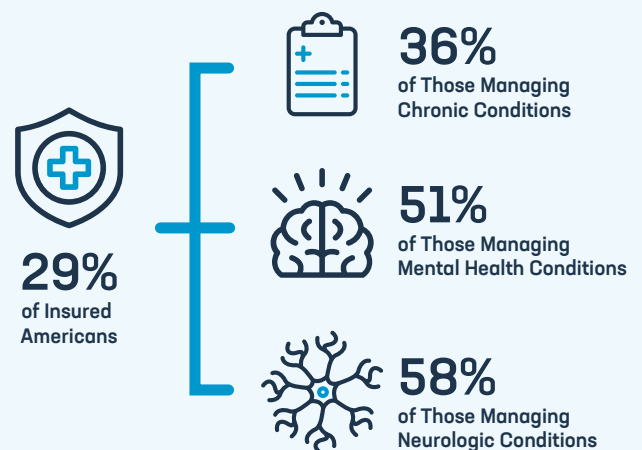


Pharmacy Benefit Managers (PBMs):

Companies that manage prescription drug benefits, including determining patient cost sharing and utilization management policies, on behalf of health insurers, such as Medicare Part D drug plans, employers and other payers

Insurance Barriers, Such as UM, Stand Between Patients and Their Medicines

% of Rx patients who selected any UM experience



Q: Have any of the following happened to you or your family over the past year (12 months)? I had to wait for my insurer to provide prior authorization for a medicine my doctor prescribed; I had to try and fail on another medicine before getting the medicine my doctor originally prescribed (also known as "step therapy"); or my insurance company set a maximum limit on the total amount of a prescription medication that could be dispensed at one time.

Base: 3,443 insured Americans taking prescription medicines
Source: Patient Experience Survey, April 4 - 17, 2023



It often feels like insurance companies and pharmacy benefit managers put profits ahead of my health care needs.

- Starla B., Kentucky

Utilization management practices can restrict or delay patients' access to medicines.

Utilization management practices, such as prior authorization, can restrict or delay patients' access to current medicines. Twenty-nine percent of insured Americans taking prescription medicines report they or someone in their family have been subject to one or more of these practices in the past year. Insured Americans taking prescription medicines and managing a chronic condition are more likely to say they have been subject to these practices (36%), as are insured Americans managing neurologic (58%) and mental health conditions (51%).

Specifically, 22% of insured Americans taking prescription medicines report being subject to prior authorization in the past year and 20% report facing formulary exclusion. These practices can lead to adherence issues, such as skipping one or more medication doses, cutting pills in half or not filling or picking up medicine from the pharmacy. Thirty-four percent of insured Americans taking prescription medicines say they experienced an adherence issue in the past 12 months and 17% say they have experienced multiple adherence issues.



When I arrive at the pharmacy, I always wonder if this is the time my insurance company will deny my care.

- Dan T., Washington



Prior Authorization:

A health care professional must submit and receive approval from the insurance company before the insurance company will cover the medicine

Insured Americans are concerned about these practices and their impact on access to prescription medicines. Fifty-six percent of insured Americans say they are concerned a medicine their doctor recommended or prescribed wouldn't be covered by their insurer (i.e., excluded from the formulary). Concern is higher among caregivers (66%), Americans in high deductible health plans (64%), Hispanic Americans (63%) and Americans managing a chronic condition (58%). Insured Americans' concern about formulary exclusion increased significantly since the last two PES reports, from 53% in January 2023³ and 45% in September 2022.⁴



Formulary:

A list of prescription drugs covered by a health plan

Additionally, 52% of insured Americans say they are concerned they would have to wait for their insurer to provide prior authorization for a medicine their doctor prescribed. Concern is higher among insured Americans managing a mental health condition (69%), those in poor health (64%), those aged 18-29 (55%) and Hispanic Americans (58%).

On top of these concerns about delays in accessing treatment, these practices create wasted time and energy for too many patients. The September 2022 PES revealed that one in five (18%) insured Americans say they spent at least two hours or more on paperwork, phone calls and other administrative tasks with their insurance company to get coverage for needed medicines.⁵ Moreover, according to the September 2022 report, 60% of insured Americans believe insurance companies are wasting time and money through practices that determine whether or not a prescription medicine is appropriate for a patient.⁶

Many face increased financial burdens from policies that limit patient assistance programs.

Many patients rely on patient assistance programs for medicines as a lifeline. For example, according to a February 2023 PhRMA report based on IQVIA data, more than half of commercially insured patients taking brand HIV medicines and more than a third of patients taking brand oncology medicines used patient assistance to access their medicines in 2021.⁷ PES data show most patients need patient assistance without surprises or jumping through hoops. Among insured Americans taking prescription medicines who use cost-sharing assistance to access medicines for them or someone in their household, 58% would have financial difficulty if the cost-sharing assistance didn't count towards their deductible. In fact, 21% say they would not be able to afford their medicines at all and 37% say it would be financially difficult.

Practices and policies that put up barriers to care also impact patients' outlook on future access and innovation.

If insurance is not working as it should, insured Americans may lose optimism about their ability to pay for health care. For example, 39% of insured Americans say they are not optimistic about being able to afford out-of-pocket costs from a visit to the hospital or emergency room (ER). Some population groups are disproportionately more likely to express concern about affording a hospital or ER visit. Approximately half of insured Americans managing mental health, neurologic or autoimmune conditions were not optimistic about their ability to afford such costs.

This uncertainty about future costs includes day-to-day health care, too. Fifty-three percent of insured Americans say they can't anticipate what they'll pay for health care services even if they are covered by their health insurance plan.



As my husband and I look at retirement, I have big concerns about being able to maintain our standard of living if our health insurance doesn't cover the medications we need.

- Mary N., Oregon

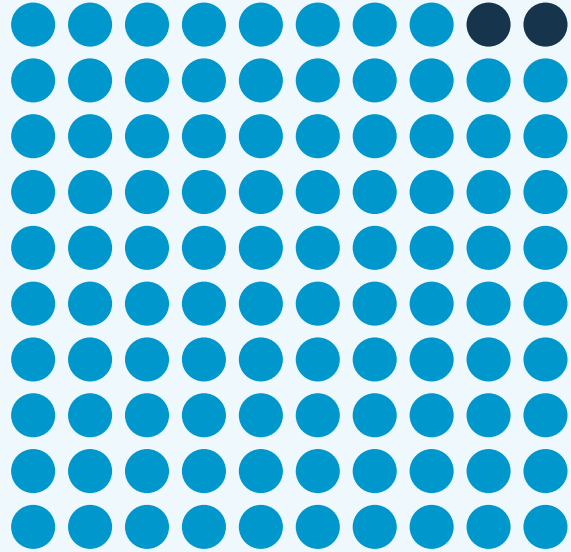


Ensuring that patients can access the best new medications is critical. Lawmakers need to pass policies that support new treatment research and development.

- Marie G., Ohio

98%

of insured Americans taking Rx in pill or tablet form say they value the ease and the portability of taking their medicines in that form.



Q: Thinking about the prescription medicine(s) you take in pill or tablet form. Please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree with each of the following statements...
Base: 3,340 insured Americans taking prescription medicines in pill or tablet form
Source: Patient Experience Survey, April 4 - 17, 2023

This concern over costs is unfortunate given that insured Americans deeply appreciate how innovations in medicine have enhanced their quality of life. The vast majority (97%) of insured Americans who take prescription medicines do so in the form of a pill or tablet. Among this group, nearly all value the ease (98%) and portability (98%) of taking their medicines in pill or tablet form. Practices or policies that could limit innovation in medicines in pill and tablet form, for instance, may run counter to patients' appreciation for innovation, especially given the country's "runaway leadership in science and technology," due to strong research institutions and biopharmaceutical industry.⁸



III. Solutions That Americans Want to See

When it comes to policy reform, PES data reveal that Americans want lower out-of-pocket costs, improved access to care and greater accountability.

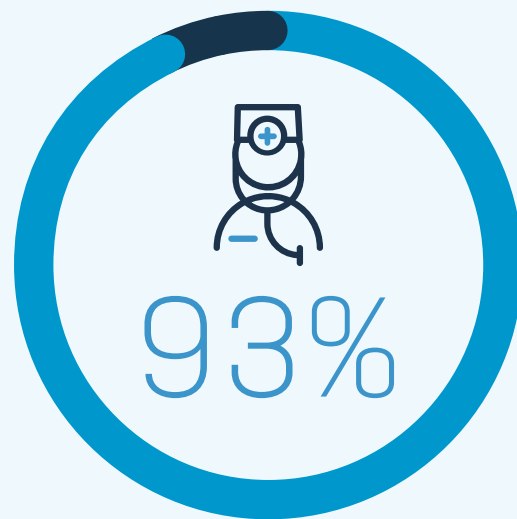
Americans are aligned on the health care coverage environment they want and need.

For Americans, effective health coverage means addressing the insurer and PBM barriers that impede their ability to access care. Ninety-three percent of insured Americans agree doctors - not insurers - should determine whether a medicine is clinically appropriate. And when it comes to footing the bill, Americans believe everyone should be



The decisions around which medications and treatments are best for me should be made by my doctor, not my insurance company.

- Omar C., California



of insured Americans agree doctors - not insurers - should determine whether or not a prescription medicine is clinically appropriate.

Q: For each of the following statements, please indicate if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree...Doctors - not insurers - should determine whether or not a prescription medicine is clinically appropriate.

Base: 4,823 insured Americans

Source: Patient Experience Survey, April 4 - 17, 2023

properly supported by their insurance coverage. Eighty-eight percent of insured Americans agree it's wrong that they can pay more for their medicine out of pocket than their insurance company or PBM. Furthermore, 84% of insured Americans agree Congress should rein in tactics by insurers and PBMs that drive up health care costs and make it harder for people to get the medicines they need.

But it's not *just* with insurers and PBMs that Americans see a need for reform; 92% of insured Americans agree hospitals should be subject to common-sense transparency and oversight requirements to ensure that patients are benefitting from discounts on the medicines that hospitals receive.

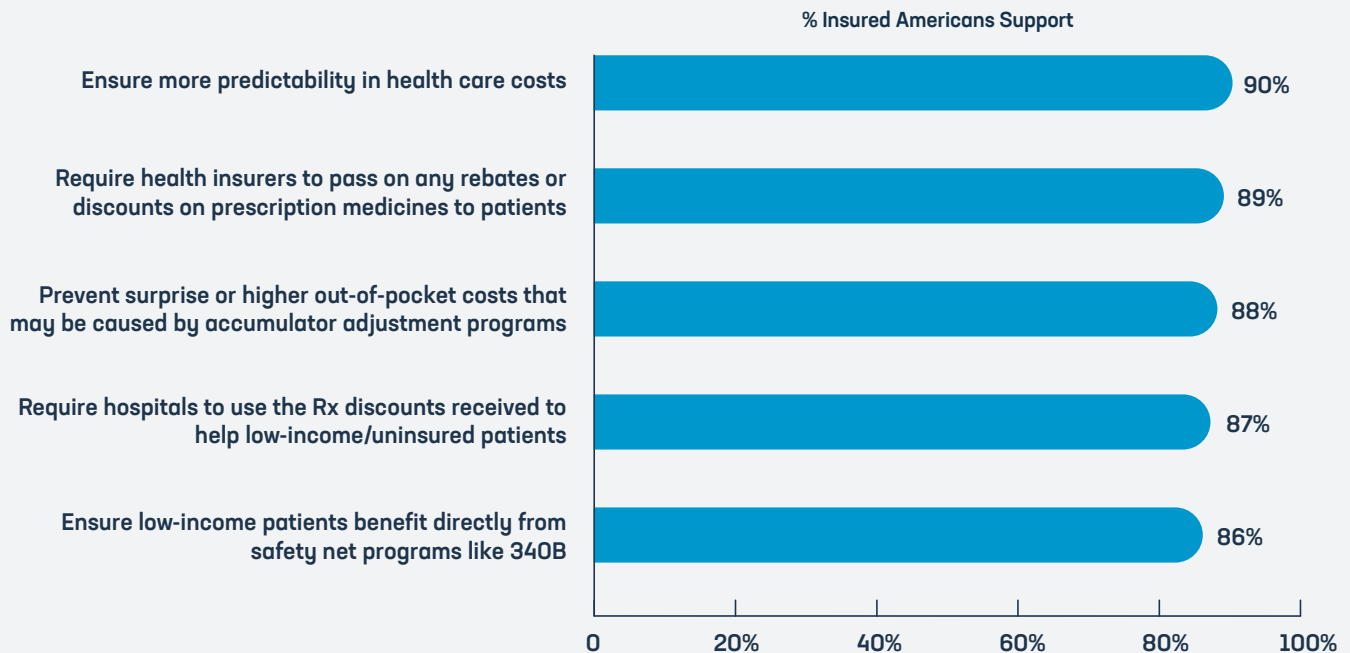
Americans overwhelmingly support policy reforms that lower out-of-pocket health care costs, increase transparency and limit surprises.

When asked what reforms policymakers should pursue to address coverage concerns, insured Americans express support for policies that safeguard affordability and improve predictability and transparency. Specifically,

nine in 10 (90%) support ensuring more predictability in health care so that people know how much they will pay for things like prescription drugs every month. Eighty-eight percent want to prevent surprise out-of-pocket costs at the pharmacy, which can occur when an insurance company does not count copay assistance from a pharmaceutical company toward a deductible and annual maximum out-of-pocket costs (i.e., accumulator adjustment programs).

Americans also want to make sure insurers, PBMs and hospitals pass along their savings, so patients benefit. Eighty-six percent of insured Americans want to ensure that low-income patients benefit directly from safety net programs like 340B that provide hospitals with steep discounts on medicines. Furthermore, 87% want to require that hospitals use the discounts they receive on prescription medicines to help low-income and uninsured patients access the medicines they need instead of for other purposes. And 89% want to require health insurers to pass on any rebates or discounts they receive from pharmaceutical companies on prescription drugs at the pharmacy counter, so patients pay less out of pocket for their medicines.

Overwhelming Support for Patient-Centered Policies



Q: For each, please indicate whether you strongly support, somewhat support, somewhat oppose, or strongly oppose the policy... (Not all options displayed.)
 Base: 4,823 insured Americans
 Source: Patient Experience Survey, April 4 - 17, 2023



Conclusion

From our perspective, *Patient Experience Survey: Protecting Lifelines to Access and Innovation* reveals coverage and affordability continue to fall short for Americans who need care. On top of burdensome out-of-pocket health care costs, insurer and PBM barriers leave a considerable number of Americans at risk and without reliable coverage, jeopardizing their access to medicines and health care services.

Such practices stand between patients and their medicines, with certain populations - such as insured Americans of color or those managing chronic conditions - particularly vulnerable. If unchecked, these practices could potentially exacerbate inequities and pose further threats to accessing medicines and care today and tomorrow.

In the face of these challenges, insured Americans are aligned on the policy reforms they want to see: lowering out-of-pocket costs, improving access to medicines and increasing predictability and accountability. As policymakers evaluate possible reforms to the U.S. health care system, leaders should consider the systemic barriers Americans face when navigating their coverage. A thorough understanding of the patient experience will help inform solutions that address patients' real pain points and protect their access to innovative, life-saving medicines.



Insurance companies and their PBMs often pocket discounts issued by pharmaceutical companies. It would be such a huge help if those savings were shared with me at the pharmacy.

- Barb C., Michigan



Appendix

About the Patient Experience Survey

PhRMA's Patient Experience Survey (PES) is a research initiative designed to explore the barriers patients face in accessing health care and prescription medicines. Launched in 2021, the survey reports the lived experiences of 5,152 Americans, including 4,823 with insurance. The research aims to understand how patients engage with the health care system, uncover the real, practical challenges Americans face around access and affordability and identify solutions that could make a meaningful difference.

Patient Experience Survey: Protecting Lifelines to Access and Innovation is the fourth report of the PES. This report notes the repercussions of insurer and PBM practices that drive up health care costs, put up barriers that stand between patients and their medicines and jeopardize access to innovation.

About the Author

The Pharmaceutical Research and Manufacturers of America (PhRMA) represents the country's leading innovative biopharmaceutical research companies, which are devoted to discovering and developing medicines that enable patients to live longer, healthier and more productive lives. Since 2000, PhRMA member companies have invested more than \$1.1 trillion in the search for new treatments and cures, including \$102.3 billion in 2021 alone.

Methodology

The Patient Experience Survey (PES) is a robust data source on patient perceptions and behaviors around access to health care and prescription medicines. A literature review was conducted around existing and relevant academic surveys, which helped to inform the questionnaire design. The questionnaire was tested and refined through a series of cognitive pre-tests and in-depth interviews to ensure measurement validity and reliability.

The survey was conducted April 4th - April 17th, 2023 by Ipsos using the probability-based KnowledgePanel®. The survey is based on a nationally representative probability sample of 5,152 adults aged 18 or older. The sample included 3,443 insured respondents who reported taking prescription medicines and 4,823 respondents who reported being insured.

The survey was conducted using KnowledgePanel, the largest and most well-established online probability-based panel that is representative of the adult U.S. population. The recruitment process employs a scientifically developed address-based sampling methodology using the latest Delivery Sequence File of the USPS - a database with full coverage of all delivery points in the US. Households invited to join the panel are randomly selected from all available households in the U.S. Persons in the sampled households are invited to join and participate in the panel. As a result of the recruitment and sampling methodologies, samples from KnowledgePanel cover all households regardless of their phone or internet status and findings can be reported with a margin of sampling error and projected to the general population.

The study was conducted in both English and Spanish. The data were weighted to adjust for gender by age, race/ethnicity, Census region by metropolitan status, education, household income, race/ethnicity by gender,

race/ethnicity by age, race/ethnicity by education, and English language proficiency. The demographic benchmarks came from the 2022 March Supplement of the Current Population Survey (CPS) from the U.S. Census Bureau, with the exception of the benchmarks for English language proficiency which were obtained from the 2021 American Community Survey (ACS) from the U.S. Census Bureau. The weighting categories were as follows:

- Gender (Male, Female) by Age (18-29, 30-44, 45-59, and 60+)
- Race/Hispanic Ethnicity (White Non-Hispanic, Black Non-Hispanic, Other Non-Hispanic, Hispanic, 2+ Races Non-Hispanic)
- Census Region (Northeast, Midwest, South, West) by Metropolitan Status (Metro, Non-Metro)
- Education (Less than High School, High School, Some College, Bachelor or higher)
- Household Income (Under \$25,000, \$25,000-\$49,999, \$50,000-\$74,999, \$75,000-\$99,999, \$100,000-\$149,999, \$150,000+)
- Race/Hispanic Ethnicity (White and Other Non-Hispanic, Black Non-Hispanic, Hispanic) by Gender (Male, Female)
- Race/Hispanic (White and Other Non-Hispanic, Black Non-Hispanic, Hispanic) by Age (18-44, 45+)
- Race/Hispanic (White and Other Non-Hispanic, Black Non-Hispanic, Hispanic) by Education (Less than Bachelor, Bachelor or higher)
- Language Proficiency (English Proficient, Bilingual, Spanish Proficient, non-Hispanic)

The margin of sampling error is plus or minus 1.46 percentage points at the 95% confidence level, for results based on the entire sample of adults.

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