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Patient Experience Survey

Navigating the Patient Experience: The Barriers and Burdens Standing Between Patients and Care



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Executive Summary

Navigating the Patient Experience: The Barriers and Burdens Standing Between Patients and Care explores the challenges insured Americans face when navigating their health care coverage, particularly the insurer-imposed barriers and cost sharing practices that stand between patients and their medicines.

The previous two waves of the Patient Experience Survey (PES) showed that health insurance is not working as it should for many Americans, and that one in three (30%) Americans - who have insurance - still cannot afford to meaningfully use it. Patients with chronic illnesses and communities of color are disproportionately impacted by insurer-imposed barriers, such as high out-of-pocket costs and administrative hurdles like prior authorization.^{1,2}

The third PES exposes another crucial problem: the frustration and confusion people have around *how* to use their coverage.

Insured Americans Are Struggling to Navigate Their Insurance Coverage

Americans are struggling to navigate barriers imposed by insurance companies and pharmacy benefit managers (PBMs), including both utilization management restrictions like prior authorization and administrative burdens such as paperwork and time on the phone navigating coverage. Thirty-nine percent of insured Americans say they don't understand what's covered by their insurance. In addition, many also worry about the fine print of their coverage, such as high out-of-pocket costs or restrictive policies. For example, 47% of insured Americans taking prescription medicines are concerned that a medicine their doctor recommended or prescribed would be excluded from the formulary.

Insurer- and PBM-Imposed Cost Sharing Leaves Americans Financially Vulnerable

Even with insurance, 15% report they would be unable to afford health care if they were to become seriously ill because of high out-of-pocket costs. This is especially the case for women, LGBTQ+ Americans, Black Americans, Hispanic Americans, those with chronic conditions and caregivers. Notably, deductibles are the primary reason for those facing difficulty with their out-of-pocket costs, with 36% saying so.

Americans Support Reforms to Make Coverage More Predictable and Affordable

Nine in 10 (90%) insured Americans express support for ensuring more predictability in health care so that people know how much they will pay for things like prescription drugs every month. Americans also favor solutions that improve their ability to navigate and access their care - by tackling the inefficiencies introduced by insurers and middlemen, like PBMs. And Americans value this predictability; 58% of insured Americans would be willing to pay more in monthly premiums if it meant better coverage, like lower out-of-pocket costs and fewer access barriers.



When I am researching insurance, you have to do a lot of legwork to find out exactly what they cover. And it gets overwhelming. Because there's a lot of things I don't understand.

- Gloria, Illinois

I. Challenges

Understanding and Navigating Coverage

The United States has one of the most innovative health care systems in the world,³ yet also one of the most complex.⁴ There is an intricate web of providers, payers and middlemen, such as pharmacy benefit managers (PBMs) who manage drug benefits on behalf of insurers, involved in the administration of patient care. And that complexity has an impact on the patients' experiences with health care.

Insurance is valuable to the extent that it is affordable and that patients understand what is covered and how to use the coverage when they need it. Unfortunately, for far too many Americans, their coverage is simply too challenging for them to use.

Identifying Americans most struggling to navigate coverage.

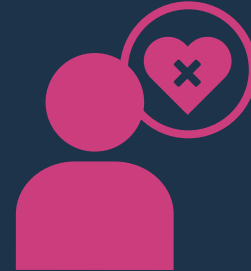
Overall, 22% of insured Americans say they have difficulty understanding, anticipating and navigating their insurance coverage. These challenges affect some patients more than others, including those in average (26%) or poor (24%) health, those managing a mental health condition (33%), those with high deductible health plans (HDHPs) (27%) and those who switched health plans in the last year (28%).



Pharmacy Benefit Managers (PBMs):

Companies that manage prescription drug benefits on behalf of health insurers, Medicare Part D drug plans, large employers and other payers

Understanding, Anticipating and Navigating Insurance Coverage Is Most Challenging for Patients Who...



Are in Poor or Average Health



Are Managing a Mental Health Condition



Are in a High Deductible Health Plan



Have Switched Health Plans in the Last Year

Insured Americans who do not understand their health insurance, cannot anticipate what they will pay for prescription medicines, and have trouble navigating their current health insurance coverage; See Appendix for methodology.

Base: 4,720 Insured Americans

Source: Patient Experience Survey, May 23 - June 1, 2022

In particular, insured Americans are struggling to figure out their health insurance coverage. Looking at specific challenges, four in 10 insured Americans don't understand what's covered by their insurance plan (39%) and say they have trouble anticipating what they will pay for health care services (42%). Difficulty navigating insurance rings especially true for those in poor health (42%) and those managing mental health conditions (50%).

On top of this uncertainty, insurance coverage creates administrative burdens for patients. For example, 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 in the past three months. This administrative burden was even higher for Americans in HDHPs (26%). Consequently, 78% of insured Americans agree too many hurdles stand between patients and the medicines prescribed by their doctors.



Reading the formulary, as well as the prescription plan, and other information like that...is very onerous, long, wordy, and then some.

- Gus, Pennsylvania



Prior Authorization:

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

Formulary:

A list of prescription drugs covered by a health plan

4 in 10

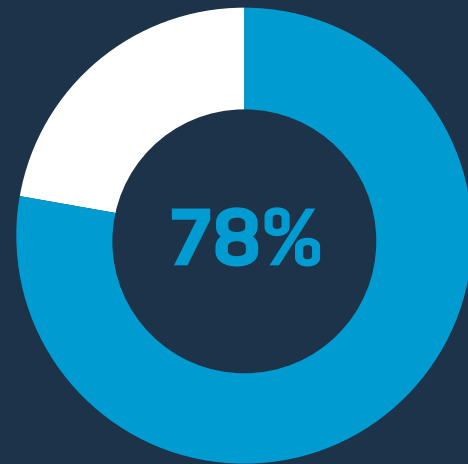
insured Americans don't understand what's covered by their insurance.



Q: Please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree with each of the following statements... I don't understand what's covered by my insurance.

Base: 4,720 Insured Americans

Source: Patient Experience Survey, May 23 - June 1, 2022



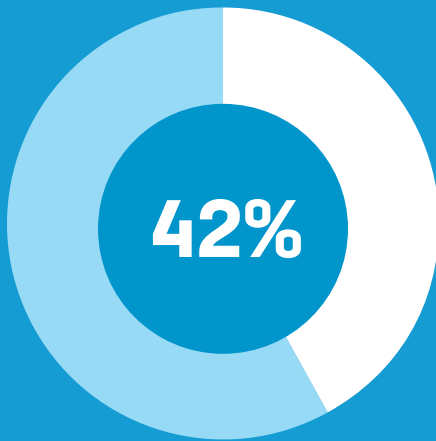
of insured Americans agree too many hurdles stand between patients and the medicines prescribed by their doctors.

Q: For each of the following statements, please indicate if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree. Too many hurdles stand between patients and the medicines prescribed by their doctor.

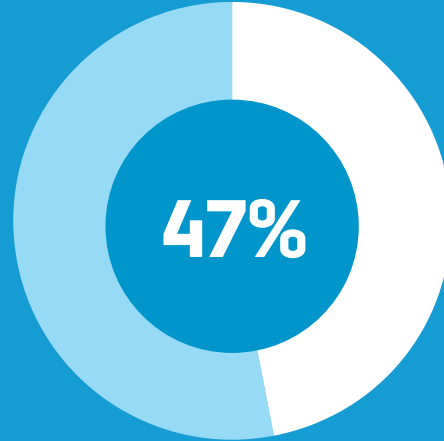
Base: 4,720 Insured Americans

Source: Patient Experience Survey, May 23 - June 1, 2022

Percent of Insured Americans Taking Rx Concerned with Insurer Practices



Concerned about prior authorization



Concerned about formulary exclusion

Q: For each of the following, please indicate how concerned you are about its impact on your ability to access prescription medicines... I would have to wait for my insurer to provide prior authorization for a medicine my doctor prescribed. A medicine my doctor recommended or prescribed wouldn't be covered by my insurer (excluded from the 'formulary').
Base: 3,361 insured Americans taking prescription medicines
Source: Patient Experience Survey, May 23 - June 1, 2022

Insurer and PBM practices create burdens and barriers for patients, particularly more vulnerable populations.

Americans are concerned that insurers and PBMs will create barriers between them and their medicines, underscoring the uncertainty many patients feel around their coverage. Forty-seven percent of insured Americans taking prescription medicines are concerned that a medicine their doctor recommended or prescribed wouldn't be covered by their insurer (i.e., excluded from the formulary). Forty-two percent are concerned that they would have to wait for their insurer to provide prior authorization before they can get medicine their doctor prescribed.

Hispanic Americans are disproportionately concerned that the medicine their doctor recommended or prescribed would be excluded from the formulary (53%) and that they would have to wait for their insurer to provide prior authorization on a prescribed medicine (48%).

Similarly, insured Americans managing autoimmune and mental health conditions have more significant concerns in these same areas, when compared with other chronic conditions. For example, 67% of patients with autoimmune and 61% with mental health conditions are concerned with a prescribed medicine being subject to formulary exclusion, compared with half of patients with cardiovascular disease (49%) and diabetes (51%).



My medication wasn't approved, and I was told that I would have to try other medications that were lower tier before the insurance will cover the higher tier medication. **I was scared and terrified...**And I wondered what would happen if I were ever in a situation like [my mom], **where I needed medicine that was lifesaving, or life preserving, and the insurance wouldn't cover it.**

- Angelitha, Georgia

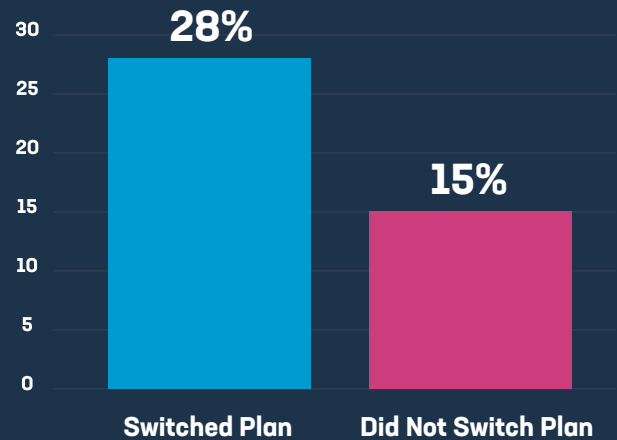
One in three (30%) insured Americans taking prescription medicines report experiencing prior authorization (i.e., having to wait for their insurer to approve the medicine their doctor prescribed). And one in five (21%) report that the medicine their doctor prescribed was excluded from the formulary.

Women, Hispanic Americans, Black Americans, those in poor health and those managing a chronic condition are disproportionately impacted by insurer-imposed barriers. For example, 33% of Hispanic Americans and 35% of Black Americans experienced prior authorization in the last year, compared with 29% of White Americans.

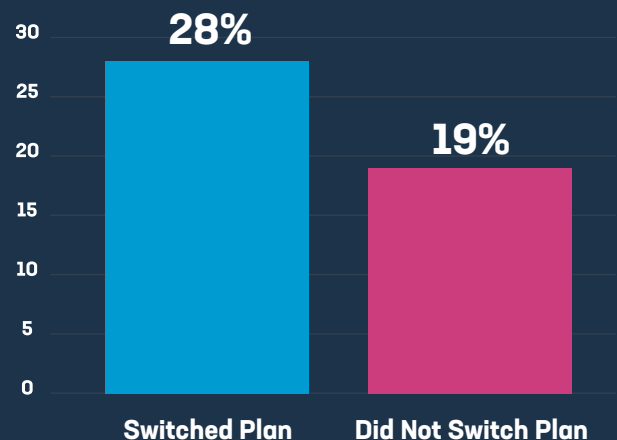
Furthermore, Americans in HDHPs are also more likely to face insurer-imposed barriers like formulary exclusions. In fact, 26% of those in HDHPs compared with 20% of those not in HDHPs report that a prescribed medicine was not covered by their insurer. And 16% of enrollees in HDHPs say their insurer would not cover the medicine their doctor prescribed, even if their doctor believed it to be most effective for treating their condition, compared with 12% not enrolled in HDHPs.

Insured Americans Who Switched Plans In the Last Year are Especially Susceptible to Insurance Hurdles and Practices:

Americans who switched insurance plans in the last year report that they have spent two hours or more engaging with insurance companies to get access to medicines...



...and are more likely to face insurer-imposed barriers like formulary exclusion



Q: Over the past three months, approximately how many hours have you spent on paperwork, phone calls and other administrative tasks with your insurance company to get the medicines you need (such as talking to insurance company representatives, filling out forms, working with your doctor's office, searching for information online etc.)? % of those who spent 2+ hours.

Q: Have any of the following happened in the past year (12 months)? A medicine my doctor recommended or prescribed was not covered by my insurer (excluded from the 'formulary').

Base: 960 Americans Who Switched their Health Plan in the Last Year
Source: Patient Experience Survey, May 23 - June 1, 2022

II. Financial Barriers Exacerbate the Burdens Patients Face

Consistent with recent studies, too many insured patients report challenges with their out-of-pocket costs. Kaiser Family Foundation (KFF), for example, finds that one-third (34%) of insured older adults say it is difficult to afford to pay their out-of-pocket costs for medical care.⁵

Insurer- and PBM-imposed cost sharing leaves Americans vulnerable to unaffordable out-of-pocket costs and creates financial barriers to care.

Overall, one in three (30%) insured Americans say they face a financial barrier to care, such as unaffordable out-of-pocket costs or a lack of savings to pay for emergency or unforeseen expenses. Again, these barriers have a disproportionate impact on certain populations, including insured women (37%), LGBTQ+ Americans (42%), Black Americans (39%), Hispanic Americans (37%), those managing chronic conditions (38%), parents (35%) and caregivers (40%).

In particular, a number of patients are being hit hardest by these financial barriers to care. Data show 15% of insured Americans say their out-of-pocket costs are more than they could afford if they had a major medical event or were diagnosed with a chronic illness - and are particularly struggling with out-of-pocket costs. This is especially the case for certain communities, including women (19%), LGBTQ+ Americans (19%), Black Americans (22%) and Hispanic Americans (21%), among others.



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

Definition of the Insured Americans Facing Financial Barriers



1. Very or somewhat difficult to afford the out-of-pocket expenses.



2. No savings that could be accessed immediately to pay for emergency or unforeseen expenses.

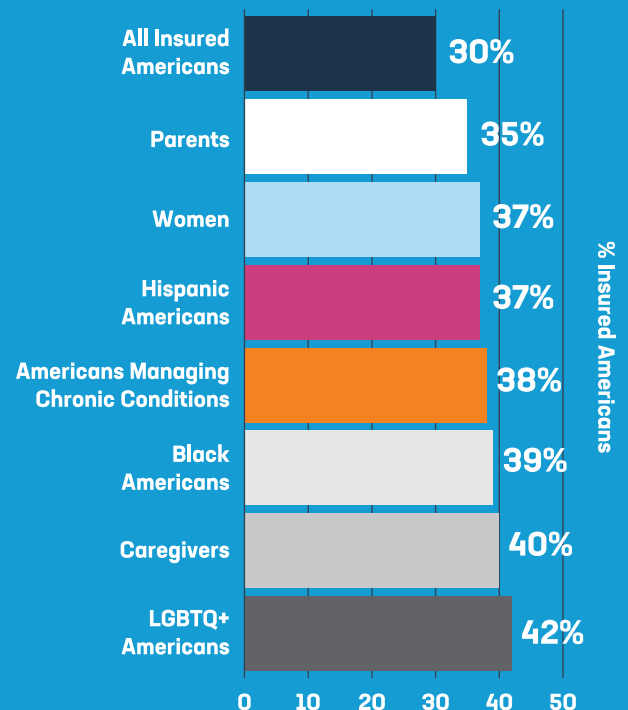


3. Reported spending more in out-of-pocket expenses than could afford last month.

Note: See Appendix for financial barrier methodology.

Insured Americans Who Are More Likely to Face Financial Barriers to Care

% Insured and Reporting Financial Difficulty by Subgroup



Insured Americans who find it very or somewhat difficult to afford OOPs, have no immediately accessible savings to pay for emergency/unforeseen expenses or spent more in OOPs than say could afford in the last month. See Appendix for financial barrier methodology.

Base: 4,720 Insured Americans

Source: Patient Experience Survey, May 23 - June 1, 2022

Deductibles are driving out-of-pocket cost challenges.

A KFF Health Tracking Poll found that 44% of insured adults worry about affording their deductible, or the amount one must pay out of pocket before insurance kicks in.⁶ This is not surprising, as 36% of patients cite deductibles as the number one factor contributing to their difficulty affording out-of-pocket costs.

Americans with high deductibles face greater financial barriers and challenges than those without high deductibles.

Americans in high deductible health plans (HDHPs) are bearing the brunt of insurer- and PBM-imposed financial barriers. This is concerning considering that the number of Americans in HDHPs has been increasing over the years. The Peterson-KFF Health System Tracker found that workers in HDHPs increased nearly 10 percentage points in four years, from 38% in 2016 to 47% in 2020.⁷

Most patients say their deductibles have increased in the last year, but Americans in HDHPs are even more likely to report that their deductible increased in the last year (86% vs. 71% not in HDHPs). One in five (20%) Americans in HDHPs say they have out-of-pocket costs that are more than they can afford, and they wouldn't be able to afford health care if they became seriously ill, compared with 14% for insured Americans without high deductibles.



Our premiums go up, but it seems like - every year our co-pays are going up. They are decreasing the medications that they want to pay for. So, we are paying more and getting less.

- Linda, Pennsylvania

How is this possible, when I have spent thousands of dollars and it's just July? How have I spent so much money and it's not going towards the deductible?

- Jessica, Georgia

Insured Americans with Unaffordable Out-of-Pocket Costs

% Insured Americans Reporting Unaffordable OOP Costs



19%
of Women



12%
of Men



31%
of Those In Poor Health



11%
of Those In Good Health



22%
of Black Americans



21%
of Hispanic Americans



13%
of White Americans



19%
of LGBTQ+ Americans



18%
of Americans Managing Chronic Conditions

Q: Which of the following comes closest to describing your situation with respect to out-of-pocket health care costs. A: 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: 4,720 Insured Americans

Source: Patient Experience Survey, May 23 - June 1, 2022

III. Policy Reforms to Make Coverage More Predictable and Lower Out-of-Pocket Costs

Americans' preferences are clear - they want improved insurance coverage to better access and afford needed health care and prescription medicines. Consequently, they support policy reforms that enhance their coverage by providing more transparency and predictability and lowering what they pay at the pharmacy counter.

To insured Americans, better coverage means lower out-of-pocket costs, increased transparency and more predictability.

Insured Americans value improved coverage. In fact, six in 10 (58%) insured Americans would be willing to pay more in premiums if it meant better coverage. When it comes to specific solutions, more than two-thirds (69%) would rather pay lower out-of-pocket costs for medicines than pay a lower premium each month. It's also important for insured Americans to know what to expect when they are at the pharmacy counter. Nine in 10 (90%) insured Americans want more predictability in their out-of-pocket costs so that they know how much they will pay for things like prescription drugs every month.



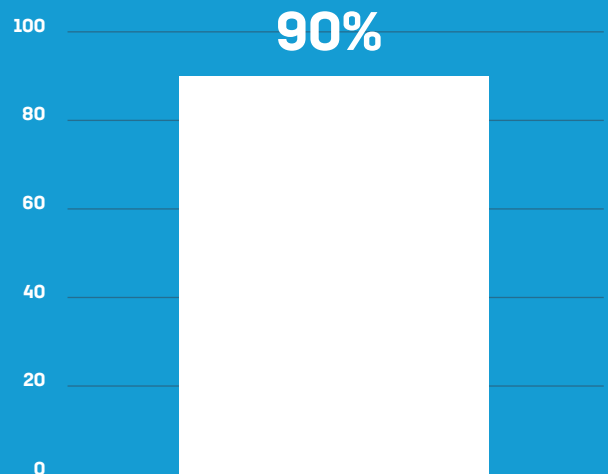
If I could pay **a little higher premium** for my insurance, but that gave me the **peace of mind** that all my pharmaceuticals would be met? I would feel like that would really be worth it.

- **David, Arizona**



Six in 10 (58%) insured Americans would be willing to pay more in premiums if it meant better coverage.

*Q: How likely would you be willing to pay more for your health insurance premiums if it meant having more services and prescription medicines covered?
Base: 4,720 Insured Americans
Source: Patient Experience Survey, May 23 - June 1, 2022*



want to ensure more predictability in health care so that they know how much they will pay for things like prescription drugs every month.

*Q: Below are some policies that the government could pursue to address health care costs. For each, please indicate whether you strongly support, somewhat support, somewhat oppose, or strongly oppose the policy: ensure more predictability in health care so that people know how much they will pay for things like prescription drugs every month.
Base: 4,720 Insured Americans
Source: Patient Experience Survey, May 23 - June 1, 2022*

Americans support reforms that address their real pain points around access and affordability.

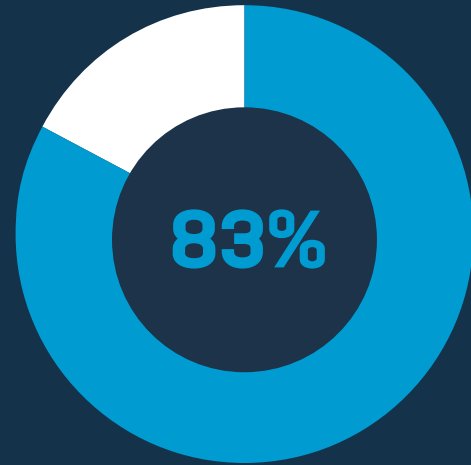
Insured Americans want solutions that pass along the savings and make needed prescription medicines and services more affordable. When asked which reforms policymakers should pursue to address their health care concerns, nine in 10 (89%) insured Americans support requiring Part D insurance plans and PBMs to directly 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. When asked to rank their top two solutions among a dozen options, addressing patients' deductibles came out on top. In fact, one-third (33%) support reducing the burden of deductibles by requiring insurance plans to cover more products and services before a deductible is met.

Insured Americans favor solutions that improve their ability to navigate and access their care by eliminating inefficiencies introduced by insurance companies and middlemen like PBMs. Eighty-three percent say that health care costs would be lower if insurance companies and PBMs spent less time managing how medicines should be prescribed by doctors.



Since PBMs are administrators and not doctors, they shouldn't have a stake in what pharmacies or insurance companies are covering, because they are not trained to know what you need to keep the patient healthy.

- Angelitha, Georgia



say that health care costs would be lower if insurance companies and PBMs spent less time managing how medicines should be prescribed by doctors.

Q: For each of the following statements, please indicate if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree...

Health care costs for patients would be lower if insurance companies and pharmacy benefit managers ("PBMs") spent less time managing how medicines should be prescribed by doctors.

Base: 4,720 Insured Americans

Source: Patient Experience Survey, May 23 - June 1, 2022



Conclusion

Americans are struggling to navigate the barriers and burdens of their insurance coverage, which too often stand between patients and their care. *Navigating the Patient Experience: The Barriers and Burdens Standing Between Patients and Care* provides a deeper exploration of what makes coverage difficult to understand, anticipate and navigate, as well as the cost sharing and other practices that make it unaffordable or inaccessible, especially for more vulnerable populations.

Administrative burdens and utilization management practices like formulary exclusions and prior authorization create challenges for patients. Insured Americans don't always understand what's covered by their insurance and how to navigate or anticipate their coverage policies. And when they are prescribed a medicine, they often face hurdles getting that prescription filled.

In addition to these obstacles, insured Americans face financial barriers to care, including insurer-imposed practices that shift more of the cost of care onto patients, such as high deductibles. The data spotlight how insurance benefit design in particular impacts the patient experience and exacerbates challenges to accessing medicines and other health care services.

Given these challenges, Americans want policy reforms that improve their insurance by providing more predictability and transparency in what is covered and

lowering what they pay out of pocket. Specifically, data reveal that they want insurance and PBMs to spend less time managing how medicines should be prescribed by doctors and more time making sure patients can access and afford the care they need.

As policymakers consider reforming the health care system, it's important to recognize that the challenges Americans face in getting the care they need run deeper than just affordability. Patient-centered reform efforts require an examination of the systemic insurance hurdles patients face that can delay or prevent them from getting their medicines and treatments. Understanding the patient experience should be a central part of all efforts to create a better U.S. health care system.



Better access and more affordable health care would allow members of my family to live as humans, and it would allow them to preserve their dignity.

- Jessica, Georgia



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 the wake of the coronavirus pandemic, which exposed many of the vulnerabilities of our health care system, the survey reports the lived experiences of 5,103 Americans, including 4,720 with insurance; the latest PES also features qualitative data from hours of in-depth interviews. 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.

Navigating the Patient Experience: The Barriers and Burdens Standing Between Patients and Care is the third report of the PES. This report examines how insured Americans navigate unclear and unaffordable insurance coverage and the disproportionate impact such coverage has on more vulnerable communities.

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) was designed to collect robust and reliable data on the perceptions and behaviors of patients 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 May 23rd - June 1st, 2022 by Ipsos using the probability-based KnowledgePanel®. The survey is based on a nationally representative probability sample of 5,103 adults aged 18 or older. The sample included 3,479 respondents who reported taking prescription medicines and 4,720 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 U.S. adult 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 United States. As a result of our 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, race/ethnicity, education, Census region, metropolitan status, household income, race/ethnicity by gender, race/ethnicity by age, and race/ethnicity by education. The demographic benchmarks came from 2021 March Supplement of the Current Population Survey from the U.S. Census Bureau.

The margin of sampling error is plus or minus 1.5 percentage points at the 95% confidence level, for results based on the entire sample of adults.

Trouble with Insurance Methodology

Respondents were categorized as having trouble understanding, navigating and anticipating their care if they answered “strongly agree” or “agree” to all three of the statements below:

Thinking about your current health insurance coverage, please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree with each of the following statements:

Trouble with Insurance Methodology		
	Insured Americans	% A, B, & C
I don't understand what's covered by my insurance company.	39%	22%
I have trouble navigating my health insurance coverage.	35%	
I can't anticipate what I'll pay for prescription medicines even if the medicines are covered by my health insurance plan.	42%	

Financial Barrier Methodology

PES explored various dimensions of how patients assess their experience accessing health care. We analyzed the data across multiple metrics and identified three core metrics to determine a financial barrier to care. The table below provides a summary of responses for each core metric and across the three metrics combined.

Financial Barrier Methodology		
	Insured Americans	% A, B, or C
Very or somewhat difficult to afford the out-of-pocket expenses not covered by health insurance.	16%	30%
No savings that could be accessed immediately to pay for emergency or unforeseen expenses.	15%	
Reported spending more in out-of-pocket expenses than could afford last month.	29%	



Endnotes

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