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## Patient Experience Survey

# Covered By Insurance But Still Exposed: Barriers to Care for Insured Americans



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## Executive Summary

### *Covered By Insurance But Still Exposed: Barriers to Care for Insured Americans*

explores the challenges facing Americans as they navigate the health care system, with a spotlight on those who pay insurance premiums but still find it difficult to afford care when they need it.

The inaugural Patient Experience Survey (PES), released in 2021,<sup>1</sup> revealed that insurance coverage is not working as it should for many Americans. The findings underscored that rising out-of-pocket costs and utilization management tools (like prior authorization and step therapy) disproportionately impact the sick and vulnerable, as well as historically underserved communities including communities of color.

The latest PES probes deeper into insurance practices that exacerbate access and affordability issues, identifying which Americans are most vulnerable to these practices and the impact of these insurer-imposed barriers on Americans' livelihoods, adherence to medicines and access to care.

### **The Insured Americans with Financial Barriers to Care**

PES data show that 37% of insured Americans still face financial barriers to care. The 37% represents insured Americans who report at least one of the following financial barriers to care: they find it difficult to afford out-of-pocket health care expenses; they lack savings to pay for emergency or unforeseen medical expenses; or they report spending more on out-of-pocket health care expenses than they could afford in the past month.

The 37% of insured Americans who report financial barriers to obtain care disproportionately are women, live in urban areas and have less formal education. Of these, more than half (51%) report having a chronic health condition, such as mental health conditions (31%) and respiratory disorders (16%).

### **Medical Debt a Problem for More Than a Quarter of Americans with Insurance**

Insurance is not protecting many Americans from falling into medical debt. More than a quarter of all Americans with insurance (27%) report having medical debt, with an average debt of \$4,000. The burden of medical debt falls disproportionately on communities of color. The majority of debt reported comes from hospital and doctors' bills.

### **Insurer-Imposed Barriers Compound Affordability and Access Issues**

Utilization management by insurers continues to make it difficult for Americans to access the care they need. Nearly half (49%) of all Americans who take prescription medicines report experiencing insurer-imposed barriers, including practices like prior authorization and step therapy in the past three months.

Communities of color are disproportionately affected by utilization management. Sixty-four percent of Hispanic Americans and 55% of Black Americans report facing at least some form of utilization management, compared to 44% of white Americans.

Insurer-imposed barriers to care like unaffordable out-of-pocket costs and utilization management tools that limit access to prescription medicines can contribute to medication adherence challenges. Seventy-five percent of those who report at least one episode of non-adherence also report that they were subject to some form of utilization management.

### **Americans Support Reforms to Make Insurance Work When it is Needed**

Overall, Americans support reforms that would address systemic challenges like unpredictable and high out-of-pocket costs. Sixty-six percent of insured Americans prioritize lowering out-of-pocket costs when they need care over paying lower premiums each month when asked about their prescription drug coverage. They ultimately want better coverage that works when they need it, including predictability around their costs and policy reforms that lower what they pay at the pharmacy counter.

# I. A Portrait of the 37%

## A Portrait of the 37% of Insured Americans Who Have Financial Difficulty Using their Insurance to Obtain Care

Having health insurance coverage doesn't guarantee access to health care. Many plans require deductibles, coinsurance and copayments on top of monthly premiums. PES data reveal that despite having insurance coverage, more than a third of Americans face financial barriers to obtaining care.

PES data show that 37% of insured Americans have financial difficulty obtaining care. **Even with insurance, they report at least one of the following challenges: having trouble paying out-of-pocket expenses; spending more in out-of-pocket expenses than they can afford in the past month; or lacking savings to pay for emergency or unforeseen medical expenses.** These individuals disproportionately are women, live in urban areas and have less formal education.

**Americans who report financial difficulty using their insurance to obtain care are among the most vulnerable, including those with chronic conditions and in poorer health.**

More than half (51%) of the insured Americans who face financial difficulty report having at least one chronic condition, such as mental health conditions (31%) and respiratory disorders (16%). They are also more likely to report being in poor health compared to all insured Americans (16% v. 8%).

**These insured Americans are also trapped in a cycle of unaffordable health care costs, with many grappling with medical debt.**

Of these Americans who have financial difficulty using their insurance to obtain care, more than a third (37%) have out-of-pocket costs that are more than they can afford, driven primarily by high deductibles. Nearly half (44%) have had difficulty paying for medical bills and expenses in the past 12 months, with hospital bills representing the largest share (31%) of those bills.

Similarly, the Kaiser Family Foundation also finds that nearly half (46%) of insured adults report difficulty

affording their out-of-pocket costs, and one in four (27%) report difficulty affording their deductible.<sup>2</sup>

In addition, PES data show that four in 10 (45%) insured Americans facing financial barriers to care are burdened by medical debt, and more than half (53%) have no savings at all. Being consistently unable to stay on top of health care expenses has a real impact, as more than a third (35%) of this group said they have foregone needed health care in the past three months. Further exacerbating the issue, half (49%) say the pandemic has made it more difficult for them to access care.

The 37% of insured Americans who face financial barriers to care are also more likely to report being subject to utilization management such as prior authorization or step therapy - **with 61% of this group experiencing a recent utilization management barrier.**

## Definition of the Insured Americans Facing Financial Barriers



1. Very or somewhat difficult to afford the out-of-pocket expenses not covered by health insurance.



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*



## Demographic Profile of the Insured Americans Facing Financial Barriers

63%

Women

70%

Urban

29%

High School (or less)

39%

Some College

36%

Men

12%

Suburban

4%

Rural

19%

College Grad

12%

Advanced Degree

Base: 1,777 Insured Americans who face a financial barrier to care  
Note: See Appendix for financial barrier methodology  
Source: Patient Experience Survey, November 30 - December 18, 2021

### Insured Americans feel the consequences of a cycle of unaffordable health care costs:

“

I've been on dialysis for the last 15 years. Using dialysis three times a week has taken a toll on my body, and specific medications can only help alleviate this. Yet, my insurance won't provide full coverage because they don't consider those medications necessary. I find myself having to rely on my family every month to help with these additional costs.



- Mauricio A., Arizona

“

I need to take daily medication for hypothyroidism and am unable to use a generic prescription due to the fillers they contain. Unfortunately, my insurance does not cover any of the costs for the alternative medicine that works for me. I then have to pay significant out-of-pocket costs for a medicine that keeps me healthy.



- Hilary C., New York

### Insured Americans with financial barriers to care are

2X more likely

to report being in poor health compared to insured Americans who do not face a financial barrier to care (16% v. 8%)

51% report having a chronic condition

31% report mental health conditions

16% report respiratory disorders

Base: 1,777 Insured Americans who face a financial barrier to care  
Note: See Appendix for financial barrier methodology  
Source: Patient Experience Survey, November 30 - December 18, 2021

## II. Obstacles to Affordability and Access Driven by Insurance Practices

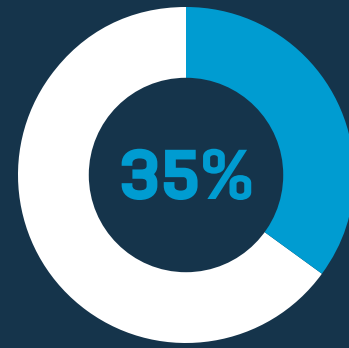
The 37% of insured Americans with financial barriers to care are not the only ones burdened by affordability and access challenges. Systemic problems with coverage design impact insured Americans broadly.

For many Americans, out-of-pocket expenses, such as deductibles and coinsurance, and utilization management tools that limit when and how patients can access health care services and medicines, such as prior authorization and step therapy, are creating significant barriers to care and deepening inequities. Affording unexpected needed medical care is a real challenge for many Americans, and as a result, can deter them from seeking care or adhering to treatment.

### Unaffordable out-of-pocket health care costs can have devastating consequences on American families.

High cost sharing required by insurance plans is contributing to Americans' inability to afford their health care. The survey asks insured Americans the maximum amount they could afford next month in out-of-pocket health care expenses for their household and then compares that to the amount respondents estimate they paid in out-of-pocket expenses in the past 30 days for their household. Thirty five percent of insured Americans report spending more in out-of-pocket costs in the last 30 days than they could afford. These same Americans cite health insurance deductibles as the main reasons that they find it difficult to afford their out-of-pocket expenses (41%).

PES data show that nearly one in five (19%) Americans with insurance would be unable to afford the out-of-pocket expenses for their care if they had a major medical event or were to become seriously ill. Three in 10 Americans (29%) would need to dip into savings or cover their out-of-pocket costs with a credit card.



Thirty five percent of insured Americans report spending more in out-of-pocket costs in the last 30 days than they could afford.

*Note: Ratio comparing reported maximum amount respondents could afford next month in out-of-pocket health care expenses to reported best estimate for how much respondents spent on out-of-pocket health care expenses in the past 30 days.*

*Base: 4,264 Insured Americans*

*Source: Patient Experience Survey, November 30 - December 18, 2021*

### Which of the following comes closest to describing your situation with respect to out-of-pocket health care expenses?

**Insured Americans**

My out-of-pockets 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.**

**19%**

My out-of-pockets are expensive, but in the event I had a major medical event or was diagnosed with a chronic illness today **I would be able to cover them with savings or credit cards.**

**29%**

My out-of-pockets are affordable. I'm confident that if I had a major medical event or was diagnosed with a chronic illness today **I would be able to cover my out-of-pocket expenses without much difficulty.**

**52%**

*Q: Which of the following comes closest to describing your situation with respect to out-of-pocket health care expenses?*

*Base: 4,264 Insured Americans*

*Source: Patient Experience Survey, November 30 - December 18, 2021*

## Insurance leaves Americans vulnerable to medical debt.

Americans are not protected from high out-of-pocket costs and from falling into medical debt by their insurance. More than one in four (27%) Americans with insurance report having medical debt, with an average debt of \$4,000. PES data show that the biggest sources of debt are hospital (30%) and doctors' bills (20%).

## Black and Hispanic Americans are disproportionately burdened by out-of-pocket costs and medical debt.

Black Americans (24%) and Hispanic Americans (21%) with insurance are much more likely to report that they would not be able to afford their out-of-pocket costs if they had a major medical event or became seriously ill, compared to 17% of white Americans.

Black and Hispanic Americans are also disproportionately burdened by medical debt, with 36% of Hispanic Americans and 33% of Black Americans with insurance reporting outstanding medical debt, compared to 26% of white Americans.



When I was first diagnosed with an autoimmune disorder, my doctors set me up with a treatment plan, so I could still enjoy life. Unfortunately, my insurance doesn't provide full coverage so my out-of-pocket expenses have increased.



**- Johnetta F., Michigan**

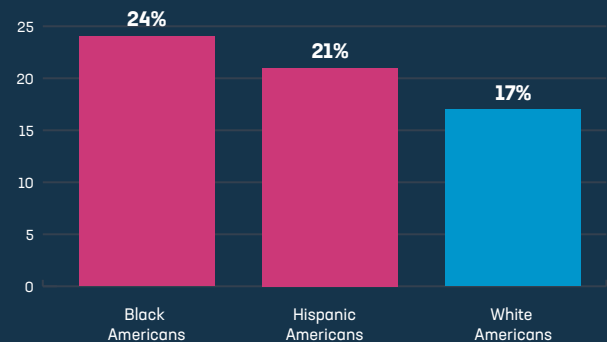


### Out of Pocket Costs:

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.

## Out-of-Pocket Costs Disproportionately Impact Black and Hispanic Americans

*Black and Hispanic Americans are more likely to report that they would not be able to afford out-of-pocket costs for unforeseen care*



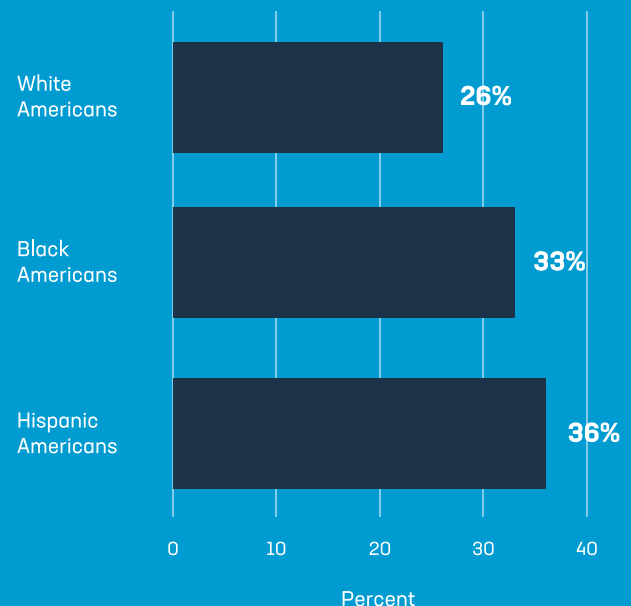
*Q: Which of the following comes closest to describing your situation with respect to out-of-pocket health care expenses?*

*Base: 4,264 Insured Americans*

*Note: See Appendix for financial barrier methodology*

*Source: Patient Experience Survey, November 30 - December 18, 2021*

## Black and Hispanic Americans Disproportionately Burdened by Medical Debt



*Q: Do you currently have any outstanding debt for medical expenses (money that you owe for health care services you could not afford at the time?) Y/N*

*Base: 4,264 Insured Americans*

*Source: Patient Experience Survey, November 30 - December 18, 2021*

**Utilization management practices like prior authorization and step therapy can stand in the way of patients and their medicines.**

In addition to high out-of-pocket costs, many Americans report other insurance-imposed barriers to care. PES data show that 49% of Americans who take prescription medicines report being subject to insurance barriers, including utilization management, like prior authorization or step therapy, in the past three months.

A recent survey by the Medical Group Management Association validates this trend of increasing insurance barriers, finding that a significant number of medical professionals report a growing use of prior authorization in recent years.<sup>3</sup>



**Prior Authorization:**

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

**Step Therapy:**

A patient is required to fail first on an alternative medicine preferred by the insurer before the originally prescribed medicine is covered.

**Have any of the following happened to you or your family over the past three months? Please answer regarding any kind of prescription medicine for any condition or illness.**

Patients who take prescription medicines  
(n=3,624)

<b>Report any insurer-imposed barrier to accessing prescription medicine</b>	<b>49%</b>
I had to wait for my insurer to provide prior authorization for a medicine my doctor prescribed	<b>31%</b>
A medicine my doctor recommended or prescribed was not covered by my insurer (excluded from the "formulary")	<b>29%</b>
My insurer required my doctor to prescribe a different medicine than the medicine my doctor believed would be most effective	<b>24%</b>
I had to try and fail on another medicine before getting the medicine my doctor originally prescribed	<b>18%</b>
My insurance company did not count amounts covered by a pharmaceutical company's copay assistance toward my deductible and annual maximum out-of-pocket costs	<b>18%</b>
I had to appeal a decision made by my insurer regarding a prescription medicine	<b>17%</b>

*Q: Have any of the following happened to you or your family over the past three months? Please answer regarding any kind of prescription medicine for any condition or illness. Base: 3,624 Patients who take prescription medicines Source: Patient Experience Survey, November 30 - December 18, 2021*



### Utilization management barriers disproportionately impact Black and Hispanic Americans and the chronically ill.

Majorities of Hispanic Americans (64%) and Black Americans (55%) report being subject to at least one utilization management barrier to accessing medicines, compared to 44% of white Americans. Among Hispanic Americans, individuals of Puerto Rican (71%) and Mexican (69%) descent are most likely to report instances of utilization management barriers to care.

Patients with serious conditions such as infectious diseases (79%), autoimmune diseases (73%) and mental health conditions (65%) also report being disproportionately burdened by utilization management barriers in access to medicines.



It took 2 months fighting our insurance company to get a chemo drug approved for my son Mattie's spinal cord tumors. Mattie required tumor debulking surgeries yearly prior to the insurance company granting drug approval. The drug has slowed his tumor growth so much that he only needs surgery every five years now, giving us much-needed time for more drug innovation, which could ultimately save Mattie's life.



**- Katie M., Georgia**

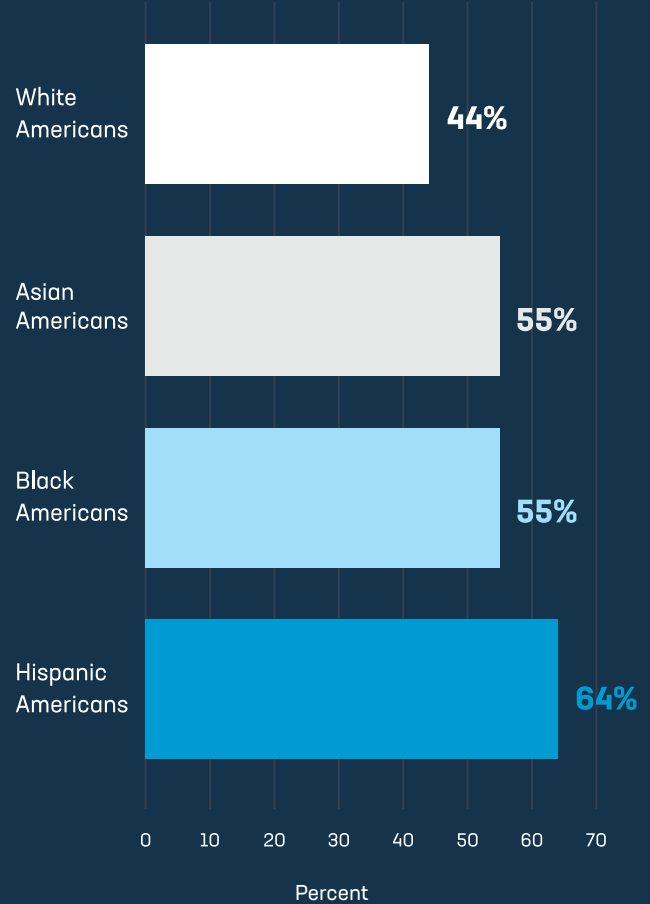


My daughter and son both have CAPS, a rare disease for which there are only 2-3 FDA approved treatments. My daughter began experiencing a lot of symptoms from one of the treatments, so her doctor prescribed another treatment. Unfortunately, our insurance plan has denied the recommended dosage for my daughter. We have submitted written commitments to using the medication and are still awaiting a response. I want the best possible treatments for both my children, and our insurance plan shouldn't get in the way of their ability to live their healthiest, best lives.



**- Kara W., Minnesota**

### Utilization Management Disproportionately Impacts Black and Hispanic Americans



#### Among Hispanic Americans...

71%

Patients of Puerto Rican descent

69%

Patients of Mexican descent

*Q: Have any of the following happened to you or your family over the past three months? Please answer regarding any kind of prescription medicine for any condition or illness.*

*Base: 3,624 Patients who take prescription medicines*

*Source: Patient Experience Survey, November 30 - December 18, 2021*

## Utilization management can contribute to medication adherence challenges.

Seventy-five percent of those who report at least one adherence issue (such as skipping one or more doses) were subject to some form of utilization management. Eighty-two percent of those who report multiple adherence issues were subject to some form of utilization management.

## Non-adherence can result in negative health outcomes.

Americans who experience prescription medicine adherence issues can face negative health outcomes as a consequence of not taking their medicines as prescribed. Nearly half (48%) of all those reporting one or more episodes of non-adherence say their health suffered as a result.



I was diagnosed with Crohn's in seventh grade, and now that I'm older, my doctor feels I should be taking my medication weekly. Despite my doctor's opinion that this treatment is medically necessary to keep my Crohn's in remission, my insurance company has denied my doctor's request because my plan only covers a biweekly maintenance dose. Meanwhile, I am not getting any medication right now because my insurance company won't cover either prescription while it's on appeal.



**- Carter R., Georgia**

## 51% of Americans Who Take Prescription Medicines Report at Least One Adherence Issue in the Past Year

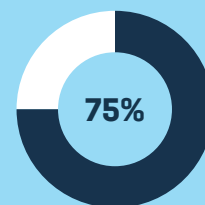
<b>Reports at least one adherence event in the past year</b>	<b>51%</b>
Skipped one or more doses	32%
Delayed picking up or taking the medicine	28%
Did not fill or pick up the medicine from the pharmacy	22%
Didn't finish all of the medicine	20%
Cut your pills in half	20%
Picked up the medicine, but did not take any of the medicine	14%

*Q: In the past 12 months, have you done any of the following related to a prescription medicine you were prescribed? (Select all that apply)*

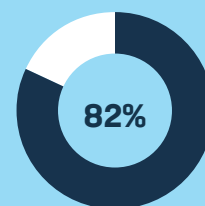
*Base: 3,624 Americans who take a prescription medicine*

*Source: Patient Experience Survey, November 30 - December 18, 2021*

## Health Insurance Barriers Can Contribute to Medication Adherence Challenges



Americans who report **at least one episode of non-adherence** report that they were subject to some form of utilization management



Americans who report **multiple episodes of non-adherence** report that they were subject to some form of utilization management

*Q: In the past 12 months, have you done any of the following related to a prescription medicine you were prescribed?*

*Base: 1,724 Patients who experienced an adherence event in the past year*

*Source: Patient Experience Survey, November 30 - December 18, 2021*

## III. Policy Solutions to Address Systemic Challenges with Affordability and Access

From insurance barriers like high out-of-pocket costs to hurdles like utilization management practices, PES data make clear that Americans continue to face systemic challenges that impact the overall affordability of care and their ability to access the care they need. As a result, Americans support reforms that would lessen these challenges and ultimately provide better coverage that works when they need it.

### Americans want relief from unaffordable out-of-pocket costs.

The second PES report underscores the impact of increasingly high out-of-pocket costs that burden patients and potentially deter them from accessing the care they need. Data reveal insured Americans rate out-of-pocket costs, such as copays, coinsurance, deductibles and out-of-network charges (15%), and the cost of health insurance premiums (15%) as the most important health care issues.

When it comes to solutions addressing prescription medicine costs specifically, by a two-to-one margin insured Americans prefer paying lower out-of-pocket costs (such as copays, coinsurance and deductibles) for medicines (66%) versus paying a lower premium each month (34%).

### Americans support other reforms that lower what they pay at the pharmacy counter.

When asked about policies the government could pursue to address health care costs, Americans want insurance companies and hospitals to share the savings directly with patients:

- Requiring Medicare Part D plans to pass on any rebates or discounts they receive from pharmaceutical companies on prescription drugs to seniors at the pharmacy counter, so patients pay less out of pocket for their medicines (87%);

- Requiring hospitals to use the discounts they receive on prescription medicines to help patients in need instead of using those discounts for other purposes (87%);
- Ensuring cost-sharing assistance patients receive counts toward their deductibles and out-of-pocket maximums (87%); and
- Giving health insurers more incentives to lower out-of-pocket costs for people who are sick and take prescription medicines (86%).

## Americans Prioritize Lower Out-of-Pocket Costs

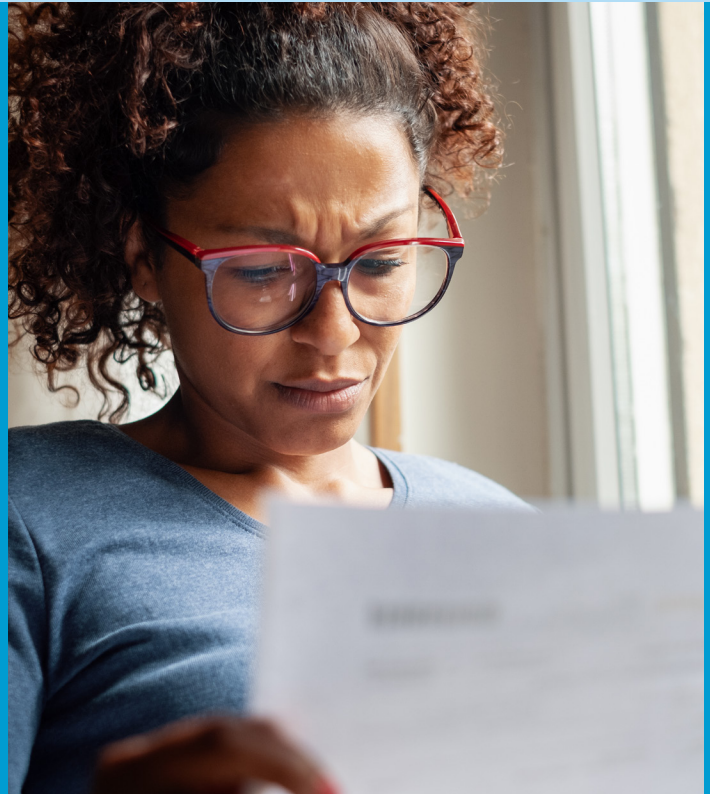
*Thinking about your health insurance, which is more important to you?*



*Q: Thinking specifically about your prescription drug coverage, which is more important to you?*

*Base: 4,264 Insured Americans*

*Source: Patient Experience Survey, November 30 - December 18, 2021*



## Conclusion

*Covered by Insurance But Still Exposed: Barriers to Care for Insured Americans* provides a deeper understanding of those struggling most to afford their care, despite having health insurance – those disproportionately in poorer health, female, with less formal education – and the unique challenges and real impacts they face within the current health care system.

PES data spotlight the shortcomings of health insurance coverage for 37% of insured Americans who, despite having insurance coverage, face financial difficulty using it. Ironically, insured Americans most in need of health care services are often the ones who have the greatest difficulty accessing care.

In order to tackle challenges with affordability and access, policymakers must understand the deeply entrenched systemic barriers insurers impose on patients. Burdensome insurance practices in the current health care system do not fall equally on all Americans. Instead, we find Black and Hispanic Americans are most likely to experience utilization management practices, unaffordable out-of-pocket costs and medical debt.

Americans want better insurance coverage that works when they need it. They prioritize lowering out-of-pocket costs over lower premiums. They want more predictability in their costs, transparency around their coverage and shared savings.

For policymakers, it's critical that they consider the entire health care landscape and patient experience in order to meaningfully address the real problems Americans face every day trying to navigate the current health care system.



## 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 5,000 Americans. (The sample for this report includes 3,624 Americans who rely on prescription medicines, and 4,264 insured Americans, of which 1,777 face a financial barrier to care.) 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.

### 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 trillion in the search for new treatments and cures, including \$91.1 billion in 2020 alone.



## Methodology

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 questionnaire was translated and cross-translated into Spanish for administration with Spanish-speaking households.

The survey was administered online among a sample of one of the largest general public and patient research panels - Dynata. Adults 18+ years of age in the United States participated in the survey. However, the study was also designed to understand specific populations of interest, especially vulnerable populations (BIPOC, LGBTQX, lower SES groups) and patients suffering from chronic and other severe health conditions. Therefore, instead of sampling these groups separately (disproportionate to their incidence in the overall population), the overall sample size was adjusted to ensure a minimum sample size of key populations.

The sample was administered by applying quotas around key demographic variables and the final data was weighted, applying a post-stratification, RIM weighting methodology across nine demographic variables using the latest Census data.

The survey was conducted between November 30 and December 18, 2021, with a final sample size of n=5,000 Americans, including n=3,624 patients taking prescription medicines and 4,264 insured Americans. Of the insured Americans, 1,777 face a financial barrier to care.

## 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 detailed analysis.

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	20%	37%
No savings that could be accessed immediately to pay for emergency or unforeseen expenses	20%	
Reported spending more in out-of-pocket expenses than could afford last month.	35%	



## Endnotes

1. PhRMA. [Patient Experience Survey](#). 25 June - 9 July, 2021
2. Kearney A, Hamel L, Stokes, M, Brodie M. [Americans' Challenges with Health Care Costs](#). Kaiser Family Foundation. 14 December, 2021.
3. Medical Group Management Association. [MGMA Stat poll](#). 18 May, 2021.