

PATIENT EXPERIENCE SURVEY

ACCESS DENIED: PATIENTS SPEAK OUT ON INSURANCE BARRIERS AND THE NEED FOR POLICY CHANGE

PhRMA

October 2024

PES 5 Executive Summary

Many Americans struggle with access and affordability navigating the health care system, and support changes to address these issues.

Access: Experience with Delay And Denial of Care

Many insured Americans have faced insurance barriers to care in the past year – with this being an even bigger issue for chronic disease patients who are most in need of reliable access to care. Roughly half can't anticipate what they'll pay for Rx and have had trouble understanding their health insurance coverage. There is widespread support for cracking down on practices by insurance companies and pharmacy benefit managers (PBMs) and that can limit patient access to medicines.

Affordability: Out-of-Pocket Costs, Medical Debt, and Deductibles

If facing a major medical event or chronic condition, many insured Americans report that their OOP costs would be expensive or more than they could afford – *even with insurance*. Sizable shares cite a rise in OOP expenses over the past year and are saddled with medical debt. Insured Americans overwhelmingly agree that patients should have consistent out-of-pocket costs for medicines they need, with no surprises. Top solutions to improve health insurance include requiring insurance plans to cover more products and services without a deductible and enforcing limits on out-of-pocket costs.

Americans' Health Care Priorities for Policymakers

Health care costs – specifically OOP costs and insurance premiums – are front and center among insured Americans. They want the candidates to focus on reducing waste in the system and on reining in costs. Moreover, they believe it's policymakers' duty to protect patient access to care at an affordable price.

Innovation: Importance of Choice, Innovation, Personalization, and Prevention for Americans

Insured Americans believe we need to focus on incentivizing and expanding access to innovative, preventive medicines, which stop disease before they take hold. They also want more choice and access to personalized medicine to meet their needs.

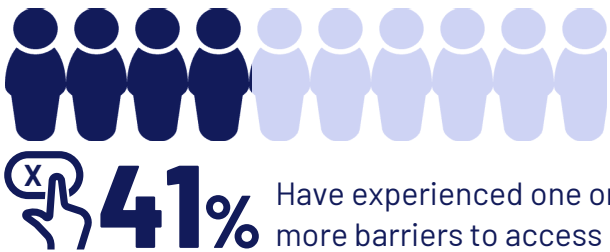


ACCESS

1

Experience with Delay And Denial of Care

4 in 10 have encountered at least one health insurance challenge, with prior auth and formulary exclusion being most common



Notable subgroup differences: Chronic disease patients on prior authorization (29%) and medicines not being covered (26%); ages 45-64 on prior auth (27%)

I had to wait for my insurer to provide prior authorization for a medicine my doctor prescribed	22%
A medicine my doctor recommended or prescribed was not covered by my insurer (excluded from the "formulary")	21%
My insurance company set a maximum limit on the total amount of a prescription medication that could be dispensed at one time	10%
I had to try and fail on another medicine before getting the medicine my doctor originally prescribed (i.e., "step therapy")	9%
I had to appeal a decision made by my insurer regarding a prescription medicine	6%
My insurance company did not count co-pay assistance from a pharmaceutical company toward my deductible and annual maximum out-of-pocket costs (i.e., "accumulator adjustment program")	5%

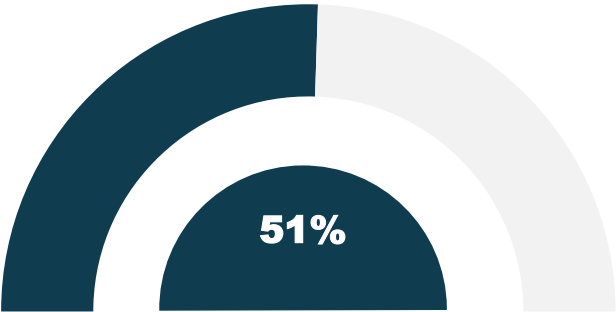
Q39. Have any of the following happened to you or your family over the past year (12 months)? Please answer regarding any kind of prescription medicine for any condition or illness.
Answer choices: Select all that apply. Base: Insured Americans taking Rx n=1676

Roughly half of insured Americans have trouble anticipating the cost of Rx medicines and understanding their coverage

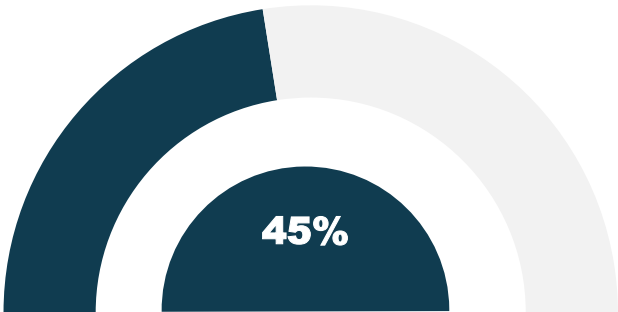
Just slightly fewer fear denial of care

Notable subgroup differences: Those ages 18-44 on difficulty understanding health insurance coverage (51%), and Hispanic insured Americans on concern for denial of future care (50%)

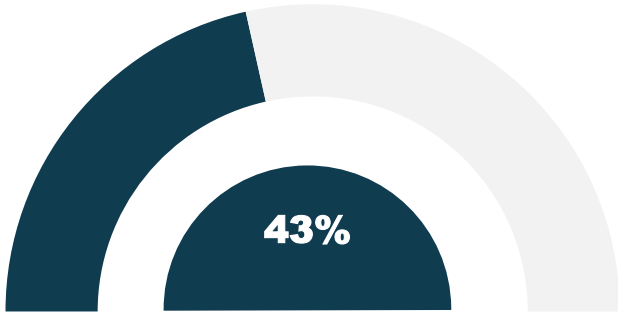
Strongly or somewhat agree



I can't anticipate what I'll pay for prescription medicines even if the medicines are covered by my health insurance plan



I have had trouble understanding my health insurance coverage



I'm concerned my insurance company is going to deny my future care

Support for greater transparency and accountability in health care

Notable subgroup differences: Chronic disease patients and seniors are more likely to strongly support all measures surveyed; Democrats are more likely to express strong support for most measures (Rx patients some measures)

Americans strongly support...



Health insurers and PBMs

	% <u>strongly</u> support
Requiring health insurers and PBMs to pass on any rebates or discounts they receive from pharmaceutical companies on prescription drugs at the pharmacy counter	63%
Cracking down on abusive practices by PBMs and health plans like inappropriate fail first (step therapy) and prior authorization	64%
Ensuring copay assistance provided by pharmaceutical manufacturers goes to patients as intended and NOT to health insurers and PBMs	65%
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	60%
Ensuring copay assistance provided by pharmaceutical manufacturers counts toward plan deductibles and out-of-pocket maximums	53%
Requiring health insurers to set a maximum limit for what patients pay out of pocket just for Rx medicines each year	48%



Hospitals

	% <u>strongly</u> support
Requiring hospitals and clinics to be more transparent about how much they mark-up the costs for prescription medicines	70%
Requiring hospitals to use the discounts they receive on prescription medicines to help low-income and uninsured patients access the medicines they need	57%
Driving greater oversight and transparency of safety net programs like <u>340B</u> to ensure that hospitals and other entities are using drug discounts they receive to serve needy patients	55%

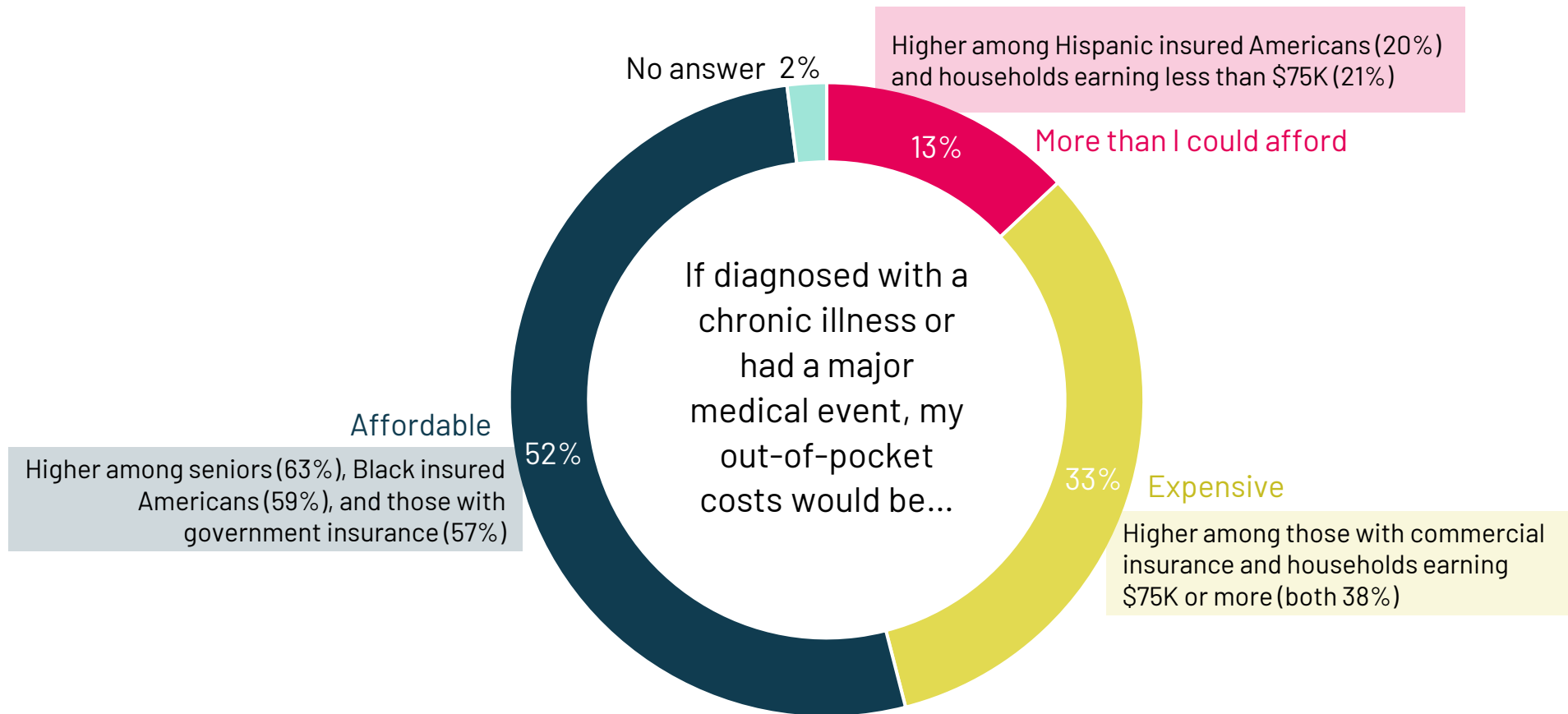
Q59. Below are some policies that the government could pursue to address health care costs. For each, please indicate whether you strongly support, somewhat support, somewhat oppose, or strongly oppose the policy... Answer choices: strongly support, somewhat support, somewhat oppose, or strongly oppose the policy. Base: Insured Americans n=2397

AFFORDABILITY

2

Out-of-Pocket Costs, Medical Debt, and Deductibles

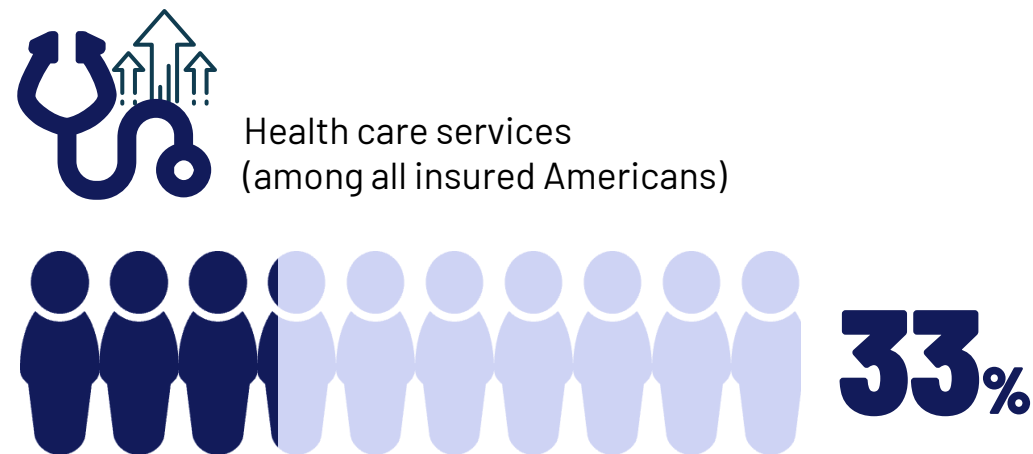
Nearly half of insured Americans find their out-of-pocket costs expensive or unaffordable



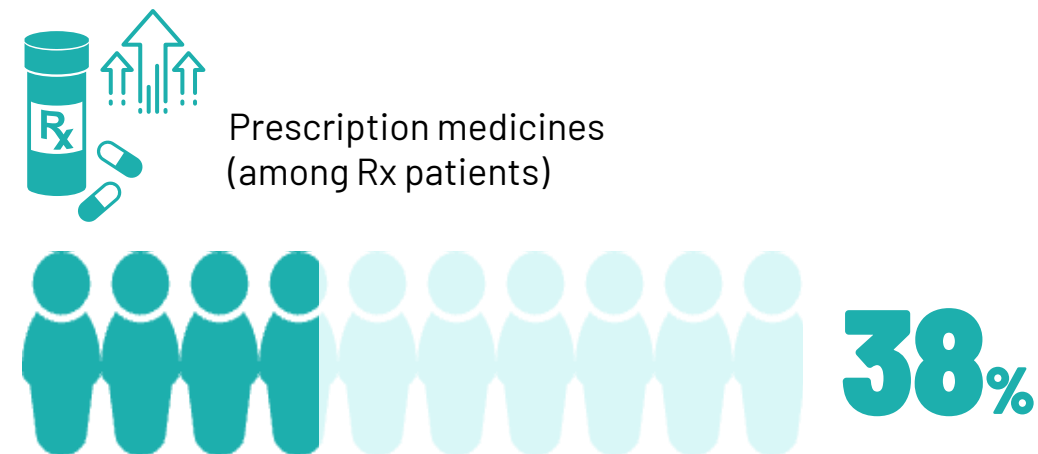
Q30A. Which of the following comes closest to describing your situation with respect to out-of-pocket health care costs...
Answer choices: Select one. Base: Insured Americans n=2397

Sizable shares of insured Americans report rising out-of-pocket costs in the past year

Amount paid for ... have increased in the last 12 months



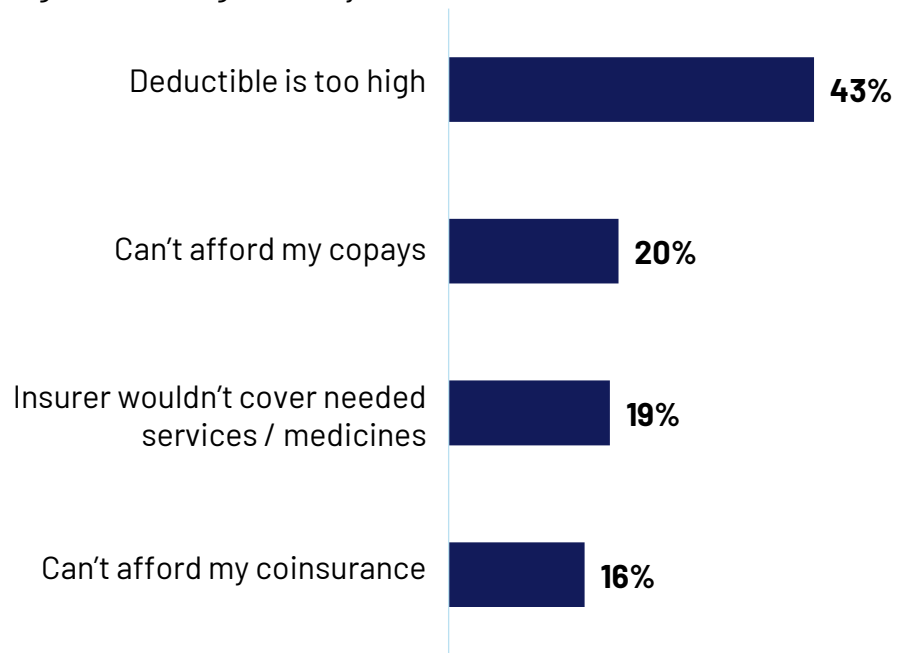
Higher among those ages 45-64 (40%), those with commercial insurance (39%), and Republicans (38%)



QRW2b. To the best of your knowledge, has the amount you pay in out-of-pocket costs for the following increased during the last 12 months?
Answer choices: Select one. Base for Health care services: Insured Americans n=2397; Base for Prescription medicines: Base: Insured Americans taking Rx n=1676

Difficulty affording health care out-of-pocket costs largely stems from high deductibles

Main reason for difficulty affording health care OOP expenses
(among those facing difficulty)



Notable subgroup differences

- On citing a high deductible: those with commercial insurance (56%) and those with HHI of \$75K+ (56%)
- On difficulty affording co-pays: chronic disease patients (27%), seniors (31%), and those with government insurance (30%)
- On insurers not covering what patients need: those with HHI of <\$75K (24%), those with government insurance (26%), and Independents/Other party ID (26%)

Q27A. What is the main reason it is difficult to afford your health care out-of-pocket expenses? Answer choices: Select one. Base: Insured Americans who have difficulty affording OOP costs n=286

1 in 3 Rx patients report adherence issues

8% cannot afford to take their medication as prescribed



33%

Have experienced one or more adherence issue:

Skipped one or more doses	20%
Delayed picking up or taking the medicine	13%
Did not fill or pick up the medicine from the pharmacy	9%
Cut your pills in half	7%
Didn't finish all of the medicine	7%
Picked up the medicine, but did not take any of it	5%

Notable subgroup differences

Those ages 18-44 are higher on skipping doses (26%) and delaying picking up their medicines (19%)



25%

Experienced one or more adherence issue **because they could not afford** their medication

This works out to **8%** of Rx patients overall

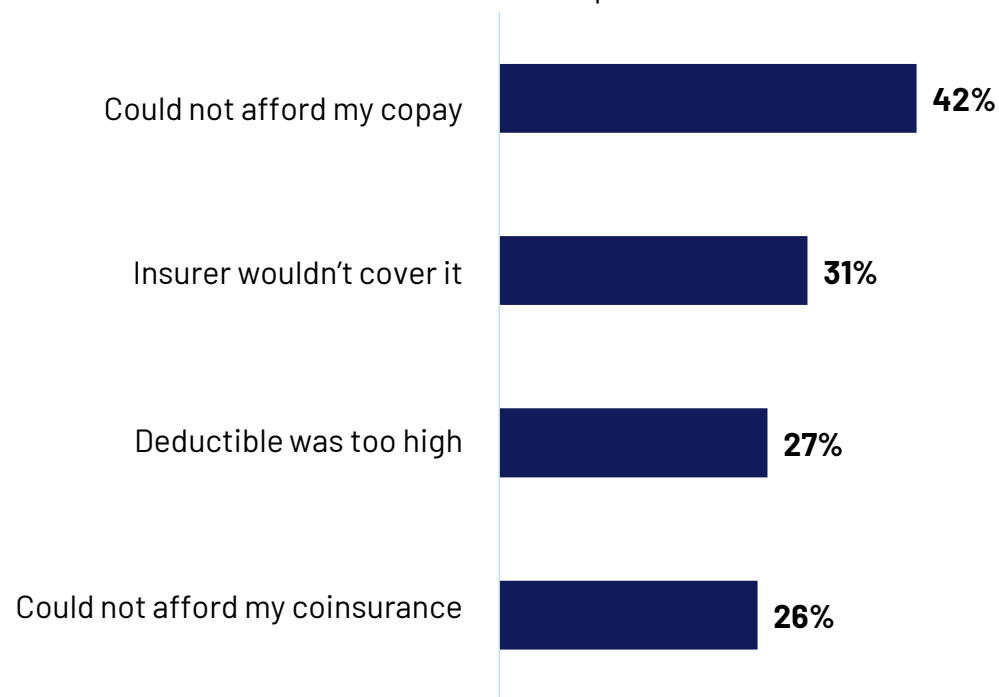
Q43. In the past 12 months, have you done any of the following related to a prescription medicine you were prescribed? Answer choices: Select all that apply. Base: Rx patients n=1676

Q46. Which of the following are reasons why you did not take your prescription medicine the way your doctor prescribed?

Answer choices: select all that apply. "I couldn't afford to pay for the medicine" shown above. Base: Rx patients who have had an adherence issue n=531

For those facing cost-related adherence issues, copays are largely to blame

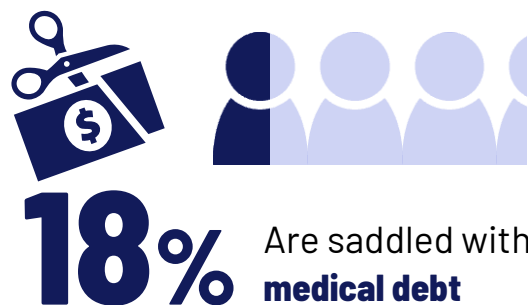
Reasons why Rx patients cannot afford to take Rx medicines as prescribed



Q64a. Which of the following are reasons why you could not afford to pay for the medicine your doctor prescribed?
Answer choices: select all that apply. Base: Rx patients who could not afford to take Rx medicines as prescribed, n=133

Roughly 1 in 5 insured Americans have medical debt

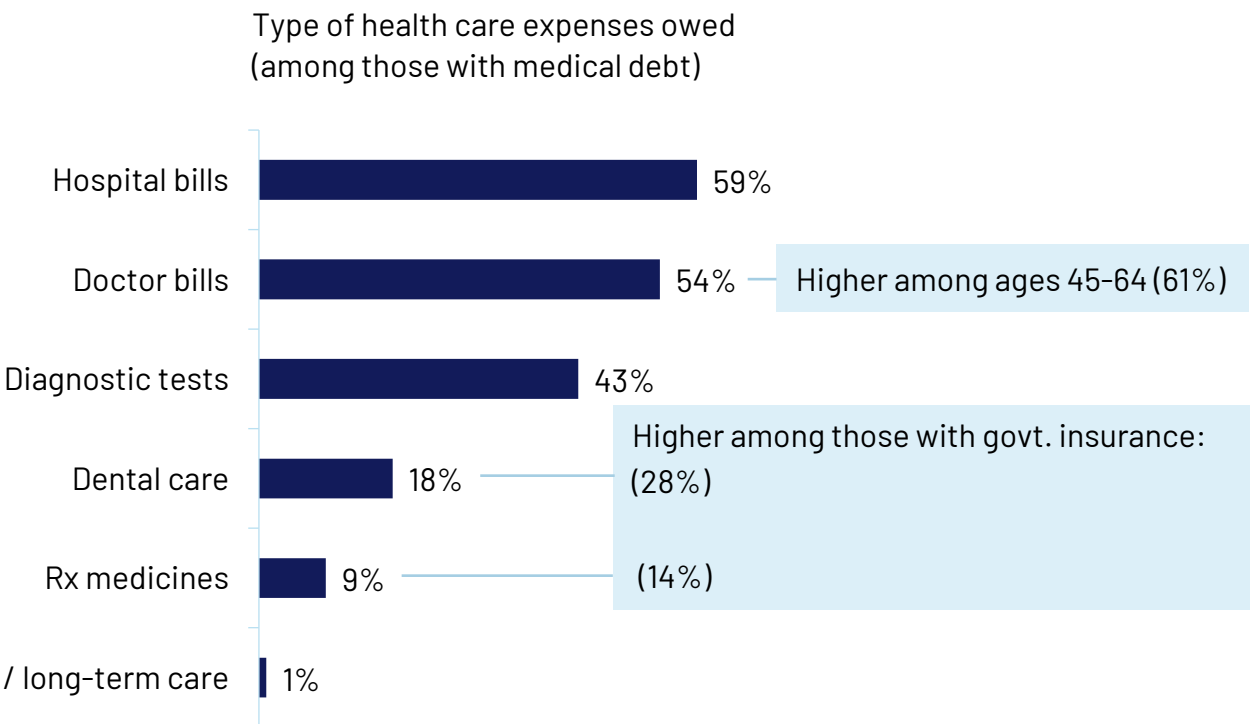
Mostly from hospital and medical bills, as well as diagnostic tests



Notable subgroup differences

Standout groups with medical debt include:

- Black insured Americans (33%)
- Chronic disease patients (24%)
- Those with HHI of less than \$75K (24%)



Q34A 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)? Answer choices: Yes, No
Base: Total Insured Americans n=2397

Q34C Which health care expenses do you owe money for as part of your total outstanding medical debt? Answer choices: Select all that apply. Base: Insured Americans with medical debt n=404

Insured Americans report a great disparity in terms of how insurance 'should' work vs. the reality

Strongly or somewhat agree that...

93%

Insurance **should work** for everyone by providing affordable access to health care when needed

28%

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

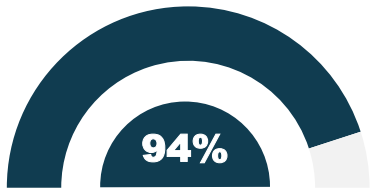
Notable subgroup differences

- Agreement is universally high that insurance *should* work for everyone
- However, a number of groups are higher on believing that insurance currently provides everyone with access to affordable care: Hispanic (41%) and Black (37%) insured Americans, as well as those with HHI of <\$75K (33%) and Republicans (36%)

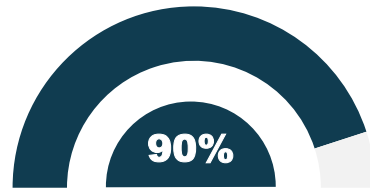
Q42. For each of the following statements, please indicate if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree. Answer choices: Select one.
Base: Insured Americans n=2397

There is room for improvement on how insurers and PBMs can work to provide access to care...

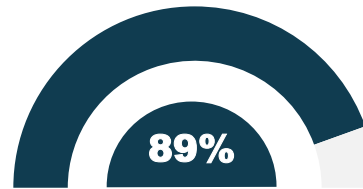
Strongly or somewhat agree that...



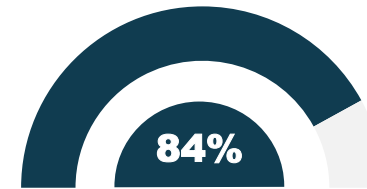
Patients should be able to get the medicines their doctor prescribes at a pharmacy that's convenient for them



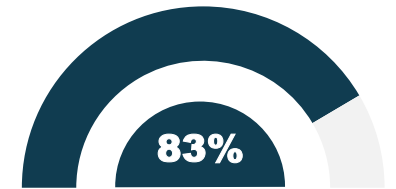
Doctors – not insurers – should determine whether or not a prescription medicine is clinically appropriate



Patients should have consistent out-of-pocket costs for medicines they need, with no surprises



Health care costs for patients would be lower if insurance companies and PBMs spent less time managing how medicines should be prescribed by doctors



It's wrong that I can pay more for my medicine out of pocket than my insurance company or PBM

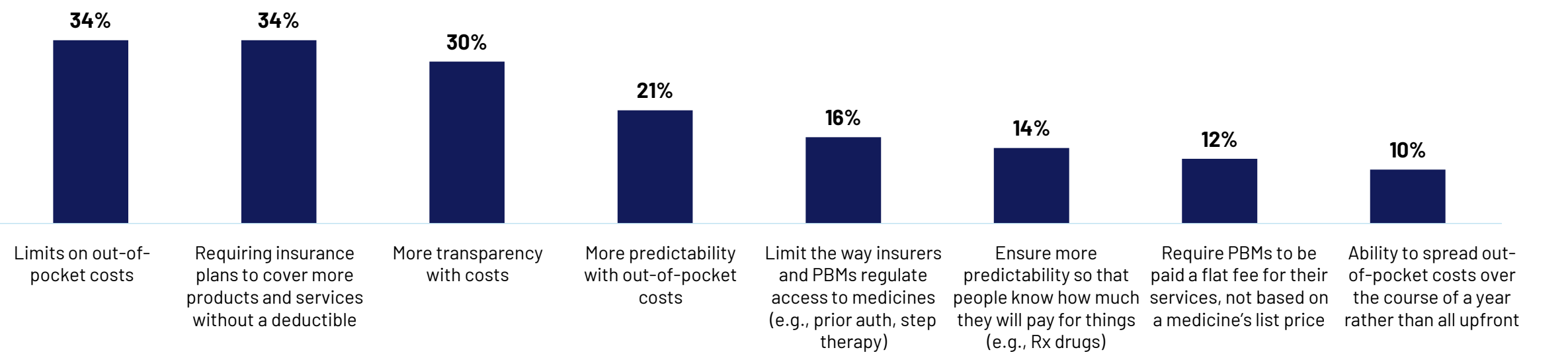
Both higher among seniors: 94% and 89%, respectively

Q42. For each of the following statements, please indicate if you strongly agree, somewhat agree, somewhat disagree, or strongly disagree. Answer choices: Select one.
Base: Insured Americans n=2397

...and insured Americans favor solutions that address out-of-pocket cost concerns

Notable subgroup differences: Race/ethnicity shows notable above-average differences: AAPI, more transparency (42%) and Black, ability to spread out OOP costs (16%); those ages 45-64 are higher on reducing the burden of deductibles (39%); chronic disease patients on limiting how insurers / PBMs regulate access to prescribed medicines (21%)

Top-2 changes to improve health care coverage



Q57A-Q57B. Below are some changes that some people have proposed to improve health insurance coverage. Please select the change that would be most / 2nd most important to you.
Answer choices: Select one. Responses with 10% or higher shown. Base: Insured Americans n=2397

KEY PRIORITIES

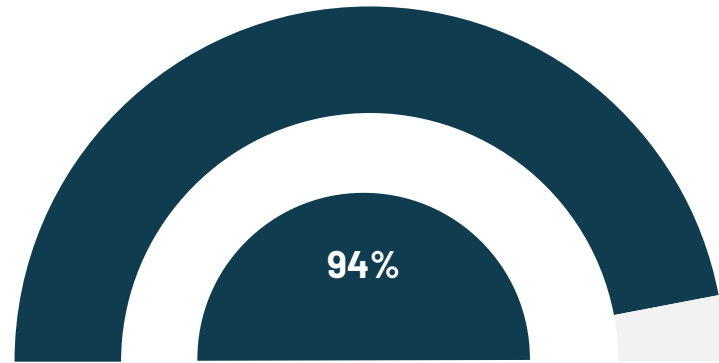
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Americans' Health Care Priorities for Policymakers

The vast majority of Insured Americans believe policymakers should understand their experiences

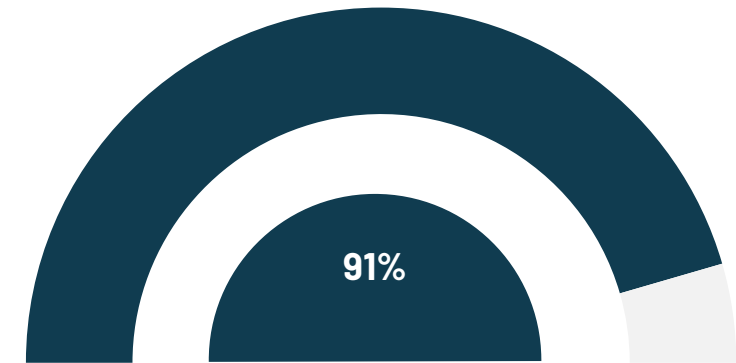
And have a duty to provide access to affordable care

Strongly or somewhat agree



It is important that policymakers understand the barriers and challenges patients face when accessing their care

72% 
strongly agree



Policymakers have a duty to protect patients' access to health care at an affordable price

67% 
strongly agree

QElect 1. Please indicate how much you agree or disagree with each of the following statements about health care and the upcoming election.
Answer choices: Strongly agree, Somewhat agree, Somewhat disagree, Strongly disagree. Base: Insured Americans n=2397

Out-of-pocket costs and insurance premiums are insured Americans' top-2 most important health care issues

Top-2 health care issues of importance	
Out-of-pocket costs not covered by your insurance	32%
The cost of health insurance premiums	28%
Inefficiency and bureaucracy in the health system	19%
The cost of prescription medicines	16%
The cost of hospital services	18%
Access to mental health care	9%
Addressing racial disparities in health care and outcomes	5%
Limited options for health care coverage	5%
Preventive care	6%

Notable subgroup differences

- Cost of health insurance premiums: those ages 45-64 (33%) and those with commercial insurance (34%)
- Cost of hospital services: those 18-44 (23%), AAPI insured Americans (33%)
- Cost of Rx medicines: chronic disease patients (22%), seniors (21%)
- Access to mental health care: those ages 18-44 (15%), Black insured Americans (16%)
- Addressing racial disparities in health care and outcomes: Black insured Americans (14%)

6% cite **health insurance costs and coverage** as the most important issue for our country today

NEWQ1 Which of the following issues, if any, do you see as the most important for our country today? Answer choices: Select one. Base: Insured Americans n= 2397
NEWQ2 From the following list, which health care issue is most important to you? Answer choices: Select two. Base: Insured Americans n= 2397

Roughly half express concern about their ability to afford out-of-pocket costs and insurance premiums over the next 12 months

Meanwhile...



Say it's extremely / very important that the health care they receive **"keeps my costs affordable"**

Very or somewhat concerned – next 12 months	
OOP health care costs (copays, deductibles etc.)	52%
Health insurance premiums	47%
Monthly groceries	51%
Hospital or doctor visits	44%
Electric bill	46%
Healthy food (i.e., groceries and meals out of home)	48%
Prescription medicines	35%
Transportation (e.g., gas, public transport)	39%
New clothing or accessories	27%
Childcare	14%

Notable subgroup differences

Standout groups on concern for health-related items include:

- Hispanic insured Americans, as well as those with HHI of <\$75K (all four health care items)

Other pockets of concern include:

- OOP health care costs: Black insured Americans (57%)
- Health insurance premiums: those ages 45-64 (53%)
- Rx medicines:
 - Rx (40%) and chronic disease (45%) patients
 - Black insured Americans (44%)
 - Those ages 45-64 and seniors (both 40%)
 - Those with government insurance (41%)

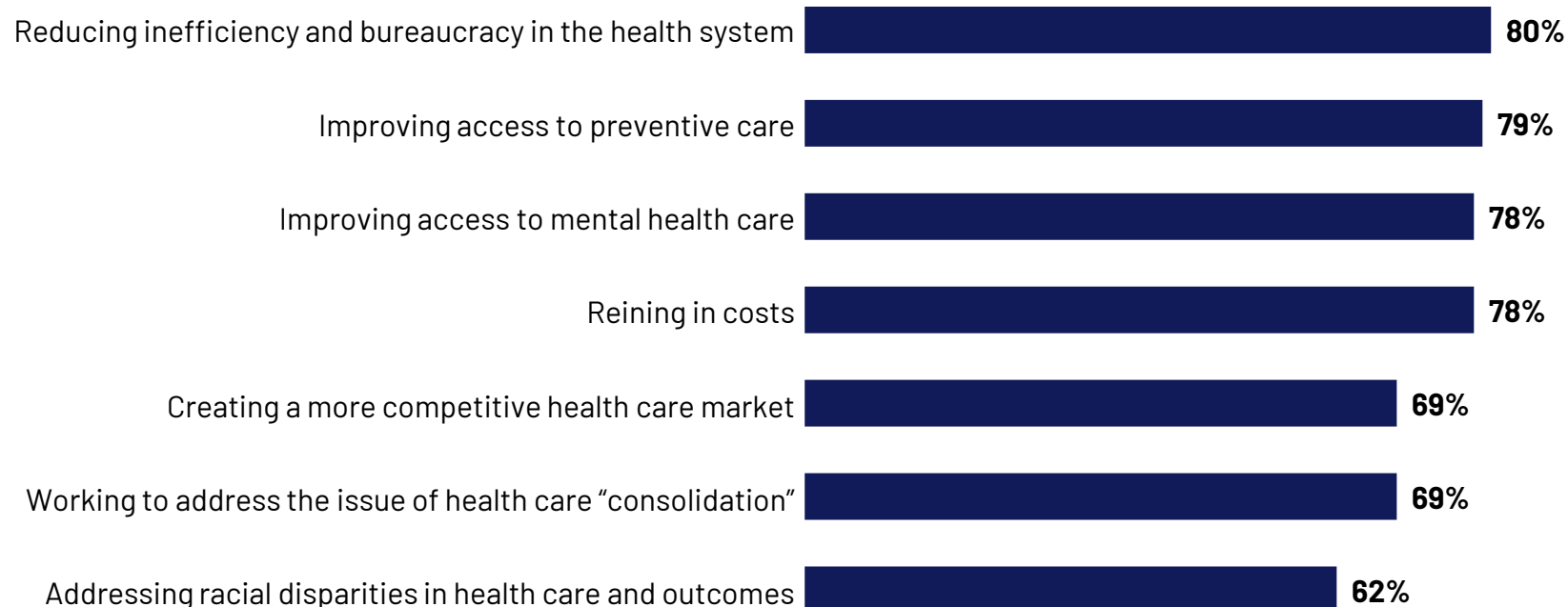
QRW1. Please indicate how important each of the following is to you, when thinking about the health care you receive.

Answer choices: Extremely important, Very important, Somewhat important, Not very important, Not at all important. Base: Insured Americans n=2397

NewQ3. Thinking about the next 12 months, how concerned, if at all, are you about your ability to afford the following? Answer choices: Very concerned, Somewhat concerned, Not very concerned, Not at all concerned. Note, the timeframe of "next 12 months" was added in current wave. Base: Total insured Americans n= 2397

Insured Americans see many ways that elected officials can help patients

Extremely or very important that candidates running for office focus on...



Notable subgroup differences

- Chronic disease patients and seniors are more likely to prioritize all issues;
- The same is true among Democrats for most issues
- Black and Hispanic insured Americans stand out on wanting elected officials to address racial disparities (77% and 70%)
- Hispanic insured Americans also prioritize addressing cost (84%), competition (76%), and consolidation (also 76%)
- Rx patients prioritize access to both preventive and mental health care (84% and 83%)

QElect2. Thinking about the upcoming election, please indicate how important it is that candidates running for office are focused on addressing each of the following.
Answer choices: Extremely important, Very important, Somewhat important, Not very important, Not at all important. Base: Insured Americans n=2397

INNOVATION

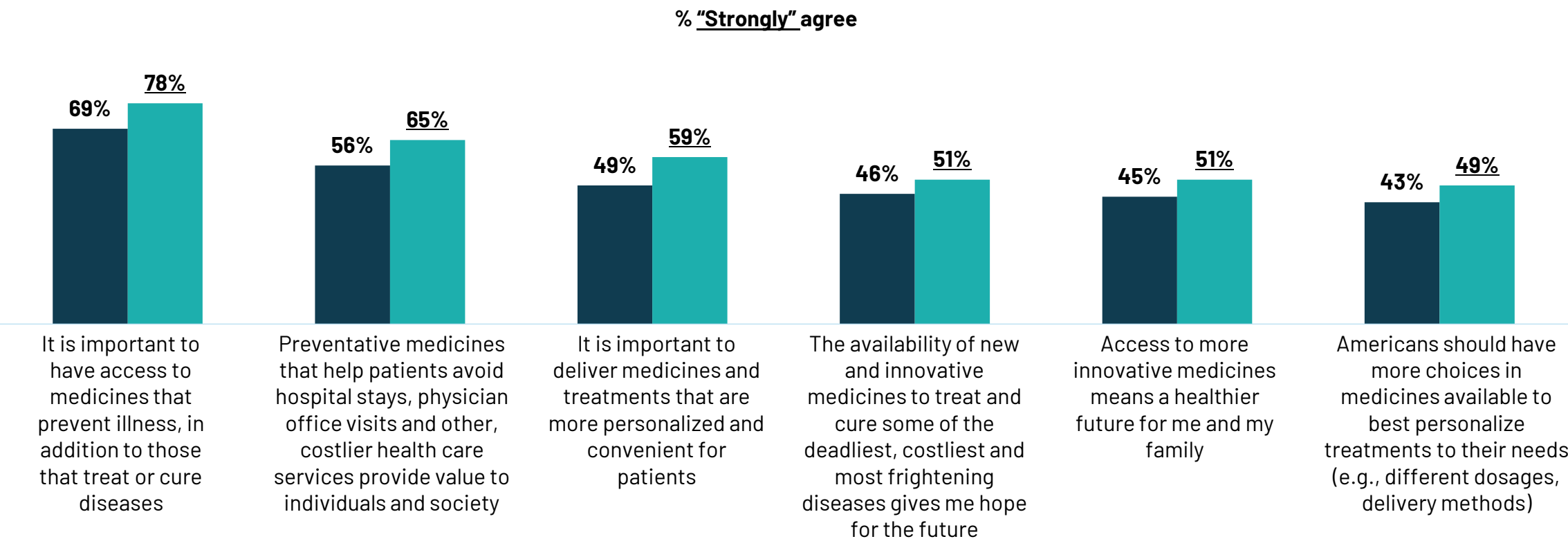
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**Importance of Choice, Innovation, Personalization,
and Prevention for Americans**

Insured Americans value access to preventive, innovative medicines

Epecially those managing chronic diseases

■ Total insured Americans
■ Chronic disease patients



QRX. Thinking about the health care you or loved ones may receive...Please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree with each of the following statements...Base: Insured Americans n=2397, Chronic disease patients n=913

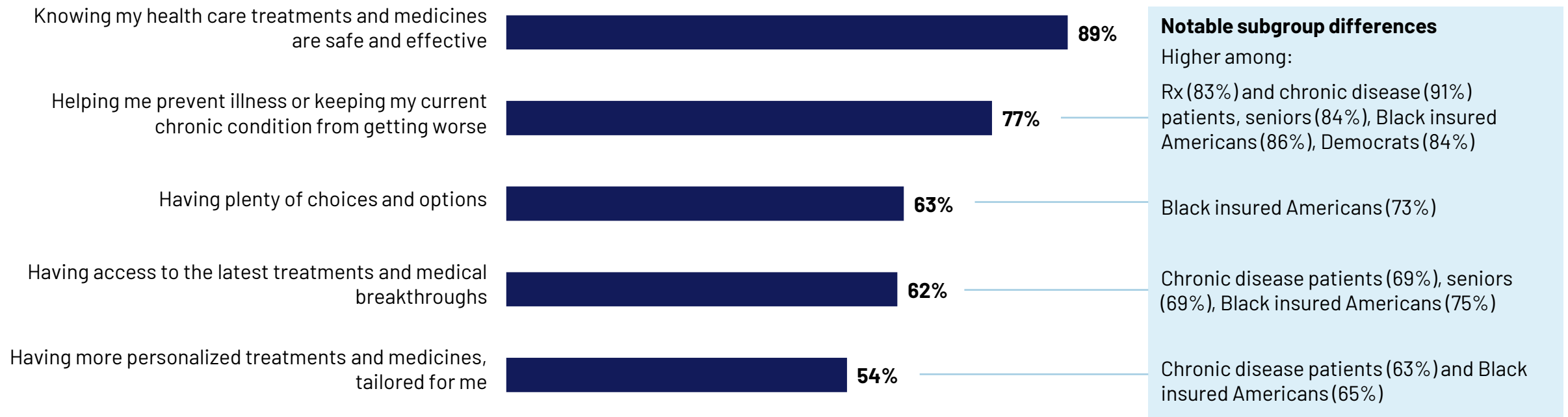
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Safety/efficacy and prevention are top health care priorities

Choice and access to medical breakthroughs, including personalization, are also important

Extremely or very important



QRW1. Please indicate how important each of the following is to you, when thinking about the health care you receive.
Answer choices: Extremely important, Very important, Somewhat important, Not very important, Not at all important. Base: Insured Americans n=2397

APPENDIX

Methodology and Sample Composition

Methodology



Field Period

July 19–August 1, 2024



Sample & Mode

The survey was conducted online among a nationally representative probability sample, using the KnowledgePanel®



Qualifications

Total sample of $n=2,592$ adults ages 18+, including $n=2,397$ who are insured (and the focus of this report)

PES Survey Respondents

Insured Americans

<i>Gender, age</i>	
n=	2,397
Gender	
Male	49%
Female	51%
Age	
18-44	43%
45-64	31%
65+	25%

<i>Race/ethnicity, HHI, Party ID</i>	
n=	2,397
Race/ethnicity	
Non-Hispanic White	63%
Non-Hispanic Black	11%
Non-Hispanic AAPI	6%
Hispanic	15%
Household Income	
Less than \$75K	40%
\$75K+	61%
Party ID	
Democrat	34%
Republican	29%
Independent/Other	37%

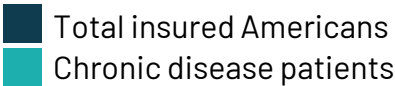
<i>Health demos</i>	
n=	2,397
Rx patient	67%
Method of taking Rx medicine (among Rx patients)	
Pill/tablet	96%
Injectable	14%
Inhale	9%
Topically	7%
Infusion intravenously	2%
Chronic disease patient	36%
Self-assessment of health	
Excellent (4, 5)	63%
3	31%
Poor (1, 2)	6%
Insurance	
Commercial	61%
Govt.	45%
Plan includes a deductible	68%
Annual deductible is... (among those with a deductible)	
Less than \$1,500/year	38%
\$1,500-\$2,999/year	33%
\$3,000/year	26%

KnowledgePanel

Ipsos's KnowledgePanel is the only large-scale representative panel of the adult population in the US for which members are recruited using a probability-based address-based sampling methodology. In order to maintain full representation of all adults, households without Internet access are provided internet-enabled devices and ISP, as well.

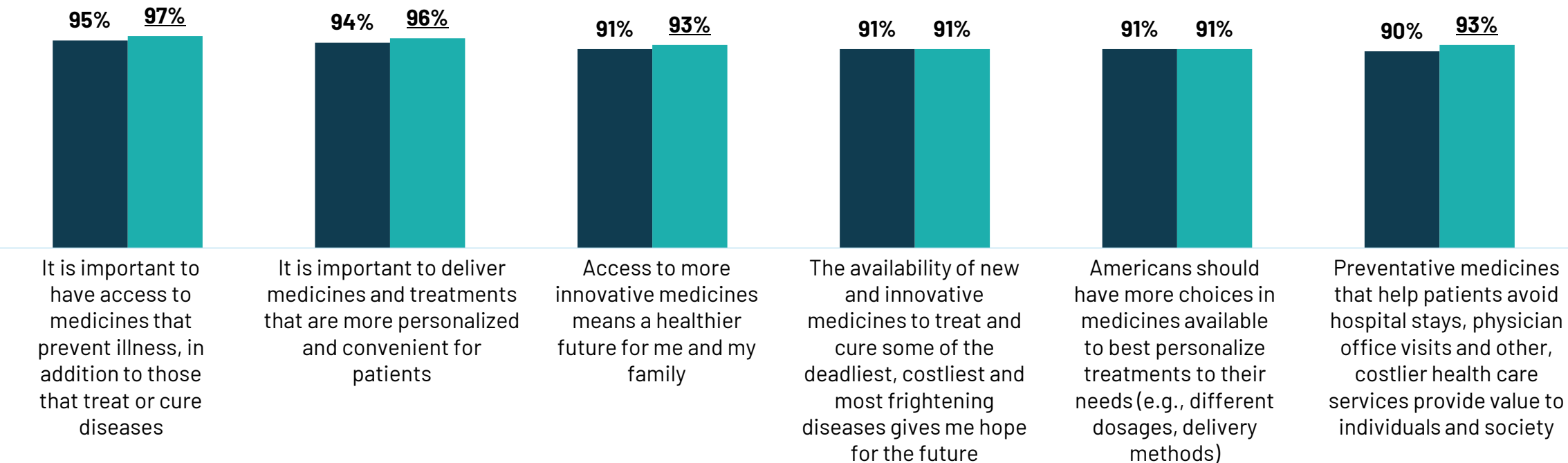
Insured Americans value access to preventive, innovative medicines

Epecially those managing chronic diseases



Underlined figure (X%) is statistically higher at the 95% confidence level

“Strongly” or “Somewhat” agree



QRX. Thinking about the health care you or loved ones may receive...Please indicate if you strongly agree, somewhat agree, somewhat disagree or strongly disagree with each of the following statements...Base: Insured Americans n=2397, Chronic disease patients n=913

