



Patients & Family Caregivers: Prescription Drug Affordability Challenges During COVID-19

Key Findings from a National Online Survey of Patients & Family Caregivers

April 29, 2021

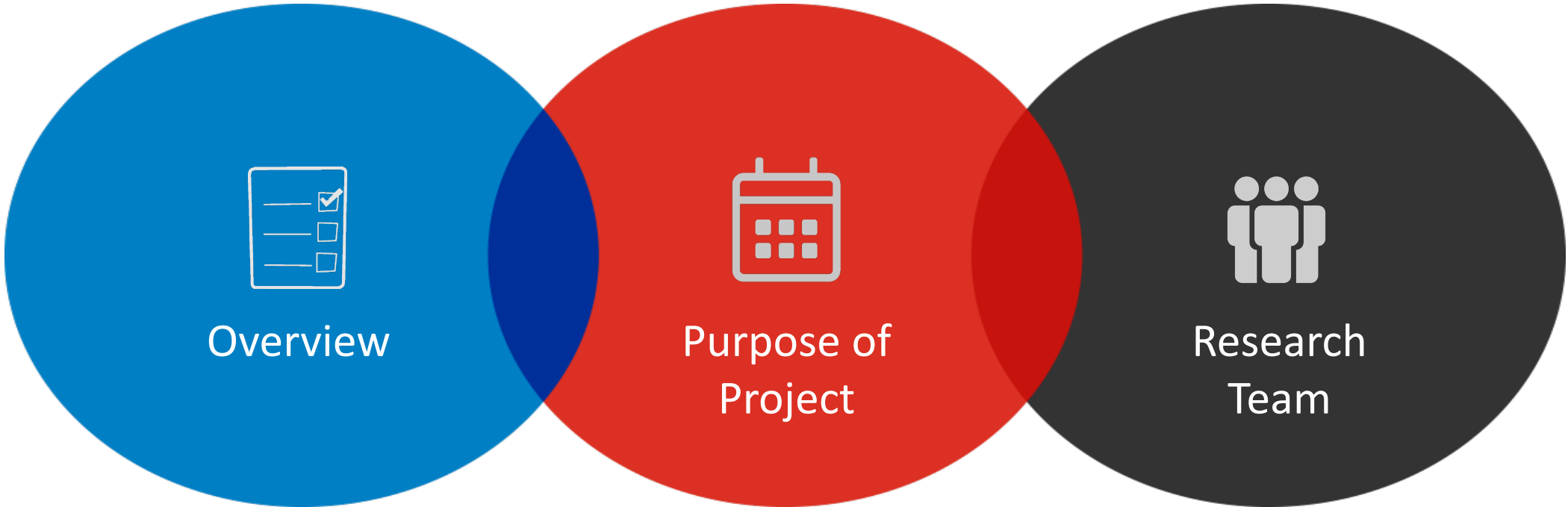
PREPARED BY:



Elizabeth Harrington, Partner

turning questions into answers

Methodology



Overview

- On behalf of the National Hemophilia Foundation (NHF) and in conjunction with AARDA, the American Kidney Fund, and the Arthritis Foundation, Public Opinion Strategies conducted a national online survey from December 18, 2020—January 31, 2021.
- The national survey was conducted among N=764 patients with serious illness and/or family caregivers of patients with serious illness (patients/loved ones who take Rx or receive treatment for their illness and have private health coverage or Medicare).

Purpose of Project

- To better understand patient and caregiver experiences with copay assistance programs.
- To explore attitudes and the impact of copay accumulator programs.
- To measure support levels for the federal government requiring health plans and pharmacies to count all funds that pay for copayments, coinsurance, and deductibles toward a patient's out-of-pocket costs regardless of the source.

Research Team

- Elizabeth Harrington, partner at Public Opinion Strategies, was the principal researcher for this project.
- Gordon Price was the project director and Cassie Bauserman provided research support.

Survey Audience Defined

The survey was conducted through the patient advocacy organizations reaching out to their patient and caregiver populations. The organizations sent email invitations to their member/supporter lists of patients and caregivers with a link to a secure website to complete the survey anonymously.

In order to qualify for participation in the survey, respondents (either themselves or a spouse or child) had to be diagnosed with one of the below diseases, take prescription medications/receive treatment for the below diseases, and have private health coverage or Medicare.

- Bleeding Disorders (such as Hemophilia or Von Willebrand Disease (VWD))
- Inflammatory Arthritis (such as Rheumatoid, Psoriatic, ankylosing spondylitis, or juvenile)
- Psoriasis
- Lupus
- Crohn's Disease or Colitis
- Multiple Sclerosis
- HIV or AIDS
- Cancer
- Kidney Disease
- End Stage Renal Disease (ESRD)



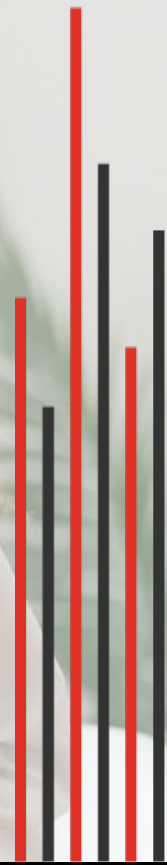
Key Takeaways

Key Takeaways

1. More than half of respondents with private coverage (55%) report they or their loved one has a high deductible health plan. Out-of-pocket health care costs is the biggest problem affecting these patients and their families.
2. Most patient and caregiver respondents say they are familiar with copay assistance programs. Roughly two-thirds report they or their loved one are either currently using or have used copay assistance programs for their medications.
3. Nearly half of respondents (46%) say they or someone in their immediate household has not been able to afford their out-of-pocket costs in the past year.
4. Two in ten respondents (20%) who use copay assistance programs report they have not been able to afford their medications or treatments because their assistance ran out.
5. Nearly all patients and caregivers (93%) say the federal government should require that health insurers and pharmacies have to apply copay assistance toward patients' out-of-pocket costs.

Key Takeaways (Continued)

6. Patients and caregivers believe there are significant negative consequences associated with the federal government not requiring copay assistance to be applied toward patients' out-of-pocket costs.
7. 6 in 10 patients and caregivers say they would have extreme difficulty affording their treatments and medications without copay assistance programs being applied to their out-of-pocket costs.
8. Nearly all patients and caregivers (92%) believe the federal government should allow drug manufacturers to offer copay assistance to Medicare beneficiaries.
9. Roughly one in four respondents (24%) has not been able to see their doctor for a health concern because of COVID-19.



Key Findings

1

More than half of respondents with private coverage (55%) report they or their loved one has a high deductible health plan.

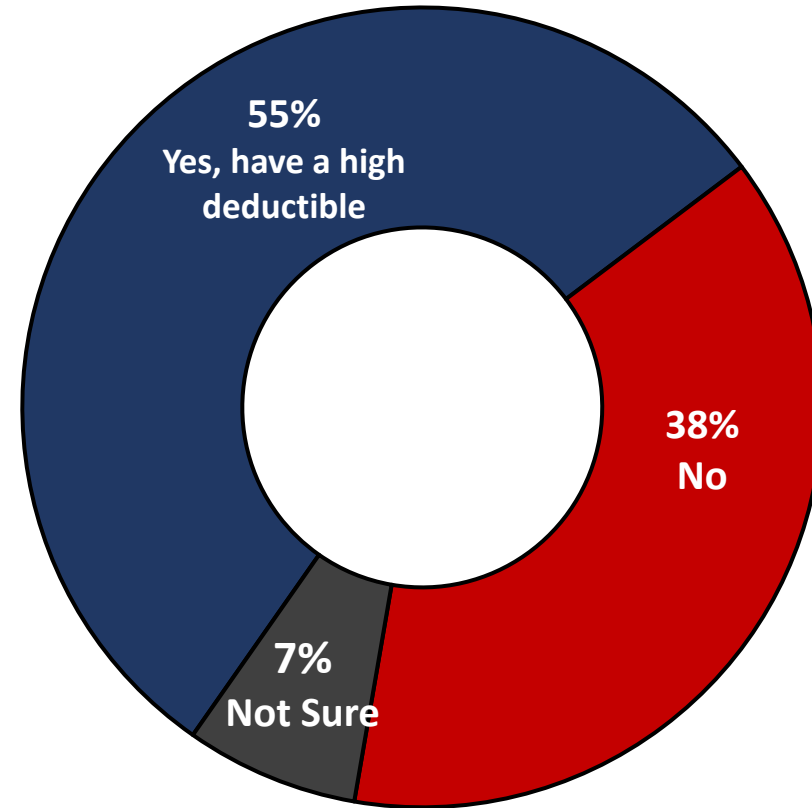
Out-of-pocket health care costs is the biggest problem affecting these patients and their families.

More than half of respondents with private coverage report they or their loved one has a high deductible health plan.

A deductible is the dollar amount that you have to pay out-of-pocket each year for covered health care services and prescription drugs before your health plan starts to pay.

A high deductible health plan is when the amount of the deductible you have to pay before your health plan starts to pay is (\$1,400 or more a year for an individual plan/\$2,800 or more a year for a family plan).

All Patients/Caregivers w/Private Coverage



(Is/was your/your spouse's/your children's) health plan a high deductible health plan?

Those patients and caregivers with lower levels of income & those with higher out-of-pocket Rx costs are more likely to report they have high deductible health plans.

A deductible is the dollar amount that you have to pay out-of-pocket each year for covered health care services and prescription drugs before your health plan starts to pay.

A high deductible health plan is when the amount of the deductible you have to pay before your health plan starts to pay is (\$1,400 or more a year for an individual plan/\$2,800 or more a year for a family plan).

<i>Among Those w/Private Insurance by Income and the Monthly \$ Amount Spend on Rx</i>	% Yes, Have High Deductible Plan
Income	
Under \$40K	69%
\$40K-\$80K	52%
\$80K+	51%
Monthly Amount Spend on Rx	
\$50 or Less	51%
\$51-100	52%
\$101-200	49%
\$201+	67%

Out-of-pocket health care costs is overwhelmingly the most important health care problem for these patients and caregivers.

Most Important Health Care Problems Ranked By Combined 1st-2nd Choices

	1 st Choice	Combined 1 st -2 nd Choices
The out-of-pocket costs that you pay for health insurance deductibles and copays for health care services and prescription medicines	58%	83%
The cost of your health insurance premiums	23%	59%
Surprise medical bills for out-of-network care	7%	26%
Your lack of access to health care services	4%	11%
Your lack of access to health insurance	2%	5%
Denial of coverage for treatment or Rx/step therapy	1%	1%
Lack of coverage for alternative therapies	0%	1%
Poor quality of care	0%	1%
Managing symptoms/disease	0%	1%
Health care providers' lack of knowledge about my disease	1%	1%
Lack of access to transportation to care	0%	1%
Lack of time and communication w/ doctors and care team	1%	1%
Limited treatment options	1%	1%
Other	1%	2%

Which two of the following would you say are the most important problems in health care affecting you and your family? Please select the most important and the second most important.

2

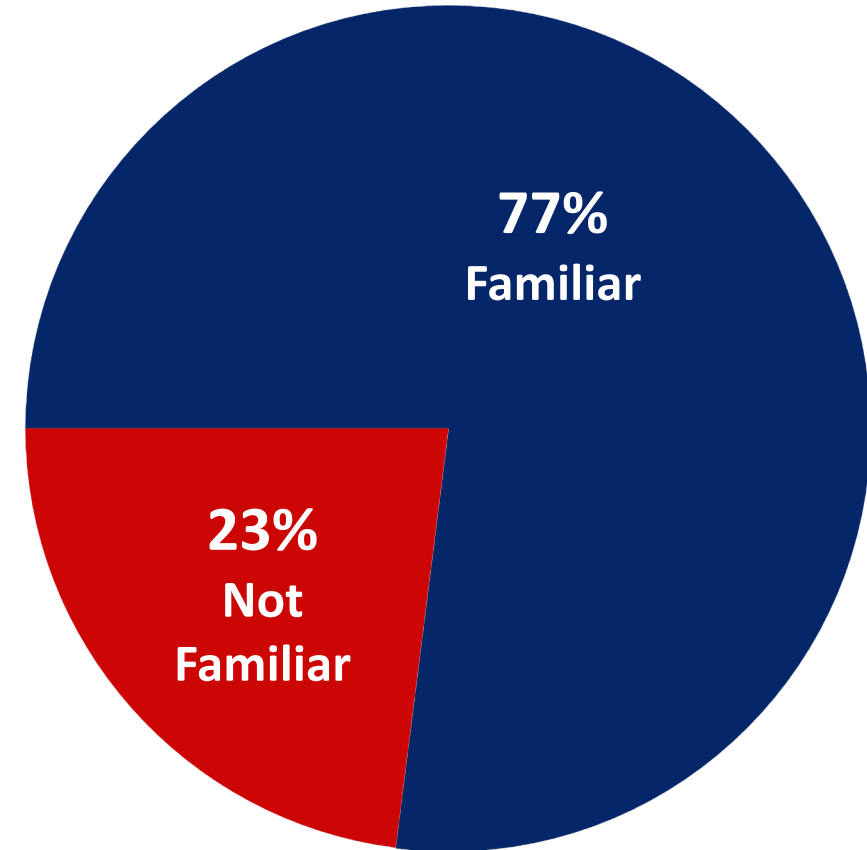
Most patient and caregiver respondents say they are familiar with copay assistance programs.

Roughly two-thirds report they or their loved one are either currently using or have used copay assistance programs for their medications.

Nearly 8 in 10 respondents report they are familiar with copay assistance programs. There are differences in reported levels of familiarity by illness and audience type.

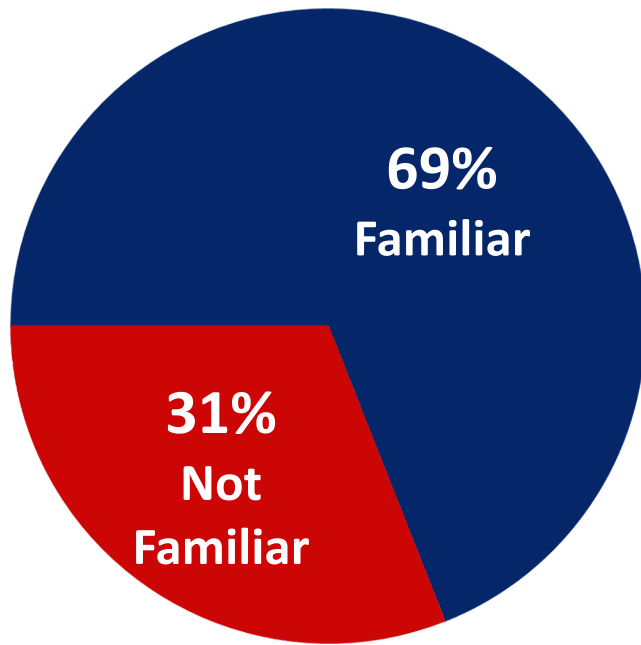
All Patients/Caregivers

Are you familiar or not familiar with copay assistance programs, discount cards or savings cards offered by prescription drug manufacturers and non-profit organizations to help patients with chronic health conditions pay for their prescription medications and treatments?

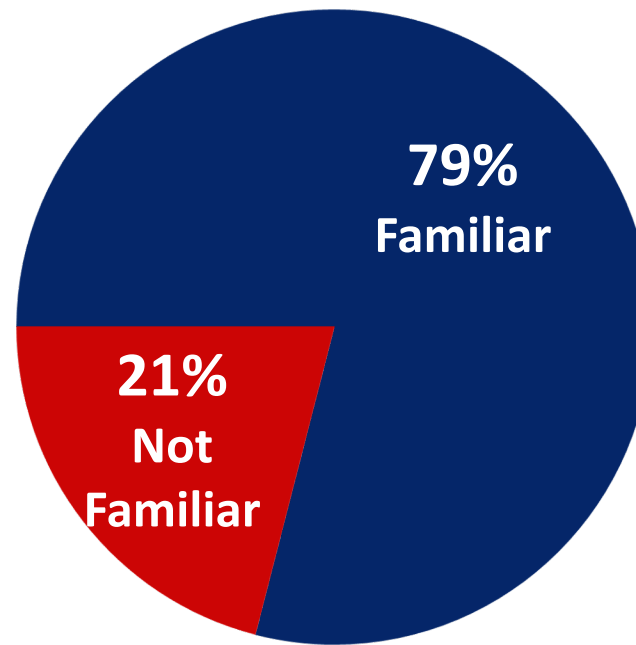


Those patients and caregivers with lower levels of income report having less familiarity with copay assistance programs.

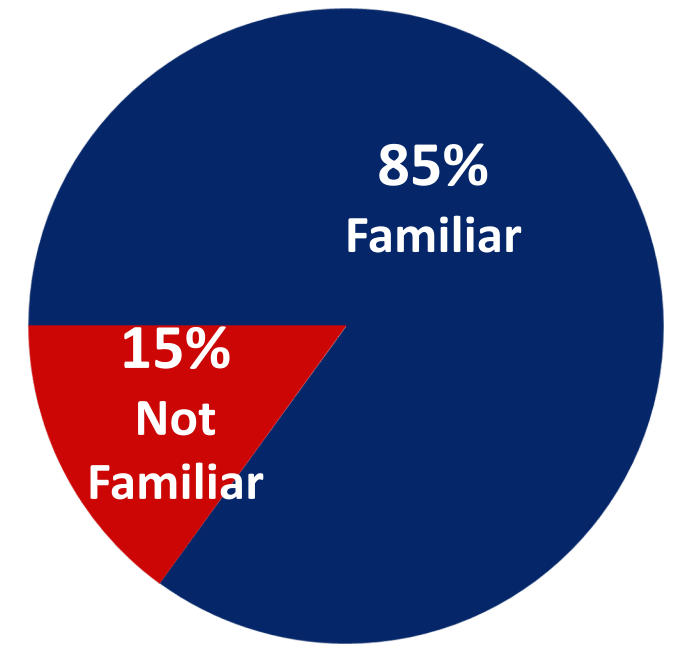
Familiar or Not Familiar with Copay Assistance Programs by Income



Under \$40K




\$40K-\$80K



\$80K+

To ensure everyone in the survey had a basic understanding of copay assistance programs we provided them with the following definition:



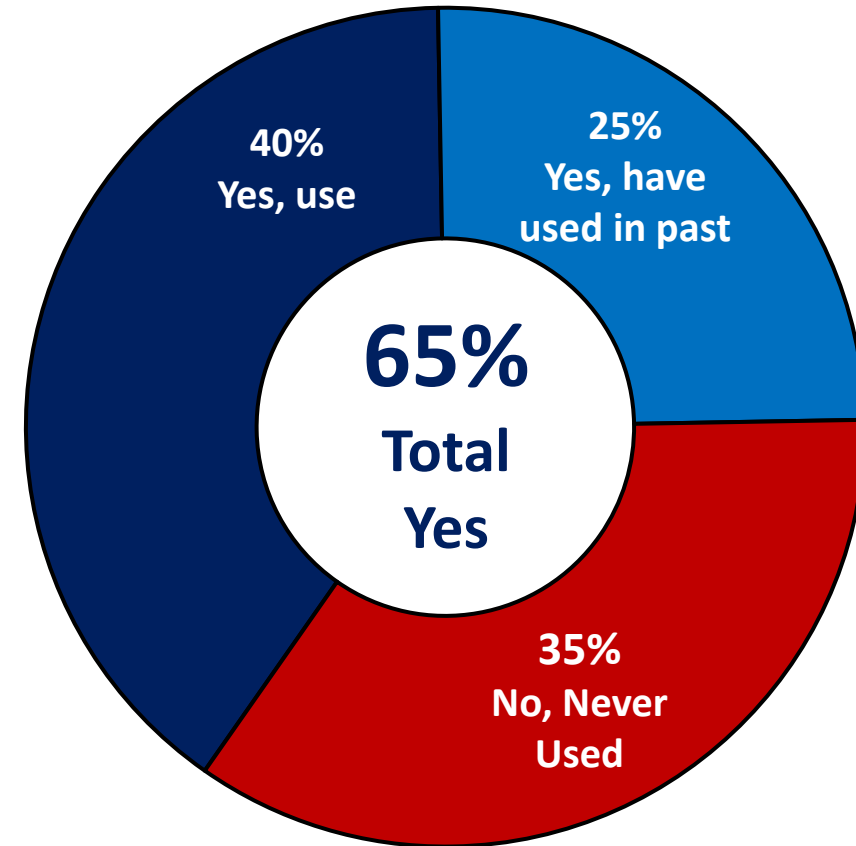
Thinking about copay assistance programs and just to ensure everyone taking the survey has the same information...

Many patients requiring advanced cancer care or ongoing treatments for chronic diseases receive financial assistance from drug manufacturers and non-profit organizations in the form of copay assistance programs, discount cards or savings cards. These help patients pay their out-of-pocket costs (such as deductibles, copays, etc.) for their prescription medications and treatments.

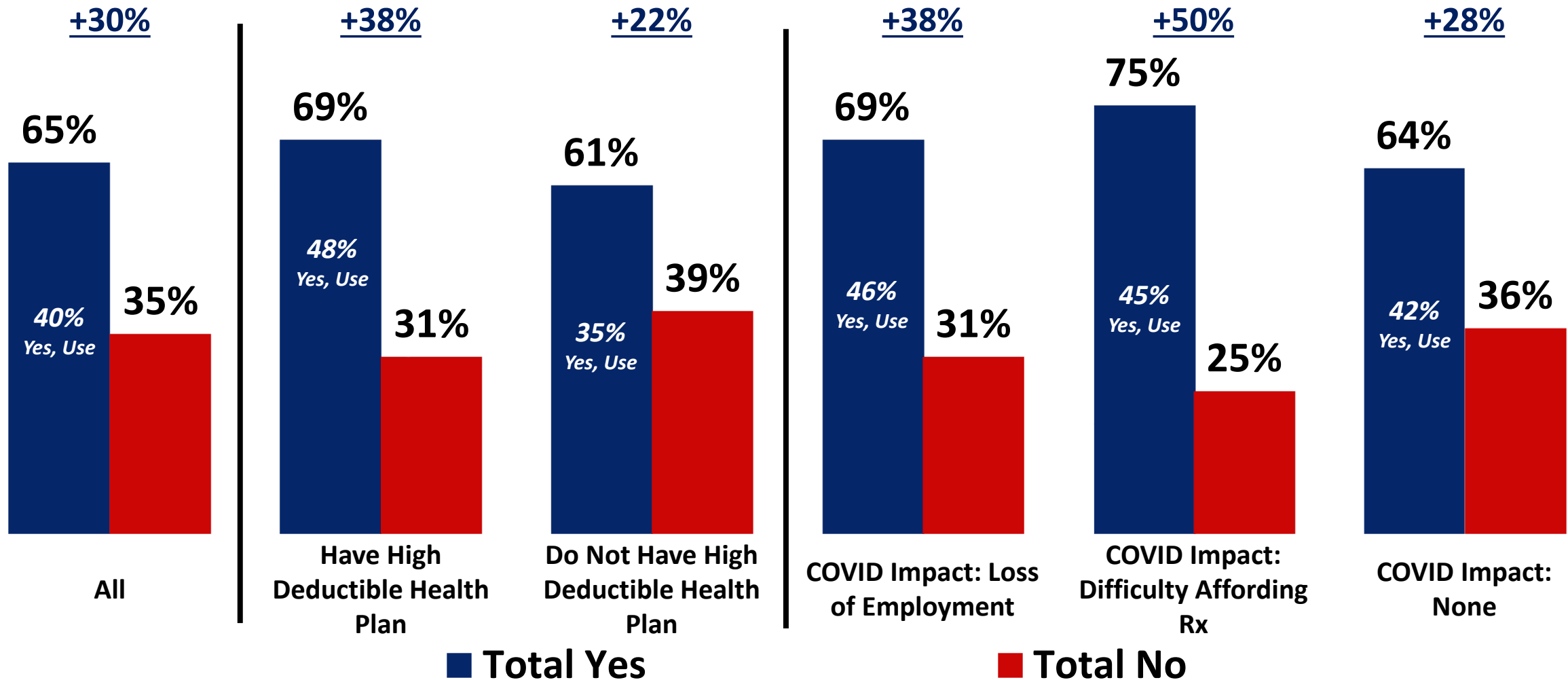
Roughly two-thirds of respondents' report either currently using or having used copay assistance programs for their medications or treatments.

All Patients/Caregivers

Do (you/your spouse/your child) use or have (you/your spouse/your child) ever used any copay assistance programs, discount cards, or savings cards that are provided by prescription drug manufacturers or non-profit organizations to help with out-of-pocket costs (such as deductibles, copays, etc.) for prescription medications or treatments?



Reported usage rates of copay assistance programs is higher among those with high deductible health plans and those who have lost their job or had difficulty affording their Rx because of COVID-19.



Patient & Caregivers Stories: Overall Summary of Their Experiences w/Copay Assistance Programs

What stories would you like to share about your experiences with either copay assistance programs, discount cards or savings cards or not being able to afford chronic health condition prescription medicines or treatments?

These patient and caregiver stories emphasize just how essential copay assistance is in helping them afford their medications and treatments. They say...

- **They would not be able to afford their treatments and medications without the copay assistance.**
- **Copay assistance has saved their lives.**
- **Their medications and treatments are very costly.**
- **Medicare does not sufficiently cover prescription costs leaving the patients and their family members in a massive amount of debt or that they have fears of debt in the future.**
- **High deductible health plans for some are the only option they have for health coverage and copay assistance helps out greatly with being able to afford their medication.**

In the space below, please write down any other stories you would like to share about your experiences with either copay assistance programs, discount cards or savings cards or not being able to afford chronic health condition prescription medicines or treatments.

3

Nearly half of respondents (46%) say they or someone in their immediate household has not been able to afford their out-of-pocket costs in the past year.

Nearly half of respondents say they or someone in their immediate household has not been able to afford their out-of-pocket costs in the past year.

Listed below are some things people have experienced in health care, for each one, please record if you have experienced this personally in the past year, if someone living in your household or an immediate family member has experienced this in the past year, both you and someone in your household or an immediate family member have experience this in the past year, or if no, this does not apply.

Ranked by % Total Yes, Experienced Past Year

	Total Yes, Experienced Past Year	
Not been able to afford the out-of-pocket costs of the health insurance copay (either a fixed copay fee or a percentage of the costs for health care services owed by the patient)	46%	} Combined Total Yes, Experienced Past Year 49%
Not been able to afford the monthly health insurance premium	23%	

4

Two in ten respondents (20%) who use copay assistance programs report they have not been able to afford their medications or treatments because their assistance ran out.

Those sub-groups most likely to have their copay assistance run out are respondents with lower levels of income, people of color, younger women, and those who have been negatively impacted by CV-19.

Among Those Who Use Copay Assistance

Yes, Have Not Been Able to Afford Out-of-Pocket Costs for Rx Because Copay Assistance Ran Out

20%

**Top Sub-Groups:
Yes, Not Able to Afford Rx Copay Assistance Ran Out (20%)**

Difficultly Affording Rx Due to COVID	43%
People of Color	33%
HH Income Under \$40K	32%
Spend \$201+ on Rx Monthly	31%
Able to Pay \$50 or Less Monthly Without Assistance	31%
Unable to Afford Out of Pocket Costs & Premiums Past Year	30%
Lost Job Due to COVID	29%
Have High Deductible Plan: Not Sure	25%
Unable to Get Treatment Due to COVID	25%
Women Ages 18-59	24%
West Region	24%

Thinking about copay assistance programs, discount cards or savings cards that (you/your spouse/your children) use or have used to help with out-of-pocket costs (such as deductibles, copays, etc.) for prescription medications or treatments... Have (you/your spouse/your children) not been able to afford the out-of-pocket costs (either deductible or copays) for prescription medications or treatments because the copay assistance program, discount card, or savings card ran out?

5

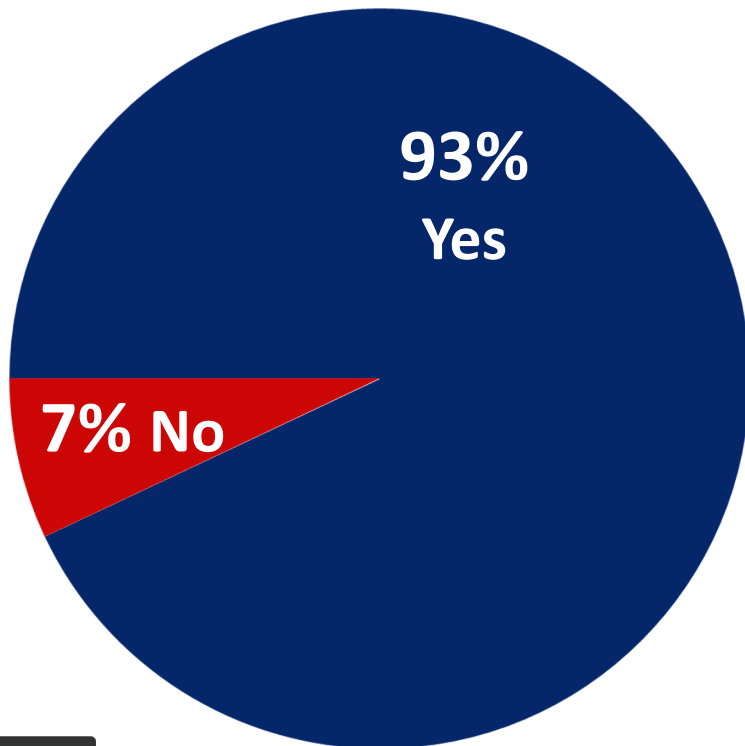
Nearly all patients and caregivers (93%) say the federal government should require that health insurers and pharmacies have to apply copay assistance toward a patient's out-of-pocket costs.

There is overwhelmingly support for the federal government requiring copay assistance be applied to patients' out-of-pocket costs among patients, caregivers, and voters.

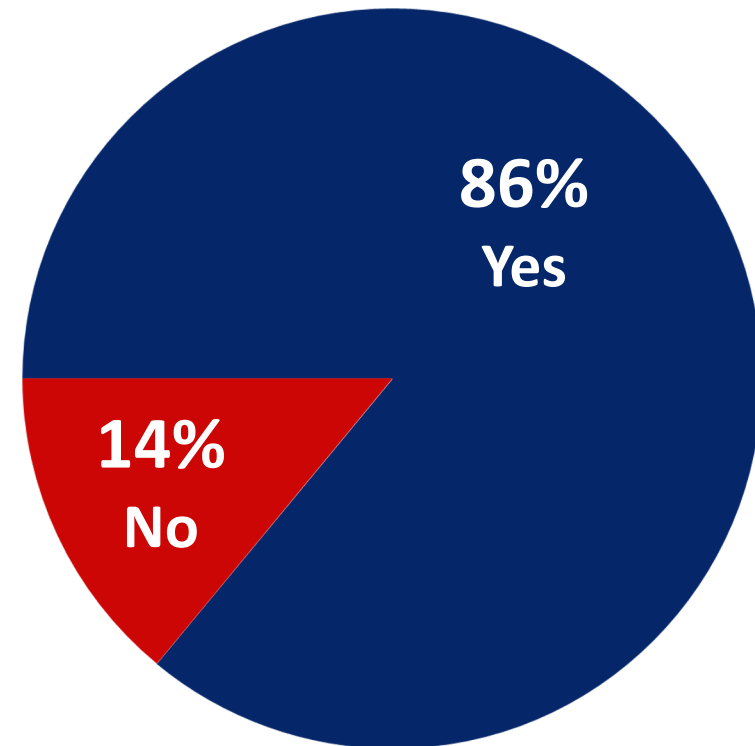
Today, health insurance companies and pharmacies do not have to apply the financial assistance provided by prescription drug manufacturers and non-profit organizations toward a patient's out-of-pocket costs.

Do you think the federal government should require that health insurance companies and pharmacies have to apply this financial assistance toward a patient's out-of-pocket costs (such as their deductible, copays, etc.)?

All Patients/Caregivers



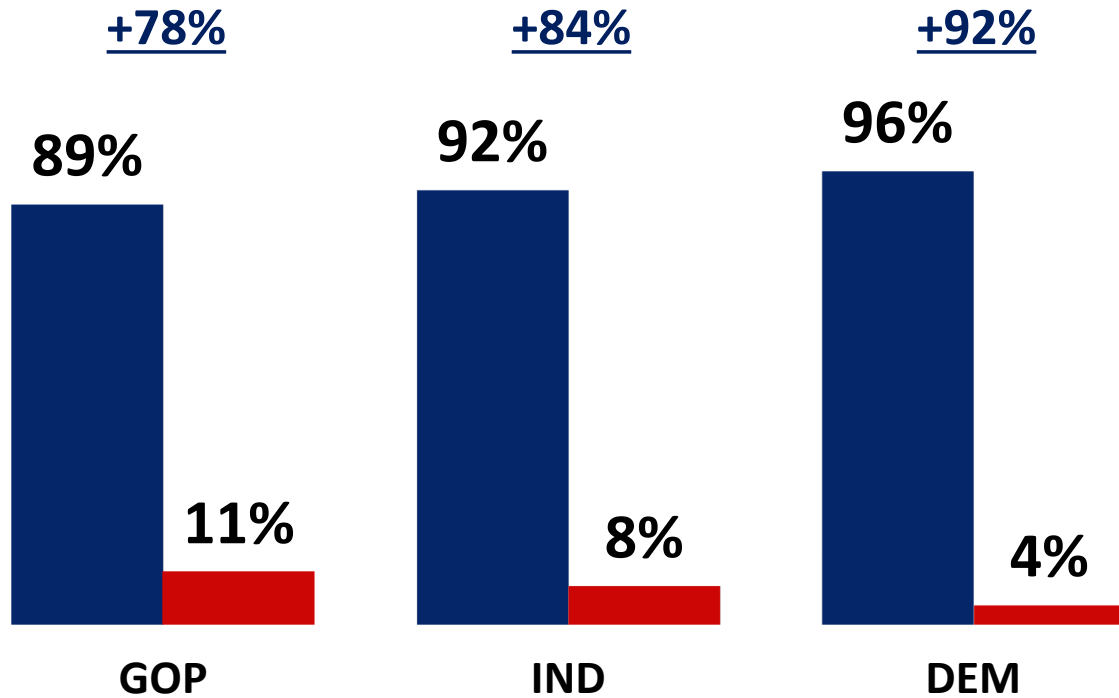
All Voters September 2020



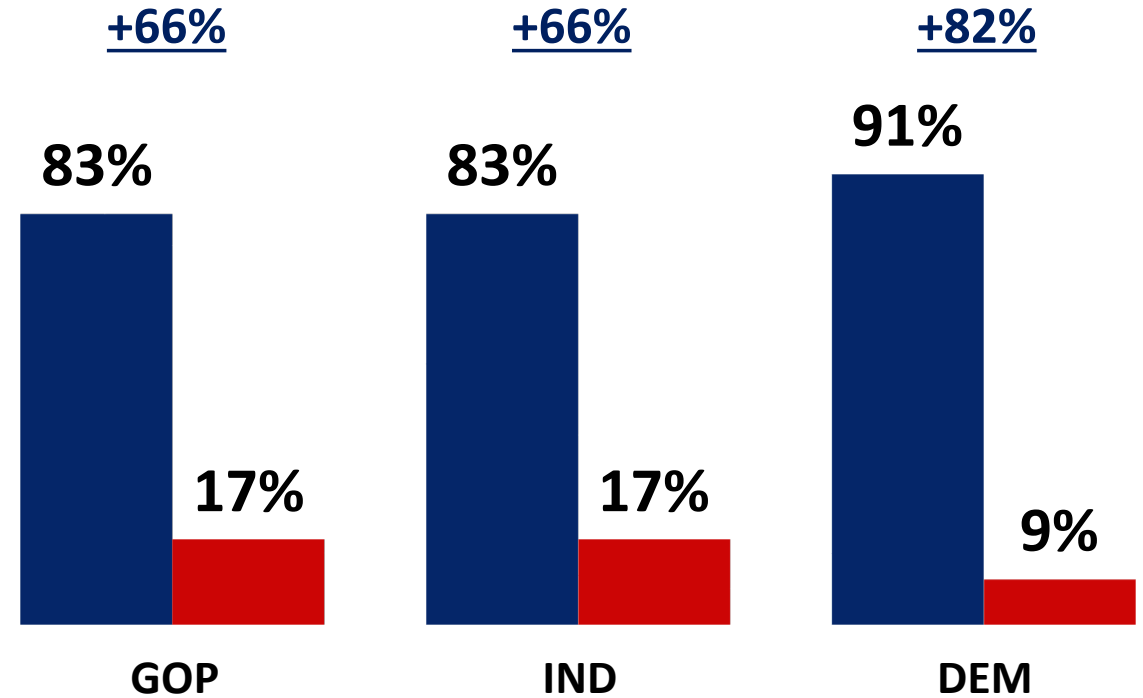
There is significant support across parties for having the federal government require copay assistance be applied toward patients' out-of-pocket costs.

Today, health insurance companies and pharmacies do not have to apply the financial assistance provided by prescription drug manufacturers and non-profit organizations toward a patient's out-of-pocket costs. Do you think the federal government should require that health insurance companies and pharmacies have to apply this financial assistance toward a patient's out-of-pocket costs (such as their deductible, copays, etc.)?

All Patients/Caregivers



All Voters September 2020



■ Total Yes ■ Total No

■ Total Yes ■ Total No

6

Patients and caregivers believe there are significant negative consequences that will happen if the federal government does not require that copay assistance be applied toward patients' out-of-pocket costs.

Respondents believe the impact of not requiring insurers to do this will be much higher out-of-pocket costs, patients not being able to afford their Rx and would result in patients skipping or stopping their treatments/Rx.

<i>Ranked by % Total Happen</i>	Total Happen	Total Not Happen	Not Sure
It would significantly increase chronic disease patients' out-of-pocket costs	85%	3%	12%
Many chronic disease patients would no longer be able to afford their treatments or medications	87%	3%	10%
It would result in many chronic disease patients skipping their treatments or medications	85%	5%	10%
It would result in many chronic disease patients stopping their treatments or medications altogether	80%	8%	12%
Drug manufacturers and non-profit organizations would stop offering these financial assistance programs to chronic disease patients	61%	15%	24%

Listed below are some things people have said may or may not happen if the financial assistance provided by prescription drug manufacturers and non-profit organizations are not counted towards a patient's out-of-pocket costs. Please record how likely you think this would be to happen.

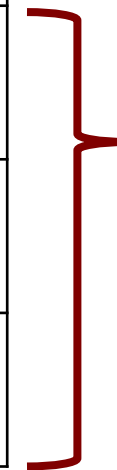
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6 in 10 patients and caregivers say they would have extreme difficulty affording their treatments and medications without copay assistance programs being applied to their out-of-pocket costs.

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If the financial assistance provided by drug manufacturers and non-profit organizations is not counted by health insurance companies and pharmacies toward a patient's out-of-pocket costs, which of the following best describes what you would need to do to afford chronic health condition's prescription medications or treatments?

	All Patients/Caregivers
I am financially stable. I would be able to afford the medications or treatments.	15%
I would have to deplete some of my savings in order to afford the medications or treatments.	22%
I would have to deplete all of my savings in order to afford the medications or treatments.	11%
I would have to take on credit card debt in order to afford the medications or treatments.	16%
There is no way I could access the medications or treatments without financial assistance.	34%



**Total: No Way
Could Access
Rx/Deplete All
Savings/Take on
Credit Card Debt**

60%

**Note: 1% Patients & Caregivers said Other*

What you would need to do to afford chronic health condition's prescription medications or treatments if copay assistance does not count – by Income:

	Income Under \$40K	Income: \$40K-\$80K	Income \$80K+
I am financially stable, I would be able to afford the medications or treatments.	3%	12%	23%
I would have to deplete some of my savings in order to afford the medications or treatments.	10%	25%	26%
Total: No Way Could Access Rx/Deplete All Savings/Take on Credit Card Debt	85%	60%	50%
I would have to deplete all of my savings in order to afford the medications or treatments.	8%	10%	14%
I would have to take on credit card debt in order to afford the medications or treatments.	12%	19%	18%
There is no way I could access the medications or treatments without financial assistance.	65%	31%	18%

If the financial assistance provided by drug manufacturers and non-profit organizations is not counted by health insurance companies and pharmacies toward a patient's out-of-pocket costs, which of the following best describes what you would need to do to afford chronic health condition's prescription medications or treatments?



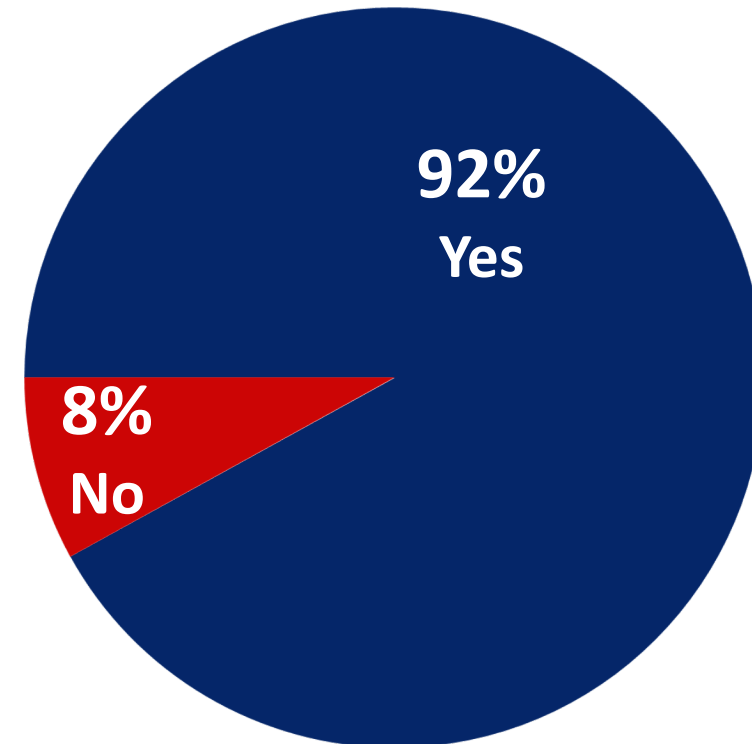
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All Patients/Caregivers

Today, prescription drug manufacturers are not allowed to provide people on Medicare with copay assistance programs, discount cards or savings cards to help with their out-of-pocket costs for their prescription medications.

Do you think the federal government should allow prescription drug manufacturers to provide this type of assistance to people on Medicare?



9

Roughly one in four respondents (24%) has not been able to see their doctor for a health concern because of COVID-19.

More than 4 in 10 patients and caregivers report having been negatively impacted by COVID-19.

<i>Impact of Coronavirus</i>	All Patients/Caregivers
Total Yes, Experienced At Least One of These	44%
You have not been able to see your doctor for a health concern	24%
Your wages or salary have been cut	12%
You have had difficulty affording your prescription medications or treatments	11%
Your work hours have been reduced	10%
You have not been able to receive treatments for your illness	9%
You have lost your job	7%
You have been furloughed from your job	3%
You have lost your health insurance coverage	3%
You contracted COVID/lost someone to COVID	1%
I have had delays in my care/treatment	1%
I/My spouse was unable to find job	1%
My spouse lost their job	0%
I am working more without being paid more	0%
I have seen my doctor only through telemedicine	0%
Other	1%

Which of these, if any, describes the impact the coronavirus has had on you? Please select all that apply.



PUBLIC OPINION STRATEGIES

turning questions into answers

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