

National Patient & Caregiver Survey: COVID-19 Has Exacerbated Treatment Affordability Challenges & Health Inequities for Vulnerable Americans Who Rely on Copay Assistance to Access Their Medications

Urgent Federal Action is Needed to Ensure Health Plans Count the Value of Copay Assistance for Patients to Improve Affordability, Health Equity & Patient Adherence Amid a Global Pandemic

WASHINGTON, D.C., MAY 19, 2021 – The National Hemophilia Foundation (NHF) today, in conjunction with the [American Kidney Fund \(AKF\)](#), [Arthritis Foundation](#), and [American Autoimmune Related Diseases Association \(AARDA\)](#), released findings from a new national online survey of patients and caregivers that illustrates the alarming challenges that many patients across the country – including those in vulnerable and underserved communities– are experiencing in affording and accessing necessary prescription medications during the COVID-19 pandemic. The national survey, *Patients & Family Caregivers: Prescription Drug Affordability Challenges During COVID-19*, was conducted to better understand patient and caregiver experiences with copay assistance programs and found that 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. Of those who reported being unable to afford their medications or treatments because their copay assistance ran out, one in three (33%) was a person of color and more than four in ten (43%) reported difficulty affording their prescription(s) due to COVID-19. More than nine out of 10 patients and caregivers surveyed (93%) said the federal government should require health plans and pharmacies to count the value of copay assistance programs towards patient out-of-pocket costs.

“The COVID-19 pandemic has exposed deep health inequities and treatment affordability challenges that exist within our healthcare system and made clear how much patient communities rely on copay assistance to afford, access, and adhere to their medications to manage their health,” said Kollet Koulianos, Senior Director of Payer Relations for the National Hemophilia Foundation (NHF). “The Administration and Congress should require health plans in the commercial market to count the value of copay assistance toward patient cost-sharing requirements, a simple solution that would protect already vulnerable patients and help them afford their prescriptions.”

A number of key findings in the survey illustrate how the COVID-19 pandemic has exacerbated health disparities and treatment affordability challenges for vulnerable and underserved populations, and that broad support exists for policy that ensures health plans count the value of copay assistance towards patient out-of-pocket costs:

- **Patients Have Experienced Affordability Challenges During COVID-19.** 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.
- **People of Color Disproportionately Experience Affordability Issues.** Of those who reported being unable to afford their medications or treatments because their copay assistance ran out, one in three (33%) was a person of color.
- **Broad Support Exists to Count the Value of Copay Assistance Towards Patient Out-of-Pocket Costs.** Ninety-three percent of survey respondents say the federal government should

require health insurers and pharmacies to apply copay assistance toward patient out-of-pocket cost responsibilities. A separate [NHF survey](#) found that 86 percent of all registered voters believe the government should require copay assistance to be applied to a patient's out-of-pocket costs.

- **A Majority of Patients Rely on Copay Assistance.** Sixty-five percent of respondents reported either currently using or having used copay assistance programs for their medications or treatments. Six 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.
- **Patient Costs are Increasing Through High Deductibles.** More than half of respondents with private health insurance coverage (55%) report they or their loved one has a high deductible health plan (HDHP). Nearly seven in ten (69%) individuals with an income under \$40,000/year who have private coverage report they or a loved one have a high deductible health plan.

More frequently, health insurers and pharmacy benefit managers (PBMs) are implementing policies that don't count the value of copay assistance towards a patient's annual deductible or out-of-pocket cost sharing responsibility. Sometimes referred to as a copay accumulator adjustment programs, these policies allow PBMs and health insurers to keep available copay assistance, received on behalf of a patient, then "double-dip" by making the patient pay it again. According to data from the AIDS Institute, in 32 states at least 2/3 of plans include a copay accumulator policy. In 14 states, every plan includes a copay accumulator policy.

For many this creates an untenable burden and results in treatment abandonment, which can certainly lead to poorer health outcomes and increase the overall healthcare burden; by accelerating the disease progression, increasing ER visits and hospitalizations and in many cases affect their ability to work and function.

"Amid the health and economic challenges of COVID-19, rising insurance premiums, and the expansion of high-deductible health plans, patients are more frequently bearing the burden of higher out-of-pocket costs for their healthcare to the benefit of insurers," said Koulianos. "This is exactly why the federal government should require health insurance companies and pharmacy benefit managers (PBMs) to count the value of all copay assistance programs towards patient cost-sharing requirements."

To date, eight states and Puerto Rico have passed laws prohibiting policies from not counting the value of copay assistance towards patient cost-sharing responsibilities, but the federal government has taken an inconsistent approach to the use of copay accumulator policies in the annual HHS Notice of Benefit and Payment Parameters (NBPP), confusing patients and exposing them to the health and financial consequences of these insurance programs.

In March, U.S. Reps. Donald McEachin (VA-04) and Rodney Davis (IL-13) lead a bipartisan [letter](#) to President Joe Biden asking him to reverse the copay accumulator policy change included in the 2021 Notice of Benefit and Payment Parameters (NBPP), adopted by the previous administration. More than 55 bipartisan members of Congress signed onto the letter, which was supported by members of the *All Copays Count Coalition (ACCC)*, including the National Hemophilia Foundation (NHF), AIDS Institute, Arthritis Foundation, American Kidney Fund (AKF), Cancer Support Community (CSC), National Multiple Sclerosis (MS) Society, and more than 60 other advocacy organizations.



“The National Hemophilia Foundation commends Rep. McEachin, Rep. Davis, and those members of Congress who have called on the Biden administration to protect patients from these harmful insurance policies,” said Koulianos.

The survey included responses representing more than 750 patients with at least one serious illness and was fielded by [Public Opinion Strategies \(POS\)](#), a leading national political and public affairs research firm.

About the National Hemophilia Foundation (NHF)

The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research. Established in 1948, the National Hemophilia Foundation has chapters throughout the country. Its programs and initiatives are made possible through the generosity of individuals, corporations, and foundations as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC). Learn more at Hemophilia.org.

About Public Opinion Strategies (POS)

Public Opinion Strategies is a national political and public affairs research firm. Founded in 1991, POS has conducted over 10 million interviews with voters and consumers in all 50 states and over two dozen foreign countries. The POS political client base includes eleven U.S. senators, six governors, 44 members of Congress, and numerous state legislative caucuses. POS is also involved in complex public policy battles, working with industry coalitions, government entities, and private companies. Learn more at POS.org.

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