

# Patient Experiences With Out-of-Pocket Medication Expenses

Access to medically necessary healthcare is critical for successful patient outcomes, yet access is often impeded or blocked entirely by cost sharing. Despite its value as a tool to limit discretionary healthcare spending, cost sharing can create insurmountable barriers between patients and medications, diagnostic tests, office visits, surgery and other needed services. There are significant concerns that cost sharing limits access to medically necessary treatment for seriously ill and economically vulnerable patients and families.

This *Issue Brief* examines results of a 2017 survey that was designed to learn more about the characteristics of people who need financial assistance to cover the out-of-pocket (OOP) costs of their prescription medications, the benefits to patients who are able to secure this assistance and the consequences for those who are not.

## PAN'S POSITION ON COST SHARING AND ACCESS TO PRESCRIPTION MEDICATIONS

The Patient Access Network Foundation believes that cost sharing should not prevent anyone from obtaining medically necessary treatment.

## Out-of-Pocket Medication Costs Are a Major Challenge for Many Americans

The impact of OOP costs for prescription medications is a topic of concern among many stakeholders, but these concerns are especially pronounced among economically vulnerable patients. Research from the Kaiser Family Foundation (KFF) highlights growing numbers of commercially insured people with more than \$1,000 per year in OOP drug expenses, and the disproportionate share of OOP expenses that these people incur. The KFF report showed that between 2004 and 2014, the share of people covered by large employers who had more than \$1,000 in OOP expenses nearly tripled from 1.0% to 2.8%. Although people with more than \$1,000 in OOP drug expenses were less than 3% of all people with commercial

insurance, these individuals incurred 33% of all OOP drug expenses.<sup>1</sup> Similar observations are evident in the Medicare population. Although establishment of Medicare Part D benefits increased access to needed medications and reduced cost burdens for older adults overall,<sup>2,3</sup> there is ample research demonstrating overwhelming OOP burdens for prescription medications among people with cancer, patients who need specialty medications and low-income Medicare beneficiaries.<sup>4,5,6,7,8</sup>

Another KFF report showed that in 2015, 3.6 million Medicare beneficiaries with Part D coverage had OOP drug costs above the catastrophic threshold of \$6,680. Of these, more than 1 million did not have federal low-income subsidies to protect them from high OOP drug costs, and the number of these individuals more than doubled since 2007.<sup>9</sup> Thus, even with Part D coverage, increasing numbers of older adults are exposed to extremely high OOP costs for their medications. OOP costs hinder access to needed treatments for economically vulnerable patients, an important issue that was explored in a previous *PAN Issue Brief*.<sup>10</sup> Recognizing the importance of OOP cost burdens on patients and families, the PAN Foundation conducted a survey to learn more about patients' OOP medication expenses.

## What Were the Goals of PAN's Patient Assistance Survey?

PAN designed a survey to build on existing research about people who are unable to cover the OOP costs for their medications. The survey explored a number of issues including:

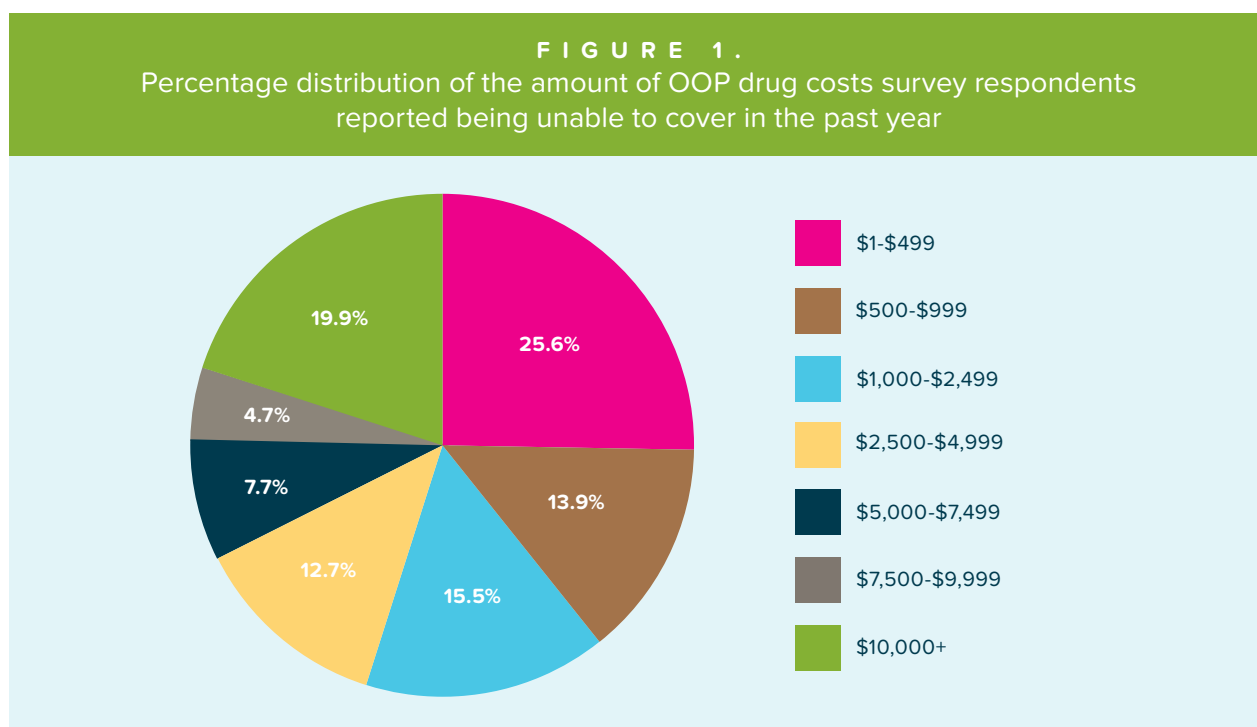
- » How much OOP medication expenses patients are unable to cover
- » Patients' level of concern about several issues linked to OOP medication expenses
- » What proportion of patients seek outside financial assistance for their OOP medication expenses, and how many received this assistance
- » Among patients who received financial assistance for OOP medication expenses:
  - Where did the assistance come from?
  - What proportion of OOP medication expenses were covered by outside assistance?
  - What outcomes are linked to receiving the assistance?
- » Reasons why patients did not seek needed assistance for their OOP medication expenses
- » Among patients who sought financial assistance for OOP medication expenses and did not receive it:
  - What were the reasons why financial assistance was not received?
  - What were the practical outcomes of not receiving needed financial assistance?

## How Was the Survey Conducted?

PAN collaborated with 21 nonprofit advocacy organizations to design, test and implement the Patient Assistance Survey. The instrument was accessed using a live link, and data were delivered directly to a secure database. Collaborating organizations deployed the survey link to their email lists, on their websites, through Twitter and Facebook, and some organizations also delivered the link to their online communities. A “screener” question at the beginning of the survey asked respondents if they were able to pay all of their OOP prescription drug costs in the previous 12 months. Respondents who answered “no” to this question were asked a series of additional questions, including whether they sought outside financial assistance for their OOP prescription drug costs, and the consequences of receiving or not receiving this assistance. PAN’s Patient Assistance survey was conducted from September 1–29, 2017.

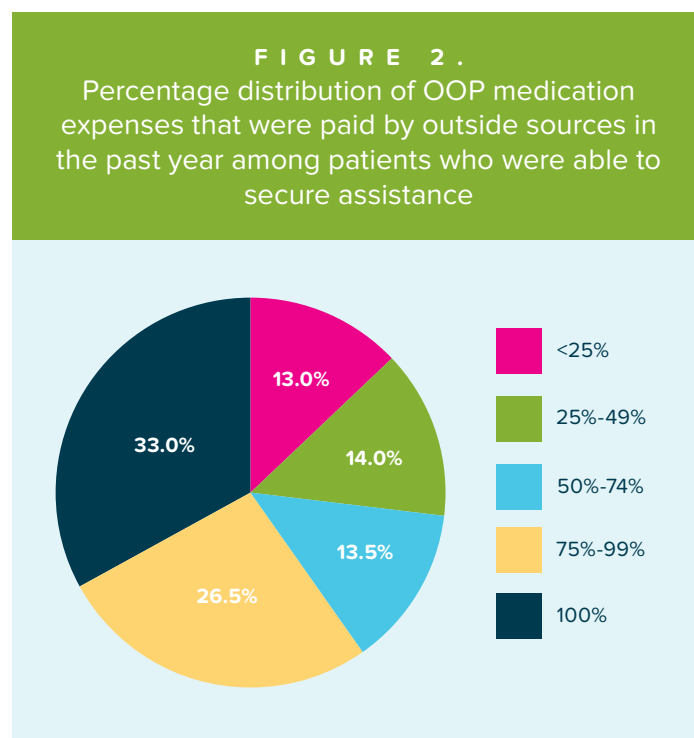
## Who Responded to the Survey?

A total of 1,897 people responded to the survey, and nearly 77% of the sample was female. Nearly 25% of the sample lived alone, and an additional 50% lived in a household with one other person. About 60% of respondents were between 55 and 74 years of age, nearly 56% had annual household income below \$60,000, and 28% had household income below \$30,000.



## What Were Some of the Key Findings?

- » Of the 1,897 respondents, 37% reported being unable to cover the OOP costs for their prescription medications. Of these individuals:
  - 27% were age 65 or older
  - 79% were female
  - Nearly 76% had annual household income below \$60,000
- » A large proportion of patients who were unable to cover their OOP medication expenses reported being “extremely concerned” about key issues related to these costs:
  - 70%: OOP medication costs would cause financial problems in the future
  - 67%: Inability to get financial assistance in the future
  - 64%: OOP medication costs would cause problems for the patient’s family
  - 59%: Inability to cover OOP medication costs over the next 12 months
- » Among people who could not cover their OOP medication costs over the past 12 months:
  - 26%: Unable to cover \$500 or less
  - 32%: Unable to cover \$5,000 or more
  - 20%: Unable to cover \$10,000 or more
- » Almost 78% of patients who were unable to cover their OOP drug costs reported that they sought outside financial assistance to cover these costs, often from multiple sources. Of these patients:
  - About 80% were successful in securing financial support
  - Nearly 38% reported seeking financial assistance from a charitable foundation
  - Nearly 66% sought assistance from a drug company’s assistance program



## What Did the Survey Show About People Who Needed and Received Financial Assistance for Their OOP Medication Costs?

- » About six in 10 patients who needed and received financial assistance reported that 75% or more of their OOP medication expenses were paid with this assistance, and one-third reported that all of their OOP expenses were paid this way.
- » A large proportion of patients who needed and received financial assistance reported that they “strongly agreed” that this assistance was beneficial:
  - 59%: Allowed the patient to continue his or her treatment plan
  - 54%: Helped the patient focus more on his or her health
  - 51%: Reduced stress
  - 50%: Allowed the patient to pay other bills
  - 48%: Allowed the patient to begin treatment quickly

## What Did the Survey Show About People Who Did Not Seek or Receive Needed Assistance?

- » Of patients who reported being unable to cover their OOP drug costs, 22% reported that they did not seek outside assistance to cover these costs.
  - More than half (54%) of these patients reported being unaware that help was available
- » Among patients who needed financial assistance but did not seek it:
  - 32%: Filled some prescriptions but made them last longer by skipping doses
  - 30%: Cut back on household expenses to pay for medications
  - 28%: Used their savings to pay for OOP medication expenses
  - 25%: Did not pay other bills in order to pay for medications
  - 24%: Did not fill prescriptions
- » Among patients who sought financial assistance but were unable to secure it:
  - 43%: Did not start their treatment
  - 37%: Skipped doses or took smaller doses to make the prescription last longer
  - 24%: Accumulated credit card debt and used personal savings to pay for OOP drug costs

## What Are the Strengths and Limitations of PAN's Patient Assistance Survey?

PAN's Patient Assistance Survey has a number of strengths, including its development in collaboration with more than 20 advocacy organizations, its relatively large sample size, its detailed examination of the demographics of people who are unable to cover their OOP medication expenses and the information it provides on reasons why people do not seek assistance and what happens when they do not receive it. The Patient Assistance Survey also has limitations that should be noted. The most important of these limitations is that the survey is not a representative sample of all patients, or all patients who need financial assistance to cover OOP medication costs. Despite this limitation, the data provide important information on a large sample of people who are unable to cover these costs, and this information contributes to a broader discussion about the ongoing challenge to ensure that all Americans have access to medically necessary treatments.

## The PAN Foundation

The PAN Foundation is an independent, national 501 (c)(3) organization dedicated to helping federally and commercially insured people living with life-threatening, chronic and rare diseases with the OOP costs for their prescribed medications. PAN provides the underinsured population access to the healthcare treatments they need to best manage their conditions and focus on improving their quality of life. Since its founding in 2004, PAN has provided nearly 1 million underinsured patients with over \$2.6 billion in financial assistance through more than 60 disease-specific programs.

For more information about this *Issue Brief*, contact Amy Niles, Vice President of External Affairs, at [aniles@panfoundation.org](mailto:aniles@panfoundation.org).

## Supporting Literature

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