



POSITION STATEMENTS

IMPROVING PATIENT ACCESS TO HEALTHCARE

JANUARY 2020

The inability to pay for healthcare is a significant problem even for people who have health insurance. Rising deductibles, premiums, co-pays and coinsurance prevent many people from being able to afford the critical treatment they need. These individuals, in essence, are underinsured; while they may have health insurance coverage, due to unaffordable out-of-pocket costs, they do not necessarily have access to the care and treatment they need.

The PAN Foundation's mission is to help underinsured people with life-threatening, chronic and rare diseases get the medications and treatments they need by assisting with their out-of-pocket costs and advocating for improved access and affordability. The following positions put patients first in our complex healthcare system and can help them access treatment at a price they can afford.

1

Out-of-pocket costs should not prevent individuals with life-threatening, chronic and rare diseases from obtaining their prescribed medications.

High out-of-pocket (OOP) medication costs frequently prevent patients from accessing their prescribed and essential medications. Research demonstrates that patients with serious health conditions who experience high out-of-pocket drug costs are less likely to fill their prescriptions, take longer to start their treatment, and experience increased interruptions and gaps in treatment.^{1,2}

In addition, multiple studies have shown that even a co-pay of \$40 for a medication can cause many patients to opt not to fill their prescriptions.^{3,4}

PAN advocates for policies that help ensure that high OOP costs do not impede access to medically necessary treatments.

2

Within today's healthcare delivery system, charitable patient assistance programs provide a critical safety net for ensuring access to medically necessary treatment.

Charitable patient assistance programs, including those provided by charitable foundations, are a lifeline for patients who have nowhere else to turn for help to cover their out-of-pocket medication expenses. These programs provide financial assistance to eligible underinsured patients, covering out-of-pocket costs associated with prescription medications, including co-payments, deductibles, coinsurance, and in some instances, premium and travel support. Older adults depend primarily on Medicare to cover their health expenses, but more than a quarter of Medicare beneficiaries are underinsured and spend a large share of their income on healthcare expenses, including prescription medications.⁵

Out-of-pocket medication expenses generally increase with the number of chronic illnesses. For millions of older adults, living with multiple health conditions is the norm. In fact, 36 percent of Medicare beneficiaries have four or more health conditions and 15.3 percent have six or more.⁶ Rising out-of-pocket healthcare costs prevent seniors from accessing needed medical treatments, exacerbating the widespread economic insecurity among our nation's older adults.⁷

Many older adults are unable to access and stay on needed medications, especially newer, innovative medications that tend to be more expensive because of high OOP costs.^{1,2}

Until policies ensure our country's most vulnerable patients can access medically necessary treatments, charitable assistance programs and foundations will continue to play a critical role in the healthcare safety net by providing patients with financial support to help afford their OOP costs.

Out-of-pocket costs for prescription medications should be capped by instituting monthly and/or annual limits.

Medicare beneficiaries are the only group of insured people in the U.S. that is not protected by a cap on annual out-of-pocket costs, forcing many to make difficult trade-offs or to forgo treatment altogether.⁸ Some beneficiaries who require expensive medications can incur many thousands of dollars out-of-pocket for their prescriptions in January alone, a pattern that requires them to have enough money early in the year to access their treatment.⁹

A monthly cap on OOP drug costs would help patients better anticipate and plan for their medication expenses throughout the year. An annual cap is another way to protect millions of seniors from high out-of-pocket costs.

In 2017, the most recent year for which claims data is available, 4.9 million Medicare beneficiaries reached the Part D coverage gap.¹⁰

The same year, one million patients with Medicare Part D progressed through the coverage gap and entered the “Catastrophic Coverage Phase,” where they continue to pay the out-of-pocket costs for their needed treatment.¹⁰

PAN advocates for limits on out-of-pocket drug spending for Medicare beneficiaries. A limit on the amount beneficiaries spend OOP each month and/or year on prescription drugs would facilitate access to needed treatments and help beneficiaries predict and plan for these costs throughout the year.



4

Out-of-pocket costs for prescription medications should be spread more evenly throughout the benefit year.

The structure of Medicare Part D prescription drug plans front loads out-of-pocket medication costs early in the benefit year. This can have a devastating impact on patients who face high cost sharing for their medications. Many patients cannot afford large OOP expenses all at once or over a short period of time, but could afford the total expenditure if spread out over time.

A recent study showed that among Medicare beneficiaries with rheumatoid arthritis, multiple sclerosis and chronic myelogenous leukemia, more than half of all out-of-pocket medication costs were incurred in the first three months of the year. For many patients, paying thousands of dollars at the beginning of the year is an enormous hardship.⁹

Commercially insured people enrolled in high-deductible health plans also experience high out-of-pocket costs that can limit access to needed treatment.^{11, 12}

Policymakers, insurers and other stakeholders should modify the structure of public and private insurance plans so that out-of-pocket costs for prescription medications can be spread more evenly over the course of the year, and patients can access and remain on the treatments they need.

5

All conditions should have at least one highly effective innovator drug on a fixed co-payment tier.

Specialty medications typically offer major treatment advances for patients with life-threatening, chronic and rare diseases, reduce the risk of disease progression and costly complications, and improve survival for life-threatening conditions.⁸

For many patients who are prescribed specialty medications, a generic or less-costly alternative is not available. However, specialty medications are often placed on the highest formulary tiers of drug plans, requiring patients to pay coinsurance—a percentage of the drug's cost—which can be as high as 50 percent.

High cost sharing for specialty medications delays initiation of treatment² and increases abandonment of established courses of therapy,¹³ delays between refills¹⁴ and interruptions in treatment.¹ Moreover, cost sharing for specialty medications has a disproportionate adverse impact on low-income patients and creates a treatment environment where the most economically vulnerable patients have the least access to innovative treatments.

Ensuring that all conditions have at least one highly effective, innovative medication placed on a fixed co-pay dollar amount formulary tier is one way to increase access to these treatments and facilitate treatment adherence.

6

The Medicare Part D structure should be modernized to reflect the current prescription drug landscape. Changes to the benefit design should improve access to medications for Medicare Part D beneficiaries.

Between 2007 and 2017, Part D program spending increased from about \$46 billion to about \$80 billion (average annual growth of 5.6 percent). In addition to those taxpayer-financed amounts, in 2017 Part D enrollees paid \$14 billion in premiums and nearly \$17 billion in cost sharing.¹⁵

With the significant growth in spending, policymakers are deliberating over changing the structure of the Medicare Part D benefit, in particular to reduce the financial burden on enrollees.

One such change was included in the Affordable Care Act to phase out the Part D coverage gap or “donut hole” by 2020. Other proposals address harmonizing the drug benefit under Part B and Part D and shifting more of the financial burden for the coverage gap payment percentage from the government to insurers and the pharmaceutical industry.

As these changes are considered, it is imperative that Medicare beneficiaries’ financial burden and access to medication are not negatively impacted.

7

The Medicare Part D Low-Income Subsidy (LIS) program should be modernized to increase enrollment and provide continuity for individuals from one year to the next.

The Medicare Part D LIS program or Extra Help was established in the Medicare Modernization Act of 2003 to help low-income seniors and people with disabilities afford needed medicines. Medicare makes additional payments to plans on behalf of beneficiaries entitled to subsidies based on income (less than 150% of poverty, or certain dollar thresholds for individuals and married couples, and asset levels).¹⁶

Despite outreach efforts, not all eligible beneficiaries have enrolled. Complex application processes and outdated eligibility thresholds have limited participation. In addition, a large number of beneficiaries are required to change plans each year because the premium for their current plan no longer falls below the low-income subsidy level. Changing plans can cause disruption to continuity of care.

The LIS program should be modernized to make eligibility easier to establish, include a larger population of beneficiaries in need, eliminate cost sharing for generics and include specific efforts to ensure all eligible beneficiaries are enrolled and taking advantage of the program.

Public and private health insurance deductibles should not be set at amounts that preclude patients from accessing treatment for life-threatening, chronic and rare diseases.

Although deductibles have long been part of the benefit structure of most commercial health insurance plans, dramatic increases in annual deductibles have prevented many people from accessing and staying on needed treatment.

To control healthcare costs, employers have increasingly turned to high-deductible health plans. People with these plans must pay thousands of dollars in out-of-pocket expenses before their insurance provides coverage. Between 2006 and 2016, the enrollment in high-deductible plans quadrupled from 11.4 to 46.5 percent. In 2017, 13 percent of employers offered these plans as their only option for health insurance.¹⁷

Additional research has found that deductibles are much higher in firms with low-wage workers, a trend that places a greater financial burden on people who can least afford it.¹⁷ High-deductible plans are particularly challenging for people who need newer or innovative medications for which there are no generic or less expensive alternatives. To remain on their medication, these patients must pay most or all of their deductible at the beginning of the year. Many people are unable to handle these upfront costs, choosing instead to abandon their treatment.

The challenges to accessing and remaining on treatment are not unique to people with commercial insurance. For patients who require expensive medications, the Medicare Part D benefit structure also concentrates out-of-pocket drug costs at the beginning of the year, a feature of these plans that has been shown to increase treatment abandonment, delay and interruption.^{1,2,9}

Policymakers and insurers must take steps to mitigate the impact that high, upfront out-of-pocket expenses have on the ability of patients to access and remain on their prescription medications.



Value-based insurance designs (VBID) that increase access to treatment for individuals living with life-threatening, chronic and rare diseases should be encouraged.

Value-based insurance designs (VBID) promote patients' use of high-value care options by changing the cost sharing consumers pay for different care options. Under a VBID approach, treatments that provide high clinical value have reduced or no cost sharing.

The American Medical Association believes that health insurance must provide access to affordable, ongoing care for patients at high risk for serious disease and/or the progression of an existing disease, and it has long supported VBID to align incentives around high-value services.¹⁸

The Centers for Medicare and Medicaid Services also supports VBID, and this is reflected in its implementation of the Medicare Advantage VBID Model. This model offers supplemental benefits or reduced cost sharing to enrollees with certain chronic conditions and focuses on services of highest clinical value to patients. Legislation passed in 2018 includes the expansion of the Center for Medicare and Medicaid Innovation's Medicare Advantage VBID Model to all 50 states.¹⁹

VBID is not only beneficial for patients with common conditions—its principles hold true for all patients, regardless of their health conditions.

The University of Michigan Center for Value-Based Insurance Design advocates for “precision medicine” when it is medically indicated. “By enhancing access to effective therapies when indicated, the application of clinically-nuanced cost sharing commits to established policies that encourage first-line therapies and supports precision medicine initiatives.”²⁰

When a therapy—even an expensive one—is medically indicated and offers high value, VBID benefit designs should facilitate access to treatment for patients.



10

The total out-of-pocket cost of care must be taken into consideration when developing policy solutions to decrease the financial burden of care and treatment for Americans.

For many patients, frequent visits to see primary and specialty providers mean numerous out-of-pocket co-payments and coinsurance obligations. While reducing out-of-pocket expenses for prescription therapies is important, it is equally important that patients have affordable access to the other healthcare they need.

For many patients, co-payments and coinsurance for primary and specialty care can preclude them from being able to see a healthcare provider. Patients sometimes have to choose between seeing their provider or getting their prescription filled; this is a choice no patient should have to make.

Patients need to be able to afford to visit their primary care or specialty providers, get a new or refilled prescription from the pharmacy and access any necessary diagnostic or other healthcare services, such as physical therapy or radiation treatment.

Policyholders should consider the total cost of care when developing policy solutions to decrease the financial burden of care and treatment for Americans.

11

Co-pay accumulators or similar programs lead to greater out-of-pocket costs for individuals with life-threatening, chronic and rare diseases and should be prohibited.

Drug manufacturer co-pay cards and coupons help underinsured patients with commercial insurance afford their prescription medications. Patients use these cards and coupons to pay for their deductibles, co-pays or coinsurance, reducing their total out-of-pocket drug costs.

Since deductibles and coinsurance have increased dramatically in recent years, co-payment cards and coupons have become even more important, particularly for economically vulnerable patients. The average annual deductible for people with employer-sponsored health insurance has increased 36 percent since 2012, and 100 percent since 2009. There has also been a marked increase in the proportion of employees enrolled in high-deductible health plans with a savings option, from 20 percent in 2014 to 30 percent in 2019.²¹

Commercial insurance co-pay accumulator policies prevent patients from using co-pay cards and coupons to pay down their deductibles, resulting in a much larger overall OOP financial burden for them as the payments do not count toward meeting their deductible. As such, meeting annual deductibles takes longer and requires patients to pay more OOP for longer into the plan year. This is especially challenging for lower-income patients who require expensive medications and those enrolled in high-deductible health plans.

Prohibiting co-pay accumulator programs will allow patients to use manufacturer co-pay cards and coupons in a manner that helps them access the therapies they need and make progress toward meeting their annual deductible.

REFERENCES

- ¹Doshi JA, Hu T, Li P, Pettit AR, Yu X, Blum M. Specialty Tier-Level Cost Sharing and Biologic Agent Use in the Medicare Part D Initial Coverage Period Among Beneficiaries With Rheumatoid Arthritis. *Arthritis Care Res (Hoboken)*. 2016 Nov;68(11):1624-1630.
- ²Doshi JA, Li P, Huo H, Pettit AR, Kumar R, Weiss BM, Huntington SF. High Cost Sharing and Specialty Drug Initiation Under Medicare Part D: A Case Study in Patients with Newly Diagnosed Chronic Myeloid Leukemia. *Am J Manag Care*. 2016 Mar;22(4 Suppl):s78-86.
- ³IQVIA. Patient Affordability Part Two. Implications for Patient Behavior and Therapy Consumption. Available at: <https://www.iqvia.com/locations/united-states/library/case-studies/patient-affordability-part-two>.
- ⁴Shrank WH, Choudhry NK, Fischer MA, Avorn J, Powell M, Schneeweiss S, Liberman JN, Dollear T, Brennan TA, Brookhart MA. The epidemiology of prescriptions abandoned at the pharmacy. *Ann Intern Med*. 2010;153(10):633-40.
- ⁵Schoen C, Solis-Roman C. On Medicare But At Risk: A State-Level Analysis of Beneficiaries Who Are Underinsured or Facing High Total Cost Burdens. Available at: <https://www.commonwealthfund.org/publications/issue-briefs/2016/may/medicare-risk-state-level-analysis-beneficiaries-who-are>.
- ⁶Centers for Medicare and Medicaid Services. Multiple Chronic Conditions. Available at: https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/MCC_Main.html.
- ⁷National Council on Aging. Economic Security for Older Adults. Available at: <https://www.ncoa.org/news/resources-for-reporters/get-the-facts/economic-security-facts/>.
- ⁸Doshi JA, Pettit AR, Li P. Addressing Out-Of-Pocket Specialty Drug Costs In Medicare Part D: The Good, The Bad, The Ugly, And The Ignored. Available at: <https://www.healthaffairs.org/doi/10.1377/hblog20180724.734269/full/>.
- ⁹Doshi JA, Li P, Pettit AR, Dougherty JS, Flint A, Ladage VP. Reducing Out-of-Pocket Cost Barriers to Specialty Drug Use Under Medicare Part D: Addressing the Problem of "Too Much Too Soon". *Am J Manag Care*. 2017;23(3 Suppl):S39-S45.
- ¹⁰Kaiser Family Foundation. How Will The Medicare Part D Benefit Change Under Current Law and Leading Proposals? Available at: <https://www.kff.org/medicare/issue-brief/how-will-the-medicare-part-d-benefit-change-under-current-law-and-leading-proposals/>.
- ¹¹Miller GE, Vistnes JP, Rohde F, Keenan PS. High-Deductible Health Plan Enrollment Increased From 2006 To 2016, Employer-Funded Accounts Grew In Largest Firms. *Health Affairs*. 2018;37(8):1231-1237.
- ¹²Agarwal R, Mazurenko O, Menachemi N. High-Deductible Health Plans Reduce Health Care Cost And Utilization, Including Use Of Needed Preventive Services. *Health Affairs*. 2017;36(10):1762-1768.
- ¹³Doshi JA, Li P, Huo H, Pettit AR, Armstrong KA. Association of Patient Out-of-Pocket Costs With Prescription Abandonment and Delay in Fills of Novel Oral Anticancer Agents. *Journal of Clinical Oncology* 2018;(36)5:476-482.
- ¹⁴Olszewski AJ, Dusetzina SB, Eaton CB, Davidoff AJ, Trivedi AN. Subsidies for Oral Chemotherapy and Use of Immunomodulatory Drugs Among Medicare Beneficiaries With Myeloma. *Journal of Clinical Oncology* 2017;35(29): 3306-3314.
- ¹⁵Statement of James E. Mathews, Ph.D. Executive Director Medicare Payment Advisory Commission Before the Subcommittee on Health Committee on Energy and Commerce U.S. House of Representatives, April 30, 2019. Available at: http://www.medpac.gov/docs/default-source/congressional-testimony/04_30_2019_medpac_drug_testimony_for_eandc.pdf?sfvrsn=0. Accessed 13 Sept. 2019.
- ¹⁶Kaiser Family Foundation. An Overview of the Medicare Part D Prescription Drug Benefit. Oct 12, 2018. Available at: <http://files.kff.org/attachment/Fact-Sheet-An-Overview-of-the-Medicare-Part-D-Prescription-Drug-Benefit> Accessed 13 Sept, 2019.
- ¹⁷Claxton G, Rae M, Long M, Damico A, Foster G, Whitmore H. Employer Health Benefits 2017 Annual Survey. Available at: <http://files.kff.org/attachment/Report-Employer-Health-Benefits-Annual-Survey-2017>.
- ¹⁸American Medical Association. Aligning Clinical And Financial Incentives For High-Value Care. Available at: <https://www.ama-assn.org/system/files/2018-12/i18-cms-csaph-joint-report.pdf>.
- ¹⁹Centers for Medicare and Medicaid Services. Medicare Advantage Value-Based Insurance Design Model. Available at: <https://innovation.cms.gov/initiatives/vbid/>.
- ²⁰Michigan Center for Value-Based Insurance Design. Precision Medicine Needs Precision Benefit Design. Available at: <http://vbidcenter.org/initiatives/precision-medicine/>.
- ²¹Kaiser Family Foundation. 2019 Employer Health Benefits Survey. Sept 25, 2019. Available at: <https://www.kff.org/health-costs/report/2019-employer-health-benefits-survey/> Accessed January 13, 2020.

