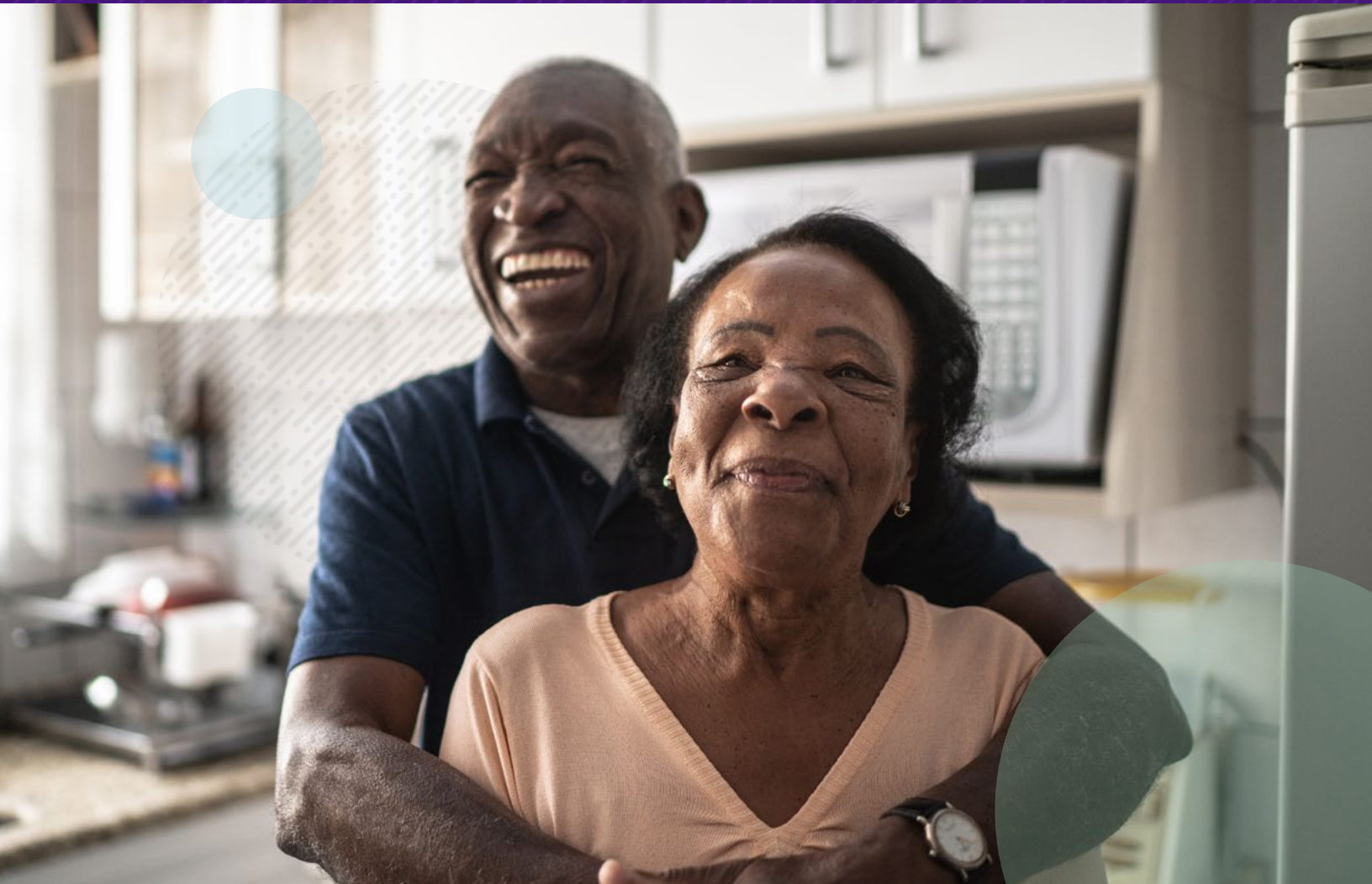




POSITION STATEMENTS

HOW TO IMPROVE HEALTHCARE ACCESS AND AFFORDABILITY

JANUARY 2021



Just having health insurance is no longer enough to ensure access to affordable healthcare.

Today, millions of people covered by commercial health plans, the Affordable Care Act, or Medicare still find themselves unable to afford the out-of-pocket costs required to start and stay on their medical treatment. Older adults, people with serious illnesses who have limited incomes, people of a minority background, and individuals living in medically underserved areas are most at risk for delaying or abandoning treatment because of cost.

The PAN Foundation is uniquely positioned to recommend strategies that improve healthcare access and affordability for those most impacted by rising out-of-pocket costs. Since 2004, the PAN Foundation has provided a critical safety net for nearly one million underinsured people with life-threatening, chronic, and rare diseases who would otherwise have gone without treatment.

Healthcare must be affordable and accessible to all Americans, regardless of their age, gender or gender expression, sexual orientation, ethnicity, race, religion, income, location, health status, diagnosis, or insurance coverage. The following recommendations prioritize patients' needs in our complex healthcare system and focus on improving healthcare access and affordability for all people living with a serious or chronic illness.

AREAS OF FOCUS



**Lowering
out-of-pocket costs**



**Modernizing
Medicare**



**Expanding access within
commercial insurance**



**Improving the
healthcare system**



Lowering out-of-pocket costs

1

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

The administration, Congress, and public and private insurers should set policies that ensure that out-of-pocket costs for prescription medications are affordable and do not prevent patients—especially those with lower or fixed incomes—from starting and staying on medically necessary treatments.

Why high out-of-pocket costs are harmful

High out-of-pocket medication costs frequently prevent patients from accessing their prescribed medications. When faced with high out-of-pocket drug costs, patients with serious conditions take longer to start treatment, are less likely to fill their prescriptions, and experience increased interruptions in treatment.^{1,2}

Multiple studies have shown that even a monthly co-pay of \$40 for a medication can cause many patients to forgo filling their prescriptions.^{3,4} With many essential medicines for serious conditions requiring much higher co-pays, high out-of-pocket costs prevent patients from the treatment they need and exacerbate widening economic insecurity for older adults.⁵

“

When I was diagnosed with Parkinson’s disease, each new prescription would eat through our savings until there was nothing left.”

Lynn Estep, Indiana
Living with Parkinson’s disease





2

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

Until policies ensure our nation's most vulnerable patients can access medically necessary treatments, the administration and Congress must recognize that charitable assistance programs and foundations play a critical role in the healthcare safety net.

Why patient assistance remains vital

Charitable patient assistance programs and foundations are a lifeline for patients who have no other means of covering their out-of-pocket medication expenses.

Charitable patient assistance programs provide grants to eligible patients who are underinsured to help pay for the out-of-pocket prescription costs for a covered illness. Millions of Medicare beneficiaries have limited incomes and multiple health conditions that require ongoing treatment. Without charitable assistance, these patients often have no other means to fill their prescription, and start and stay on treatment.

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

Congress and the Centers for Medicare and Medicaid Services should set a limit on the amount Medicare beneficiaries must spend out-of-pocket on prescription drugs. A monthly or annual cap would facilitate access to needed treatments, protect patients from high out-of-pocket costs, and help beneficiaries predict and plan for these costs throughout the year.

Why a cap is needed

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.⁶ Some patients who require expensive but life-saving medications can incur thousands of dollars throughout the year in out-of-pocket for their prescriptions.



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My co-pays are out of this world.
Something has to be done about it.”

Joan Durnell Powell, California
Living with myelodysplastic syndrome

[WATCH JOAN'S VIDEO](#)

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

Congress, insurers, and other stakeholders should modify the structure of public and private insurance plans to spread out-of-pocket costs for prescription medications evenly over the course of the year so that patients can access and remain on the treatments they need. This strategy is also commonly referred to as “smoothing.”

Why smoothing is needed

The structure of Medicare Part D prescription drug plans concentrates out-of-pocket medication costs early in the benefit year. This benefit design can have a devastating impact on patients who face high cost sharing at the beginning of the year for their essential medications. Most patients cannot afford large out-of-pocket expenses all at once or over a short period but could afford the total cost if spread out evenly throughout the benefit year.



“

As a senior, I want cost predictability. I don't want to stay up at night wondering if my next prescription is going to cost \$800.”

George Valentine, Texas
Living with chronic lymphocytic leukemia

[WATCH GEORGE'S VIDEO](#)

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

Public and private insurers should place at least one highly effective, innovative medication on a fixed co-pay formulary tier for all conditions to increase access and treatment adherence.

Why all conditions need at least one innovator drug with a fixed co-pay

For patients with chronic and rare diseases, specialty medications offer significant treatment advances, reduce the risk of disease progression, and improve survival rates.⁶ In most cases, a generic or less expensive alternative is not available for their condition.

High cost sharing for specialty medications—which can be as high as 50 percent of the drug’s cost—increases the chance patients will delay starting therapy², skip prescription refills⁷, and interrupt or abandon treatment.⁸ Placing a sizeable financial responsibility for specialty medications on patients creates an environment where the most economically vulnerable people have the least access to innovative therapies.





Modernizing Medicare

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.

The administration and Congress should modernize the Medicare Part D benefit design to improve prescription medication access and reduce the financial burden on beneficiaries.

Why Congress should modernize Medicare Part D

The Part D program and its beneficiaries have seen significant health spending growth over the last decade. Between 2007 and 2017, Part D spending increased from \$46 to \$80 billion.⁹ The current benefit design is not working to control costs for the Medicare program or its patients.

Part D reforms should reduce the financial burden on enrollees and improve access to prescription medications. Several proposals include harmonizing the drug benefit under Part B and Part D or shifting some of the government's cost-sharing responsibilities to insurers and the pharmaceutical industry.



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.

Congress should modernize the LIS program (also known as Extra Help) to help more patients, eliminate cost-sharing for generic drugs, and ensure all eligible beneficiaries enroll in the program.

Why Congress should modernize LIS

The LIS program's eligibility criteria require patients to have an income under 150 percent of the federal poverty level.¹⁰ Because the income limits are low, millions of Medicare beneficiaries who are economically insecure are ineligible for extra help with their out-of-pocket medication costs.

The program also requires cost sharing for generic drugs, and the application process is complicated, leaving many to miss out on support altogether. Lastly, many eligible patients do not enroll because of the program's complexity. Specific efforts to ensure the program reaches the people who need it most are essential.



8

Vaccine co-pays should be eliminated under Medicare Part D.

Congress, the Centers for Medicare and Medicaid Services, and insurers should eliminate vaccine co-pays in the Medicare Part D program in order to make them accessible to all beneficiaries.

Why vaccine co-pays should be eliminated in Medicare Part D

Older adult vaccination rates remain low. According to the Centers for Disease Control and Prevention, more than 50,000 adults die annually from vaccine-preventable diseases.^{11,12} Treatment for these preventable illnesses is estimated to have cost the Medicare program \$106 billion from 2016 to 2018.¹³ Although many Part D plans cover vaccines, they usually require co-pays. The higher the co-pays, the more likely it is that patients will forgo the vaccine.

9

Medicare should be expanded to include dental, hearing, and vision benefits.

Congress should expand Medicare to include and ensure adequate dental, hearing, and vision coverage and minimize out-of-pocket spending for these services.

Why Medicare should include these benefits

The need for dental, hearing, and vision coverage among patients on Medicare is significant. Almost two-thirds of Medicare beneficiaries—37 million people—do not have any dental coverage.¹⁴ Only one in four Americans diagnosed with hearing issues uses a hearing aid, with the cost being a major barrier to obtaining them.¹⁵ And, 92 percent of Medicare beneficiaries require eyeglasses.¹⁶

Older adults who forgo or delay these services are at greater risk for emergency department visits and hospitalizations, dependence on family caregivers or skilled nursing facilities, and depression and dementia.¹⁷ Policymakers can minimize out-of-pocket spending by creating a benefit modeled after Medicare Part D that limits out-of-pocket expenses.





Expanding access to commercial insurance

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.

Insurers must mitigate the impact that high upfront deductibles in commercial health insurance plans have on patients' ability to start and stay on their prescription medications.

Why high deductibles are harmful

Although deductibles have long been part of most commercial health insurance plans, annual deductibles have dramatically increased over the last decade. Patients often pay thousands of dollars in out-of-pocket expenses before their insurance provides coverage.

High-deductible insurance plans are most common in companies with low-wage workers, placing a significant financial burden on people who can least afford it.¹⁸ These insurance plans are also challenging for people who need specialty medications with no generic alternative, who must meet a deductible as high as \$10,000 at the beginning of the benefit year to fill their prescriptions. Many people are unable to handle these upfront costs and delay or abandon treatment.



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.

Congress, the Centers for Medicare and Medicaid Services (CMS), and insurers should prohibit harmful co-pay accumulator programs and allow commercially-insured patients to use manufacturer co-pay cards and coupons to meet their deductibles.

Why co-pay accumulators should be prohibited

Deductibles, co-pays, and coinsurance have increased dramatically in recent years, and co-payment cards have become even more crucial for economically vulnerable patients. However, commercial insurance co-pay accumulator policies prevent patients from using co-pay cards and coupons to count toward their deductibles, resulting in a much larger overall out-of-pocket financial burden. These policies are especially harmful to lower-income patients who require expensive medications and those enrolled in high-deductible health plans.

“

For years, I was able to use co-pay cards from the drug manufacturers to pay for my medications. That changed when my husband's company switched to a high-deductible insurance plan that would not allow co-pay cards. It was shocking to have a \$10,000 surprise in January. It had taken us years to build our savings and then they were gone.”

Robin Lancaster, Kentucky
Living with primary myelofibrosis





Improving the healthcare system

12

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

Public and private insurers should adopt value-based insurance designs to facilitate access to medically necessary and high-value therapies for patients with life-threatening and chronic conditions.

Why value-based insurance design works

Under a value-based insurance design approach, treatments that provide high clinical value have low or no patient cost-sharing to increase patient access, ensuring more affordable care for patients.

The Centers for Medicare and Medicaid Services (CMS) supports value-based insurance design. CMS implemented the Medicare Advantage Value-Based Insurance Design Model, which offers supplemental benefits or reduced out-of-pocket costs for high clinical value services to patients with certain chronic conditions.

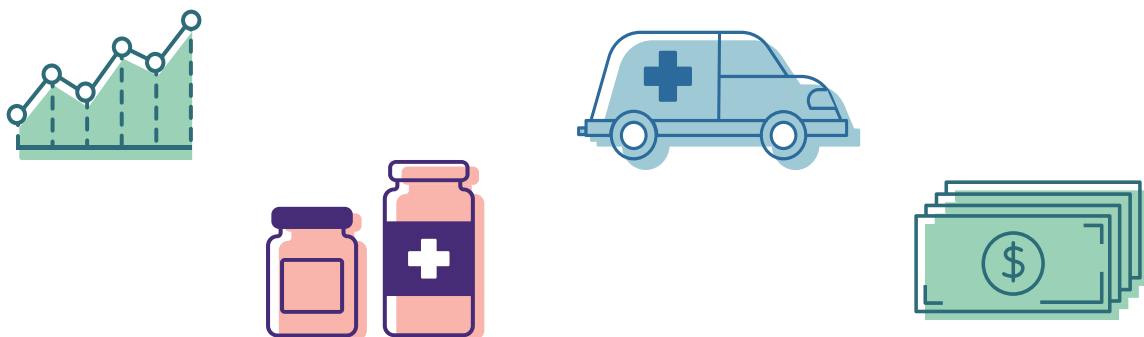
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The total out-of-pocket cost of care must be taken into consideration when developing policy solutions to decrease the financial burden of care and treatment for Americans.

Policymakers should consider the total cost of care when developing policy solutions to decrease patients' financial burden for medical treatment.

Why the total out-of-pocket cost of care is essential

While reducing out-of-pocket expenses for prescription therapies is an important goal, it is equally vital that patients have affordable access to the other healthcare services. Co-pays for visits to primary or specialty providers, and out-of-pocket costs for services such as diagnostic tests, physical therapy, radiation, or any other form of treatment, should not prevent patients from getting the care they need, nor force patients to make difficult trade-offs between health care and paying for other essentials like food and groceries.



Public and private insurers should adopt policies that address social determinants of health to mitigate barriers that prevent patients from adhering to their medications.

Public and private insurers should adopt policies that mitigate barriers to treatment. Addressing social determinants has the potential to improve patient health outcomes and reduces avoidable healthcare spending.

Why we must address social determinants of health

Socioeconomic factors like economic stability, education, healthcare access and quality, neighborhood and environment, and social and community context drive more than 80 percent of health outcomes.¹⁹ Leaving social factors unaddressed leads to preventable disparities in health status, medication adherence, and disease outcomes.

For example, lack of affordability is one of the primary reasons patients do not adhere to therapeutic recommendations. Research finds the annual cost of medication non-adherence is \$100 to \$289 billion.²⁰ This problem is especially concerning among people with lower incomes who manage a chronic condition.

Potential policies could include payment models that incentivize screening patients for social needs and connecting them with needed services and education.

About 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 out-of-pocket costs for their prescribed medications. Since 2004, we have provided nearly 1 million underinsured patients with \$4 billion in financial assistance.

LEARN MORE AT

[PANFOUNDATION.ORG/ADVOCACY](https://panfoundation.org/advocacy)

PAN Foundation



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