



POSITION STATEMENTS

# HOW TO IMPROVE HEALTHCARE ACCESS AND AFFORDABILITY

2022



# INTRODUCTION

Just having health insurance is not 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 disabilities, people with limited incomes, people of color, 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 more than 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



**Increasing health equity**



**Improving the healthcare system**



**Lowering out-of-pocket costs**



**Expanding access within commercial insurance**



**Modernizing Medicare**



# **Increasing health equity**

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## Healthcare must be affordable and accessible to all, without discrimination.

The administration and Congress should establish a national effort to end longstanding health inequities.

### **Why policymakers at all levels must focus on making healthcare accessible to all:**

Disparities in healthcare and health outcomes persist in the United States. Health disparities are attributed to broad structural, socioeconomic, political, and environmental factors that are rooted in years of systemic racism. Certain populations are more likely to experience worse health outcomes, limited access to healthcare services, and lower quality of care based on race, ethnicity, gender, sexual orientation, disability status, or geographic location.

An analysis from the W.K. Kellogg Foundation and Altarum found that disparities amount to approximately \$93 billion in excess medical care costs and \$42 billion in lost productivity per year, as well as additional economic losses due to premature deaths.<sup>1</sup>

An intentional focus on and understanding of health inequities and disparities can serve as a catalyst for change across multiple sectors, including employment, housing, education, healthcare, public safety, and food access. Achieving health equity will require coordinated leadership at the national, state, and local government levels and with the private sector to address social determinants of health, increase access and affordability of healthcare services, and collect and analyze data to track progress.





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## **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.<sup>2</sup> 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. Challenges with affordability are especially concerning for people with lower incomes who manage one or more chronic conditions.

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



# Lowering out-of-pocket costs

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## 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.<sup>3,4</sup>

Multiple studies have shown that even a monthly co-pay of \$40 for a medication can cause many patients to forgo filling their prescriptions.<sup>5,6</sup> With many essential medicines for serious conditions requiring much higher co-pays, high out-of-pocket costs prevent patients from accessing the treatment they need and exacerbate widening economic insecurity for older adults.<sup>7</sup>

“

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



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## 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.



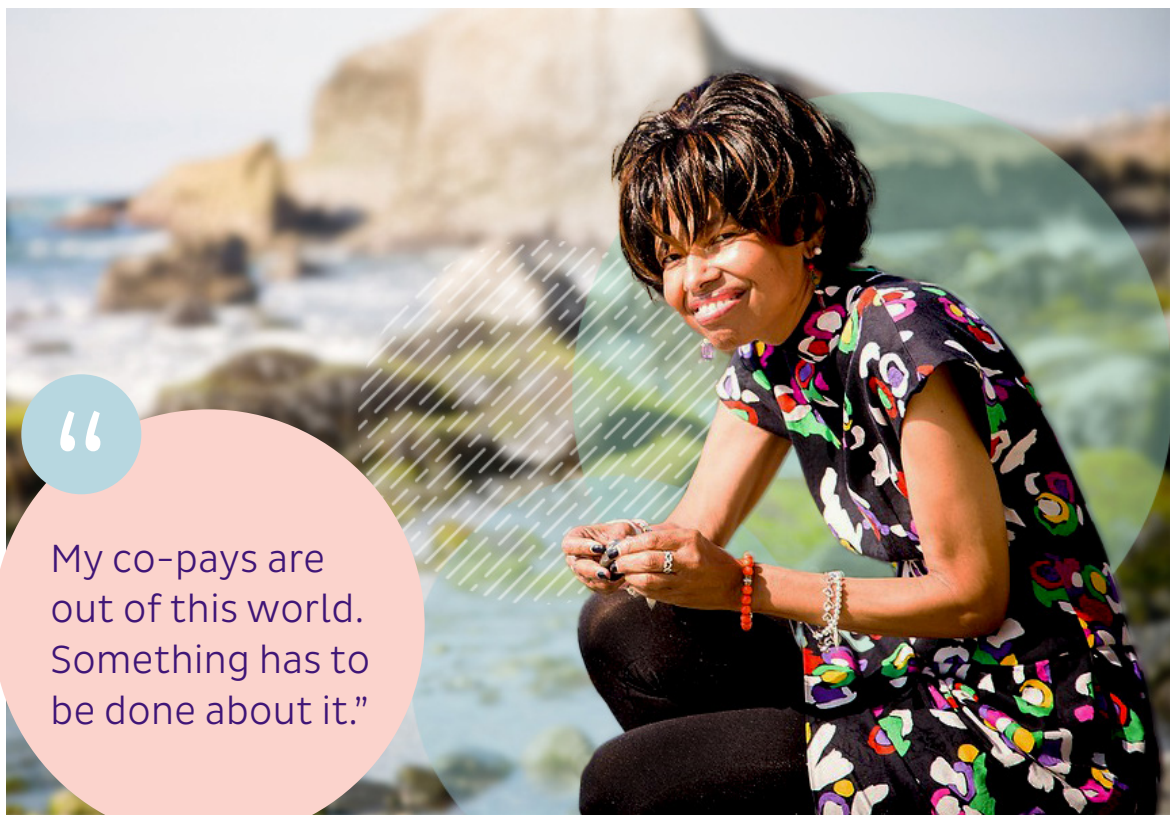


## Out-of-pocket costs for prescription medications should be capped by instituting monthly or annual limits.

Congress and the Centers for Medicare and Medicaid Services (CMS) 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.<sup>8</sup> Some patients who require expensive, but life-saving medications can incur thousands of dollars throughout the year in out-of-pocket costs for their prescriptions.



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

Joan Durnell Powell, California  
Living with myelodysplastic syndrome

## 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

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## 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.<sup>6</sup> 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 therapy<sup>2</sup>, skip prescription refills,<sup>9</sup> and interrupt or abandon treatment.<sup>10</sup> Placing a sizable 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

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## **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 2008 and 2018, Part D spending increased from \$49 to \$95 billion.<sup>11</sup> The Congressional Budget estimates that Part D spending will total \$111 billion in 2022.<sup>12</sup> 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.

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## **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.<sup>13</sup> 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.

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

Congress, the Centers for Medicare and Medicaid Services (CMS), 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.<sup>14,15</sup> Treatment for these preventable illnesses is estimated to have cost the Medicare program \$106 billion from 2016 to 2018.<sup>16</sup> 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.

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## 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.<sup>17</sup> Only one in four Americans diagnosed with hearing issues uses a hearing aid, with the cost being a major barrier to obtaining them.<sup>18</sup> And, 92 percent of Medicare beneficiaries require eyeglasses.<sup>19</sup>

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.<sup>20</sup> 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.<sup>21</sup> 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 and the Centers for Medicare and Medicaid Services (CMS) should prohibit harmful co-pay accumulator programs and require health insurance plans to apply financial assistance received on behalf of a patient toward their out-of-pocket maximum.

### Why co-pay accumulators should be prohibited:

With high-deductible health plans on the rise, patients with serious conditions often turn to financial assistance to afford their out-of-pocket prescription medication costs in a variety of ways. They might seek help from charitable assistance foundations, manufacturer assistance programs, friends and family, faith-based communities, and even crowdfunding sites. These forms of assistance are a lifeline for people who need ongoing access to expensive specialty drugs required to treat their conditions.

Commercial insurance co-pay accumulator policies prevent patients from using financial assistance 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.



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For years, I was able to use patient assistance to help meet the out-of-pocket responsibility before accessing my medications. It was shocking to have a \$10,000 surprise in January. It had taken us years to build our savings and then it was gone.

Robin Lancaster, Kentucky  
Living with primary myelofibrosis



# **Improving the healthcare system**

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## **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 considering 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 healthcare and paying for other essentials like food and groceries.

## Older adults should have access to affordable mental health services and support, including appropriate medications.

Congress and the Centers for Medicare and Medicaid Services must ensure coverage and availability of mental health services and medications.

### **Why Congress should address equitable access to mental health services and medications:**

Access to appropriate mental health treatment is critical for older adults' health and well-being, and yet seniors' ability to secure mental health services is often impeded or blocked entirely by out-of-pocket costs and lack of access to appropriate healthcare professionals. Medicare does not cover key mental health services such as psychiatric rehabilitation, peer support services, or assertive community treatment—specialized care delivered by an integrated care team. The burden of living with one or more chronic diseases can impact patients' physical and emotional well-being. One study showed that older adults with chronic health conditions are 62 percent more likely to experience depressive symptoms than seniors without these conditions.<sup>22</sup>

Medicare Part D plans are required to cover six “protected” drug classes, and these include antidepressants and antipsychotics, drugs that are often used to treat severe mental illness. It is imperative that Congress continue requiring Part D drug plans to cover these drugs, so out-of-pocket costs do not serve as a barrier to treatment. Additionally, Medicare should be expanded to ensure access to needed mental health services.



## Telehealth services provide access to healthcare and should continue to be an option, particularly for those in rural and underserved areas.

Congress and the Centers for Medicare and Medicaid Services (CMS) should keep telehealth services including coverage for audio-only services.

### **Why telehealth services are vital to expanding healthcare access:**

Telehealth can help expand access to care and maintain continuity of care for all patients. For Medicare beneficiaries, access to telehealth services is especially important. From July to September 2020, 15.1 million Medicare beneficiaries had a telehealth visit with a doctor or other healthcare professional, according to the Kaiser Family Foundation—nearly half of beneficiaries whose providers offered telehealth services.<sup>23</sup>

It is important to allow the use of audio-only equipment for a wide range of Medicare services as well, to ensure that telehealth is accessible to underserved groups. Among Medicare beneficiaries who had a telehealth visit, 56 percent reported accessing care using a telephone only. Among Medicare beneficiaries who are over 75, live in rural areas, identify as Hispanic, or have Medicare and Medicaid, a majority reported using audio-only telehealth services.<sup>24</sup>

Audio-only visits will ensure that those in areas with limited or no broadband won't lose access to critically needed services, particularly older adults and younger individuals with disabilities who rely on Medicare for essential behavioral healthcare.



## Case management should be made more widely available.

Congress and the administration should expand case management to address both the health and social needs of patients.

### Why case management should be expanded:

The healthcare and social services systems in the U.S. are complex and not easy to navigate. Patients and families may not be aware of their eligibility for programs that provide financial assistance or services that are essential to staying in care, receiving social support, and maintaining health and wellness. Case management and case managers seek to address the medical, physical, functional, emotional, financial, psychosocial, behavioral, and spiritual needs of the individuals they serve.

Comprehensive case management should be more widely available to those eligible for Medicare. Eighty percent of adults 65 and older have at least one condition, while 68 percent have two or more.<sup>25</sup> Case management can help Medicare beneficiaries navigate the healthcare system, coordinate care between multiple providers, identify social needs, and assist with enrollment in additional benefits. Value-based payment models, in addition to coordinating care, should 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 over 1 million underinsured patients with \$4 billion in financial assistance.

LEARN MORE AT

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

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