EACH/PIC COALITION

October 2, 2026

The Honorable Ron Wyden
Ranking Member
Committee on Finance
United States Senate

RE: Request for Information on Health Coverage that Works for Everyone

Dear Ranking Member Wyden and Members of the Committee:

On behalf of the patient populations we represent, the undersigned organizations appreciate the opportunity to provide input on the Senate Finance Committee's Request for Information regarding improving health care coverage. Ensuring Access through Collaborative Health and Patient Inclusion Council (EACH/PIC) is a coalition of patient organizations, allied stakeholders, patients, and caregivers committed to advancing policies that improve prescription drug affordability while preserving timely access to the therapies patients rely upon.

As policymakers consider reforms to make insurance more affordable and effective, we encourage the committee to focus not only on whether individuals have coverage, but whether that coverage provides affordable, predictable, and reliable access to the care they need.

Patient Perspectives on Coverage and Affordability

EACH/PIC conducted a comprehensive Patient Experience Survey to better understand how patients and caregivers experience prescription drug affordability. The survey was designed to capture the context often missing from traditional affordability assessments, including how insurance coverage, out-of-pocket costs, financial assistance, and other healthcare expenses affect patients' ability to access and remain on prescribed treatment.

Importantly, the results demonstrate that insurance coverage, or the lack of it, was among the most frequently cited reasons patients experienced affordability challenges. Respondents described insurance-related challenges as significant barriers to accessing and remaining on needed medications.

Among patients who stopped taking a medication, 95 percent cited insurance-related challenges, including formulary changes, accumulators, step therapy, non-medical switching, loss of coverage, and high deductibles. Similarly, among patients who reported never starting a prescribed medication, 72 percent cited insurance-related challenges, including coverage denials and high out-of-pocket costs despite having insurance.

Affordability can also shift significantly over time, even for patients taking the same medication. Among patients whose out-of-pocket costs changed for the same drug, 51 percent reported that their medication was affordable at one point and unaffordable at another. More than half of those experienced substantial variation in what they paid over time. For some, those swings were particularly dramatic: 15 percent reported paying as little as $0–$10 at one point and more than $1,000 at another. These findings demonstrate how unpredictable changes in patient costs can turn an affordable treatment into an unaffordable one and contribute to financial hardship.

Financial assistance also played an important role in patients' experiences of affordability. Among respondents taking specialty medications who discussed financial assistance, 71 percent said that assistance was the reason their medication was affordable. At the same time, patients reported that insurance design could prevent assistance from being applied, cause them to lose access to assistance, or create uncertainty about whether support would remain available.

Policy Recommendations

Based on the experiences patients shared through our survey, we encourage the committee to consider the following reforms:

Make Patient Costs More Manageable and Predictable

Patients managing chronic conditions often face healthcare expenses that are unpredictable and can vary significantly over time. Changes in deductibles, premiums, cost-sharing requirements, or insurance coverage can cause sudden shifts in out-of-pocket costs, creating financial uncertainty and contributing to hardship even for patients who previously considered their care affordable.

Congress should consider policies that directly limit patients' financial exposure, including lower deductibles, reasonable annual out-of-pocket maximums, limits on premium increases tied to inflation, and other protections against sudden or unmanageable costs. Policymakers should also expand opportunities for patients to smooth healthcare costs throughout the year rather than requiring significant expenses to be paid early in a coverage period. These approaches can make expenses more predictable and help patients maintain continuity of care.

Importantly, reforms should consider the total financial burden associated with managing a chronic condition. Policymakers should also recognize that patients experience costs cumulatively. The full financial burden of managing a chronic condition can make an individual healthcare expense unaffordable even when that expense appears relatively modest in isolation.

Ensure Coverage Provides Reliable Access to Care

Insurance coverage is only valuable to patients if they can use it to access the care prescribed by their healthcare providers. Administrative barriers and unexpected coverage changes can delay treatment, increase costs, or disrupt therapies that are working for patients.

Congress should advance reforms that reduce unnecessary delays and disruptions associated with prior authorization and step therapy and ensure patients have access to clear and timely appeals when coverage is denied. Patients who are stable on an effective treatment should also be protected against non-medical switching driven by changes in coverage rather than their individual healthcare needs.

Greater transparency is equally important. Patients should have clear information about formularies, prior authorization and step therapy requirements, and changes to those policies. Insurers should provide sufficient notice of changes that could affect access to treatment and establish meaningful mechanisms for patients and providers to address coverage problems when they occur. These recommendations reflect the insurance-related barriers patients repeatedly identified through the survey.

Protect and Expand Patient Financial Assistance

Financial assistance programs can provide an important safeguard for patients who would otherwise struggle to afford prescribed treatment. Congress should protect and expand access to Patient Assistance Programs for individuals with low incomes, disabilities, or without insurance and support awareness of manufacturer copay assistance available to commercially insured patients. Application and enrollment processes should also be simplified so that eligible patients can more readily access available support.

At the same time, insurance design should not undermine the value of that assistance. Copay assistance should count toward a patient's deductible and annual out-of-pocket maximum. Accumulator and similar policies can prevent financial assistance from counting toward insurance cost-sharing requirements, undermining the value of that assistance and contributing to affordability challenges.

Improve Transparency and Align Incentives with Patients

Finally, reforms should address incentives within the healthcare marketplace that can affect patient costs and access. This includes prohibiting spread pricing, replacing percentage-based PBM compensation with flat-fee service models, ensuring negotiated rebates and discounts are passed through to patients, and increasing transparency around PBM contracts, rebate flows, and formulary design.

Greater transparency should extend to how coverage decisions affect patients. Policymakers should be able to determine whether changes in formularies, utilization management, cost

sharing, and other insurance practices are improving affordability or simply shifting costs and barriers elsewhere in the healthcare system.

Conclusion

We applaud the work of the committee to advance reforms that make health coverage work better for the people who depend on it, and we encourage policymakers to consider patient affordability, access, and continuity of care as core measures of success. We look forward to working with Members to advance patient-centered solutions that improve health coverage and affordability.

Sincerely,

EACH/PIC
ADAP Advocacy
AiArthritis
The AIP BIPOC Network
Allergy & Asthma Network
American Behcet's Disease Association (ABDA)
Applied Pharmacy Solutions
Autoimmune Association
Biomarker Collaborative
California Chronic Care Coalition
Chronic Care Policy Alliance
Diabetes Leadership Council
Diabetes Patient Advocacy Coalition
Exon 20 Group
GLOBAL ALLERGY & AIRWAYS PATIENT PLATFORM
Healthy Men Inc.
HIV+Hepatitis Policy Institute
ICAN, International Cancer Advocacy Network
Infusion Access Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
MET Crusaders
Milwaukee Rheumatology Center
Multiple Sclerosis Foundation
National Association of Nutrition and Aging Services Programs (NANASP)
National Consumers League
National Infusion Center Association
Neuropathy Action Foundation
Nevada Chronic Care Collaborative
NRG1 Energizers
Partnership to Improve Patient Care
Patient Empowerment Network
Patients Rising
PDL1 Amplifieds
PlusInc

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RetireSafe
StopAfib.org
ZERO Prostate Cancer