August 28, 2026

RE: Ensuring the Voices of People Living & Aging with HIV Remain Central to the Medicare Drug Price Negotiations

Dear Administrator Oz:

We, the undersigned organizations, represent Americans nationwide who are aging with HIV and other complex, chronic conditions, and the caregivers who support them. Due to the communities we serve, our organizations bring awareness of the clinical and lived realities of aging with HIV. We share your commitment to making medicines more accessible for the Americans who depend on them to stay healthy, and we write to help ensure that the third cycle of the Medicare Drug Price Negotiation Program (MDPNP) reflects the needs and lived experiences of the patients it is intended to support.

With negotiations ongoing for treatments selected within the MDPNP for initial price applicability year 2028, including an antiretroviral therapy that many older Americans rely on to manage HIV, we respectfully urge the agency to ensure that the extensive input already submitted by patients, caregivers, and advocates is fully reflected in the negotiation process and throughout its implementation. That input was submitted at considerable effort, often by patients navigating real barriers to participate.

We appreciate efforts from CMS to engage stakeholders throughout this negotiation cycle, including patient-focused roundtables, clinical town halls, and the formal comment period. Input from those individuals reflects the clinical and lived realities that price data alone cannot capture, including real concerns about how negotiation could affect access to the treatments patients depend on. Those perspectives deserve to carry weight through the conclusion of the negotiation process and into implementation.

As a result of decades of biopharmaceutical innovation, HIV has been transformed from a fatal diagnosis into a manageable chronic condition – people with HIV are living longer than ever before. In the United States, more than half of people living with HIV are now over the

age of 50, and that share is only expected to grow. This public health success is one worth celebrating and reflects the reality that the population CMS is making decisions for is increasingly older and managing HIV alongside other age-related conditions.

Antiretroviral treatments for HIV are not automatically interchangeable. They carry specific clinical considerations, including cross-resistance, adherence requirements, and long-term toxicities, that make forced switching or reliance on "therapeutic alternatives" inappropriate for many people living with HIV. Older adults are especially affected: in a recent national survey of people aging with HIV, 81% reported taking a medication for a chronic condition other than HIV, and 17% had already had to adjust their HIV regimen because of interactions with other medications. For these patients, continuity of the regimen developed with their provider is not a matter of convenience; it is essential to maintain viral suppression and avoid drug resistance.

Patient experience shows that lowering a negotiated price does not automatically lower what patients pay or preserve access to care. Several real-world dynamics determine what patients pay out of pocket and whether they can even fill their prescription in the first place, including:

Utilization management practices, such as non-medical switching, step therapy, and adverse tiering, can further restrict access to drugs selected for negotiation; one analysis found prior authorization requirements increased for drugs selected for the program's first two cycles.

Of the first 24 medicines selected for negotiation, average out-of-pocket costs rose for 14 of them in 2025, compared to 2024 levels, by as much as 46% for some.

More than 60% of independent pharmacists surveyed in 2025 said they were considering not stocking one or more medicines with a federally set price.

These are the dynamics that decide whether the intended benefits of negotiation reach patients at all, or whether new barriers simply take the place of old ones.

Participating meaningfully in MDPNP public engagement opportunities incurs time, resource, and emotional burdens. Patients and advocates who provided detailed input did so precisely because these decisions will shape their access to care for years to come.

We respectfully urge CMS to ensure that the patient and caregiver perspectives shared through the patient-focused events and during the formal comment period are meaningfully incorporated into the negotiation process and its implementation. We ask that the agency account for the clinical realities of HIV treatment, including the risks of forced switching and disrupted continuity of care, and monitor and address the downstream access effects that ultimately determine whether patients benefit.

Older Americans and others living with HIV have overcome immense challenges and deserve policies that protect their access to care, not ones that risk it. On behalf of the communities our organizations represent, we thank you for your leadership and your attention to these concerns, and we stand ready to partner on solutions that advance both affordability and access. We would welcome the opportunity to discuss these concerns further or answer any questions you may have.

Sincerely,

Global Coalition on Aging

ADAP Advocacy

Aging and HIV Institute

AIDS United

Alliance for Aging Research

American Federation for Aging Research

Biomarker Collaborative

Black, Gifted & Whole

Caregiver Action Network

Caring Ambassadors Program

Community Access National Network

Equitas Health

Exon 20 Group

GJPI INC

HealthHIV

ICAN, International Cancer Advocacy Network

Latino Commission on AIDS

MET Crusaders

National Working Positive Coalition

NMAC

NRG1 Energizers

Patients Rising

PDL1 Amplifieds

PlusInc