

July 23, 2021

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services (HHS)
Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, D.C. 20201

RE: Comments in Response to Request for Information Regarding Reporting on Pharmacy Benefits and Prescription Drug Costs

Dear Secretary Becerra:

We, the undersigned 57 organizations, on behalf of millions of patients and American consumers who live with complex conditions such as HIV, autoimmune diseases, cancer, diabetes, lupus, multiple sclerosis, and hepatitis, write in response to the *Request for Information Regarding Reporting on Pharmacy Benefits and Prescription Drug Costs*. The patients we represent rely on prescription drugs to treat their health conditions and prevent others. We are pleased that the Biden administration is moving forward with the requirement that insurance plans must report on various data points associated with prescription drug spending. We believe with this greater understanding and transparency of prescription drug costs, you can better implement policies and measures that increase competition, improve prescription drug affordability and access for the American people.

Patients today face significant prescription drug affordability challenges that have only grown worse due to the cost of medications along with insurance benefit design, including high deductibles and high patient cost-sharing often in the form of co-insurance. This negatively impacts patient adherence and leads to worse health outcomes and increased costs across the healthcare system.

As you implement the prescription drug cost reporting requirements for health plans, we recommend that you include the following:

- 1. Require Plans to Report on the Treatment and Accounting of Copay Assistance.** Many health plans are instituting policies that do not count drug manufacturer copay assistance towards a patient's annual deductible or out-of-pocket maximum. In doing so, issuers are collecting the value of the assistance, which often exceeds the out-of-pocket maximum, and then, after it runs out, collecting additional payments by the patient until the out-of-pocket maximum is reached again. In another scheme, plans designate certain medicines as "non-essential" and then raise the cost-sharing to ensure that they collect all of the patient assistance offered by the manufacturer. Under this scheme, the plans often collect payments far exceeding the out-of-pocket maximum. While we continue to urge you to prohibit both of these practices, in the meantime, these double and excess payments to the insurer must be

reported and considered a violation of the Affordable Care Act (ACA) out-of-pocket limit.

- 2. Proper Accounting of Rebates and Pharmacy Benefit Managers.** We are pleased that you are proposing to collect data on the amount of rebates, fees and other remuneration paid by drug manufacturers to the plan and how these rebates reduce premiums and out-of-pocket costs for patients. The high level of rebates influences the list price of drugs. Since more and more health plans carry high deductibles and utilize co-insurance to determine patient cost-sharing, patients are unfairly being overly burdened with higher out-of-pocket costs. Additionally, while the portion of rebates plans receive may be benefiting all enrollees by reducing premiums, those who rely on prescription drugs and are responsible for generating those rebates for the plans are not directly benefiting. We hope the collection of rebate information will create greater drug price transparency and help establish a system in which patients who rely on prescription drugs can directly benefit from the rebates that they generate. Enrollees benefit from negotiated discounts for all other medical services. It is time that patients benefit from prescription drug discounts.

We realize that the amount of rebates, fees and other remuneration is often cloaked in secrecy by pharmacy benefit managers (PBMs), insurers, and drug manufacturers and affected parties are concerned with disclosure of competitive practices, however we urge you to overcome any obstacles. PBMs, which are frequently not regulated at the state level, have successfully and artfully tried to escape any attempt to report on how the billions in rebates and other fees they collect are distributed to plans, patients, or to their profits. To further add to the complexity, the three largest PBMs, which now account for over 75 percent of all drug claims are either owned or own an insurance company. We urge you to resist their attempts to limit transparency and move forward with these statutory required data reporting without further delay.

- 3. Consider the Benefits of Prescription Drug Costs.** The law requires you to collect data from the plans on the cost of certain prescription drugs. As you utilize this data in the future, we urge you to consider the benefits of these costs to individual patients, their families and friends, and society as a whole. These drugs are keeping people healthy and alive and reducing spending on other healthcare costs, including hospitalizations, which are the largest component of healthcare spending. Prescription drugs are also curing people of once deadly illnesses and preventing future diseases and illnesses. These are not excuses for high prescription drug prices, but factors that should be not ignored as future policy decisions are made.

We thank you for the opportunity to share these recommendations and look forward to working with you and each of the other agencies implementing the prescription drug data reporting system.

If you have any questions or comments please contact Carl Schmid, Executive Director of the HIV+Hepatitis Policy Institute at cschmid@hivhep.org and Molly Murray, President and CEO of American Autoimmune Related Diseases Association (AARDA) at mmurray@aarda.org.

Sincerely,

ADAP Advocacy Association
 Advocacy Options LLC
 AIDS Action Baltimore
 Aimed Alliance
 Alliance for Aging Research
 Alliance for Patient Access
 Allies for Independence
 American Autoimmune Related Diseases Association
 American Cancer Society Cancer Action Network
 American Diabetes Association
 Asthma and Allergy Foundation of America
 Autistic Self Advocacy Network
 Beyond Type 1
 California Chronic Care Coalition
 CancerCare
 Caregiver Action Network
 Caring Ambassadors Program
 Chronic Care Policy Alliance
 Community Access National Network (CANN)
 Easterseals
 Equality California
 Global Healthy Living Foundation
 Global Liver Institute
 HealthyWomen
 Hemophilia Federation Of America
 Hepatitis B Foundation
 Hep B United
 Hepatitis C Mentor and Support Group, Inc. - HCMSG
 HIV+Hepatitis Policy Institute
 Human Rights Campaign

ICAN, International Cancer Advocacy Network
 Immune Deficiency Foundation
 International Foundation for Autoimmune & Autoinflammatory Arthritis (AiArthritis)
 Lupus and Allied Diseases Association, Inc.
 Lupus Foundation of America
 Men's Health Network
 Multiple Sclerosis Foundation
 National Alliance on Mental Illness
 National Association of Nutrition and Aging Services Programs
 National Consumers League
 National Eczema Association
 National Hemophilia Foundation
 National Viral Hepatitis Roundtable
 Partnership to Fight Chronic Disease (PFCD)
 Patients Rising
 Patients Rising Now
 RetireSafe
 Rheumatology Nurses Society
 San Francisco Hepatitis C Task Force
 Silver State Equality-Nevada
 Sjögren's Foundation
 Susan G. Komen
 The Sumaira Foundation for NMO
 Triage Cancer
 TRIO (Transplant Recipients International Organization)
 U.S. Pain Foundation
 ZERO - The End of Prostate Cancer

cc: Laurie Bodenheimer, Office of Personnel Management
 Rachel D. Levy, Internal Revenue Service
 Carol A. Weiser, Department of the Treasury
 Ali Khawar, Department of Labor