

PRESS RELEASE

October 3, 2022

Contacts: Jennifer Burke

jburke@hivhep.org

301-801-9847

Colleen Kmiecik

colleen@autoimmune.org

248-515-9058

**71 Patient Groups Comment on How Nondiscrimination in
Healthcare Rule Can Improve Prescription Drug Access**
Proposed Rule Expands Protections but Must be Enforced

WASHINGTON, DC... The **HIV+Hepatitis Policy Institute** ([HIV+Hep](#)) and the [Autoimmune Association](#), along with 69 other patient organizations, [commented](#) on how the Section 1557 nondiscrimination in healthcare [proposed rule](#) can be used to improve patient access to prescription drugs.

In their [comment letter](#), the patient groups expressed strong support for the “meaningful steps to improve upon current regulations to ensure that people are not discriminated against in healthcare. In several instances, you have proposed to restore protections that had been included in the past but later withdrawn. In other instances, you have provided further clarity on what constitutes discrimination. In any instance, we emphasize that the law and whatever is finalized in regulation must be strictly enforced.”

One area that the patient groups agreed with HHS as potential discrimination is the use of excessive **utilization management** techniques that issuers and PBMs employ that limit access to prescription drugs. While the proposed rule calls utilization management techniques such as prior authorization and step therapy “standard industry practices that are permitted,” they must be “applied in a neutral, nondiscriminatory manner Excessive use or administration of utilization management tools that target a particular condition that could be considered a disability or other prohibited basis could violate Section 1557.”

The patient groups also expressed support for the proposed rule raising the potential discriminatory nature of **value assessments** in deciding healthcare coverage. It identified value assessments that use methods for calculating value that penalize individuals or groups on the basis of age or disability, such as placing a lower value on life-extension for a group of individuals. The groups wholeheartedly agreed that they may violate Section 1557 and specifically mentioned the use of quality-adjusted life-years (**QALYs**), which are fundamentally discriminatory towards patients with chronic disease. In their letter, the groups wrote, “Because these groups may not ever be able to reach a completely healthy state, their overall gains from the lens of the QALY are lower, and treatments are accordingly wrongly assigned lower value...”

Since Section 1557 bans discrimination on the basis of age and disability, we believe the use of QALYs in health programs and activities should be prohibited.”

The groups also voiced support for HHS’ focus on **discrimination in benefit design**, which includes “coverage, exclusions, and limitations of benefits; prescription drug formularies; cost sharing (including copays, coinsurance, and deductibles); [and] utilization management techniques (such as step therapy and prior authorization).” One area that the groups are particularly supportive of is HHS’ intent to apply nondiscrimination in benefit design to indirect mechanisms that affect the implementation of a benefit design within the covered entity’s control, such as utilization management practices, provider reimbursement, contracting out to third party-contractors such as **PBMs**.” The groups wrote, “Since PBMs play a key role in determining which drugs are on a formulary, cost-sharing and tiering, utilization management and pharmacy access, we are extremely supportive of this provision. For far too long PBMs have escaped proper regulation.”

The groups also asked HHS to identify copay accumulator adjustment programs as discriminatory since they only impact people who have serious health issues who rely on prescription drugs.

“While the Biden administration has prioritized the importance of nondiscrimination in healthcare, too often we have witnessed insurers that continue to discriminate against people, particularly those who experience serious health conditions, but no action is taken at either the state or federal levels,” said **Carl Schmid, executive director** of the **HIV+Hepatitis Policy Institute**. “While we are very supportive of the proposed rule, we urge HHS and states to devote the necessary resources to investigate complaints and benefit design that can lead to discrimination and take the proper enforcement against violators.”

“Any law or regulation is worthless if it is not properly and fully enforced,” commented **Quardricos Driskell, vice president of public policy and government affairs** of the **Autoimmune Association**. “Since the enactment of the Affordable Care Act, patients, particularly those with serious and chronic conditions who rely on prescription medications, have experienced discrimination through benefit design. Now it is important that state and federal regulators take the necessary steps to fully enforce the law and regulations.”

In addition to the **HIV+Hepatitis Policy Institute** and **Autoimmune Association**, other groups that signed the letter include the American Cancer Society Cancer Action Network, American Kidney Fund, Crohn’s & Colitis Foundation, Diabetes Leadership Council, Global Liver Institute, Hemophilia Federation of America, Lupus Foundation of America, National Minority Quality Forum, and National Psoriasis Foundation.

You can read the full letter [here](#).

###

The **HIV+Hepatitis Policy Institute** is a national, nonprofit organization whose mission is to promote quality and affordable healthcare for people living with or at risk of HIV, hepatitis, and other serious and chronic health conditions. For more information, visit hivhep.org. The **Autoimmune Association** is dedicated to the eradication of autoimmune diseases and the alleviation of suffering and the socioeconomic impact of autoimmunity through fostering and facilitating collaboration in the areas of education, public awareness, research, and patient services in an effective, ethical, and efficient manner. For more information, visit autoimmune.org.