

January 29, 2020

The Honorable Alex M. Azar II
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C., 20201

Secretary
U.S. Department of the Treasury
1500 Pennsylvania Avenue, NW
Washington, D.C., 20220

The Honorable Steven Mnuchin

The Honorable Eugene Scalia Secretary U.S. Department of Labor 200 Constitution Ave, NW Washington, D.C., 20210

Re: Transparency in Coverage CMS-9915-P

Dear Secretary Azar, Secretary Mnuchin, and Secretary Scalia:

The HIV + Hepatitis Policy Institute, a new national, non-profit 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, is pleased to submit comments on the proposed rule to increase price transparency in healthcare. People with HIV, hepatitis, and other serious and chronic conditions must know their costs up front so they can make informed decisions regarding their healthcare. While the proposed rule encompasses numerous elements, HIV + Hep will address just four issues: 1) co-insurance for prescription drugs must be translated into actual dollars; 2) patients should be made aware of the negotiated rate for prescription drugs; 3) co-pay accumulator policies must be included in the disclosure section; and 4) transparency requirements should not only be required for enrollees, but be made available to health plan shoppers and prior to the use of a health service.

HIV + Hep congratulates the Trump administration for focusing on the issue of transparency in healthcare. This is a critical component of the Patient Protection and Affordability Care Act that, to date, has not been fully realized. People who purchase and use healthcare must know

how much their health plan and health services, including prescription drugs, will cost them. In addition to the annual premium they need the plan's deducible, out-of-pocket maximum, and costs of each health service. With this information, they can make informed decisions based on their expected healthcare needs regarding what plan they should select for themselves and their families. Once they have health insurance, knowing the cost of their health services will help them decide, with their provider, what health services are appropriate for their care.

People with or at risk of HIV and people with chronic hepatitis and other serious and chronic health conditions depend on prescription medications to remain healthy, to prevent disease, or to be cured of their illness. Some of the treatments are for a short term while others can be required for an entire lifetime. With the development of new therapies, many of these drugs are brand name and can be very expensive. People need to know how much they will need to pay for these medications and how their specific health insurance plan will work for them and their family's specific health circumstances. This information is particularly needed as more health plans require beneficiaries to shoulder more of the costs of prescription drugs compared to other health services. According to a study conducted by Ezra Golberstein analyzing 2017 National Healthcare Expenditure Accounts data, beneficiaries were responsible for 14 percent of all prescription drug costs compared to only 3 percent for hospital care, the largest component of all healthcare spending.

1) Plans Must Translate Co-insurance into Actual Dollars: HIV + Hep is highly supportive of the proposal to ensure patients are provided their real cost-sharing liability in actual dollars. This is especially important as more plans move from utilizing fixed co-pays to co-insurance. A 2019 study by the Robert Wood Johnson Foundation examined patient cost sharing for all Silver plans across the nation and found that for costs of preferred specialty drugs after the deductible, only 10 percent of the plans utilize co-pays, while 69 percent use co-insurance, with the median amount being 40 percent. The problem for patients is that they have no idea how much the co-insurance translates into actual dollars and what they will pay. They do not know if it is \$400 for a \$1,000 drug or \$4,000 if it were a \$10,000 drug, even though both were subject to 40 percent co-insurance. Knowing the actual cost sharing liability is extremely important for patients.

HIV + Hep is aware that some plans have stated that it is difficult to translate the actual dollar cost for patients since the price of the drug fluctuates. This should not be used as an excuse not to require plans to provide beneficiaries the transparency they need. First, plans negotiate the price of the drug in advance and set contracts for long periods of time; the price does not

fluctuate frequently. Secondly, plans know the price of the drug and they can simply calculate for beneficiaries their costs. Third, while it is not in the best of interest of the patient, the basis for determining co-insurance in most instances is on the list price of the drug and does not reflect the actual cost the plan pays for the drug. That price does not frequently change.

2) Patients should be made aware of Negotiated Rate for Prescription Drugs: HIV + Hep is supportive of the proposal to require health plans to provide the negotiated rate for prescription drugs if it is used to determine patient cost sharing. Given the current national discussion on the cost of prescription drugs, patients should be provided information on what plans pay for their drugs, particularly since their co-insurance is unfairly based on the list price and not on the net price. Additionally, plans and PBMs are extracting significant rebates from drug manufacturers, which greatly inflate the list price of drugs. A recent study by Berkeley Research Group found that in 2018 hospitals, health insurers, pharmacy benefit managers, the government, and others retained 47.5 percent of what was spent on brand medicines, with drug manufactures recouping the remaining amount. Five years ago, the amount retained by middlemen and others was 33 percent, demonstrating their increased role in the drug supply chain. Knowing this data and information is very important.

Due to the growing level of rebates, discounts, and fees associated with the overall cost of prescription drugs, **HIV** + **Hep** is supportive of the disclosure of the negotiated rate for prescription drugs in other instances as well.

3) Co-pay Accumulator Policies should be included in the Disclosure section: HIV + Hep is supportive of the proposed "disclosure" section for beneficiaries as part of the transparency requirements health plans must provide. We strongly believe that health plans should disclose in this section if they do not count co-pay assistance and other third-party payments in the calculation of the beneficiary's deductible and out-of-pocket maximum. As more plans implement co-pay accumulators and do not count these payments, issuers must disclose these policies to their beneficiaries. To date, most plans bury these policies in plan contracts and leave patients unaware of the increase patient costs. This can leave them surprised mid-year when they may be faced with thousands of dollars in unexpected drug costs. This can easily lead to drug abandonment and lack of adherence and impact the patient's health and well-being. While we are very opposed to the practice of co-pay accumulators, if plans are allowed to implement them, beneficiaries must be clearly made aware of them. Including them in the "disclosure" section of the proposed transparency requirements seems to be the appropriate place.

4) Transparency Must be Required Up Front: Your departments are to be congratulated for proposing that group health plans and health insurance issuers disclose cost sharing information upon request to a participant, beneficiary, or enrollee and estimate cost-sharing liability for covered items and services. However, patients need this information prior to the selection of a health plan. Therefore, HIV + Hep strongly recommends that these transparency requirements be made applicable for the public while they are in the shopping and plan selection phase, not just after someone is enrolled in a plan. If we are to have true cost transparency, people need to know this information up front. This will help beneficiaries better determine which plan is best for themselves and their family and appropriately addresses their health and financial needs.

HIV + Hep thanks you for the opportunity to provide these comments in support of transparency of patient cost sharing in healthcare. With this increased transparency, people living with or at risk of HIV, hepatitis, and other serious and chronic health conditions will be better able to access quality and affordable healthcare.

Should you have any questions, please feel free to contact me at cschmid@hivhep.org or (202) 462-3042. Thank you very much.

Sincerely,

Carl E Schmid II
President