



September 7, 2022

Francis S. Collins, MD, PhD
Acting Science Advisor to the President
The White House
Washington DC 20500

Re: Comments on Proposed National Elimination Plan for Hepatitis C

Dear Dr. Collins:

Thank you for including the **HIV+Hepatitis Policy Institute** and me in the recent White House meeting at which you announced the National Elimination Plan for Hepatitis C. As someone who has long advocated for hepatitis C elimination, particularly since the advent of curative therapies, you cannot imagine how thrilled I am to hear of the administration's plans to eliminate hepatitis C over the next several years. **HIV+Hep** stands ready to work with you to help develop the initiative, to ensure it becomes a reality, and is fully implemented. Given my experience and leadership in advocating for and implementing the *Ending the HIV Epidemic* initiative and devising a national PrEP program, I believe my expertise can be especially helpful. I look forward to participating in the September 8th Patient Advocate meeting and support the list of questions submitted by a number of patient groups. Since you requested feedback on the proposal, I thought I would share with you some of my initial comments.

- 1) **How will the initiative be funded and authorized?** Given the level of funding (\$8-10 billion over 5 years) and the need to direct the funding to various entities and activities, what is the vehicle to fund and authorize the initiative? For example, will this be appropriated dollars or mandatory spending? The administration requested a mandatory spending program for PrEP and Congress has not expressed an interest in supporting it. For fiscal year 2023, the administration requested a \$13.5 million increase to the CDC's Hepatitis Division. Thus far, the Appropriations Committees' leadership has supported it, but it has not yet passed the Congress. This would bring the division's total funding to only \$54.5 million. This not only supports hepatitis C activities, but all hepatitis programs for the entire country. Last year, Congress only supported a \$1.5 million increase. Obtaining these minimal increases has not been easy. How will we

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realize the amount of resources needed to eliminate hepatitis C? Will legislation be drafted? What is the timeline?

- 2) **Where will the initiative be housed?** The CDC seems like the appropriate agency. Any initiative to end hepatitis C will require entities to conduct surveillance, outreach and education, testing and linkage to treatment, along with provider outreach. These are the most critical elements of an elimination program for which funding is needed but does not currently exist. The CDC can utilize its grant program to fund and carry out these activities. But it must be dramatically expanded and scaled up.
- 3) **Why is there a need for the government to purchase medications?** It seems that a large component of this initiative involves the government purchasing curative hepatitis C medications. However, payers, including private insurance, Medicare and Medicaid, already cover hepatitis C medications. I realize that initially there were concerns about the list price of the drugs and worries of an avalanche of people wanting to obtain them. However, while there was a pent-up demand at first, the dire predictions of millions of people asking for the drugs never did occur. As we explained to state Medicaid programs at the time, about half of the people with hepatitis C are not even aware they have the virus and we need education and testing campaigns first before they can access the drug. In any event, due to competition the price of the drugs has come way down since their initial launch.

By law, state Medicaid programs must cover hepatitis C drugs and as CMS has noted in the past, states should not impose restrictions that are not medically necessary. We believe the White House should take steps now to ensure that every state Medicaid lifts all their remaining restrictions on hepatitis C drugs. As the CDC recently noted, states that have Medicaid restrictions were 23 percent worse than other states in timely access to hepatitis C treatments.

Payers should be covering hepatitis C drugs and they should not be relieved of their legal obligation to do so. The White House should also focus on the barriers that people with health coverage are currently experiencing in accessing their hepatitis C drugs. As the CDC recently reported, only one-third of people with hepatitis C who have coverage are accessing curative drugs within one year of their diagnosis.

There is no need to fund a new and separate program to purchase drugs funded by the federal government when payers for those drugs already exist. Where there is a need for a system to provide medications is for those who lack any type of health insurance. That is what the drug component of the elimination program should focus on.

If a new system was put in place for the purchase of medications, I would presume that states and other entities would lose the significant rebates that they collect that are used to help fund programs, including for those who are uninsured.

Again, thank you for your strong interest in this extremely important endeavor. We are so thankful for outstanding leadership and look forward to working together to eliminate hepatitis C in our country.

Thank you very much.

Sincerely,



Carl E Schmid II
Executive Director

cc: Rachael L. Fleurence, PhD, Senior Advisor
Carolyn Wester, MD, Director, Div. of Viral Hepatitis, CDC