HIV Funding Was Canceled Even Before Trump Took Office

HPTN 096 went from a celebrated study to another casualty of deprioritization even before the new administration targeted health programs. #NBHAAD

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Numerous global organizations are struggling in the wake of sudden cuts to health funding by President Trump's new administration. But for LaRon Nelson, PhD, dealing with disappeared funds has been the status quo even before President Biden left office.

Nelson is the co–protocol chair of HPTN 096: Building Equity Through Advocacy—a three-year multisite HIV prevention study sponsored by the Division of AIDS (DAIDS) at the National Institute of Allergy and Infectious Diseases (NIAID) of the National Institutes of Health (NIH). The study is investigating whether using community-led strategies can increase health care engagement among Black men who have sex with men (MSM) who are living in the Southern United States and ultimately reduce HIV cases by increasing viral suppression rates and uptake of the HIV prevention regimen pre-exposure prophylaxis (PrEP).

And though HPTN 096 was well received at its May 2024 presentation to the NIAID HIV/AIDS Clinical Trials Networks Strategic Working Group—with HPTN's leadership offering $50 million to fund the study, writing that "significant starting funds will be provided up front"—to date, only $1.99 million of its promised budget has been delivered. As Nelson explains to POZ, that amount was only enough to fund work through the end of March 2025, "Which means we can't even sign contracts with facilities, because we can't institute a one-year contract with three months of funding. So the study has to stop."

Nelson says that normally a study that has been approved for three years will receive a third of its funding before the start of its launch year. But given the promise from the NIH that significant starting funds would be provided up front, he and his colleagues were expecting to receive $25 million to conduct their work.

Alarm bells about the lack of funding did not sound right away, Nelson says. After all, he'd received enthusiastic responses about the study from community members and from HPTN's leadership. The study's design had even been highlighted for its impactful strategies by DAIDS director Carl Dieffenbach, PhD, during his presentation at the June 2024 HPTN Annual Meeting.

By September 2024, HPTN 096 had received its protocol and begun recruiting participants at health care facilities in Dallas; Montgomery, Alabama; and southern Florida. And while Nelson says the rollout was incredibly successful, it soon became clear that the promised funding was not forthcoming. After seeing that HPTN 096 had not been included in the annual notice of approved studies, Nelson reached out to NIH's leadership, asking where the study's funding was. He says he was told, "We don't know."

"There's been rhetoric about NIH's support for the study," Nelson says. "But it has not translated to financial support for us. And that comes at great risk, not just to the study but to the communities that we work with that have invested so much of their time into helping us prepare for this." In December 2024, Nelson sought assistance from the HPTN Black Caucus, which provides support to studies that focus on historically underrepresented communities. The group responded by conducting an investigation. POZ was invited to sit in on one of the caucus's planning meetings. Though the proceedings are anonymous, one member noted, "Project 2025 started under the Biden administration." After coming to an agreement with all its collective members, on January 5, 2025, the caucus sent NIAID and DAIDS's leadership a letter titled "A Call to Action for HPTN 096 Funding."

"The precarious predicament of HPTN 096 sends a troubling message about the network's genuine investment in addressing HIV inequities," the letter states. "Particularly for Black/African American MSM, to ensure that no community is left behind in the fight against this urgent public health crisis," the letter continues. "This message will have exponential negative ramifications for the public standing and reputations of Black researchers, stakeholders and community advocates engaged in HPTN 096, who have invested decades of their lives in building the trust of Black community members. It is the ethical responsibility and a monumental act of integrity for NIAID/DAIDS and the HPTN to honor their financial commitment to HPTN 096."

A few hours after the letter was sent, Myron Cohen, PhD, co–principal investigator of HPTN, responded, "We are all well aware of the situation you summarize, discussed at every call with NIH. I am sure you are also aware [that] NIH does not know its budget, which surely plays a critical role." The following day, Sheryl Zwerski, DNP—the director of NIH's Prevention Sciences Program, who set HPTN 096's budget at $50 million—wrote, "We are in process of finalizing a funding supplement that will carry the work through March, and we also plan to issue another larger funding supplement for the FY25 projected needs with a target date of March 14th."

When contacted for comment about HPTN 096, HPTN co–principal investigator Wafaa El-Sadr, MD, responded in an email to POZ, "We have discussed with NIH and highlighted the urgency for securing the funds to continue HPTN 096. NIH recognizes the importance of the study. We are hopeful for a rapid resolution."

For Nelson and his colleagues, these words might as well be another set of empty promises. "Not unlike the [HIV] epidemic in general," Nelson says, "all of these social structures come together to protect certain people—white people—and leave Black communities vulnerable. Many other studies are exposed, but they got [their funding] in November. Now we're exposed, and they are

trying to scramble to borrow money from this new administration."

With its projected budget of $50 million, HPTN 096 would have been the largest investment that the NIH had ever made into the study of African-American MSM. It would have been a stark turnaround from the NIH's history of awarding disproportionately more NIH Research Projects (R01) to white scientists over Black scientists. That's one reason why Darren Whitfield, MD, who served as a protocol member for HPTN 096, tells POZ that, while he has "never seen a case where a study of this magnitude has lost funding," he is not surprised by the outcome. With an eye on the paucity of studies that focus on Black queer men in NIH's portfolio, Ernest Hopkins, senior strategist and adviser of San Francisco AIDS Foundation, tells POZ in an email, "That oversight precedes this Administration and should be viewed with great shame."

But the final word on the issue comes down to what it means to the community. While speaking with POZ, Damon Jones, the cofounder and CEO of Afro Pride Federation—whose center has participated in HPTN 096—explains: "The program worked because it brought in money and empowered the community. It's important that we educate our peers so that they can educate our other peers about what's going on. And it's important to choose the people we know, because we are more inclined to trust them."
