

CDC Staffing Upheaval Disrupts HIV Projects and Wastes Money, Researchers Say

Researchers were laid off just before they put the finishing touches on in-depth, national surveys about HIV.

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Dozens of HIV experts at the Centers for Disease Control and Prevention received emails on Wednesday revoking notices they received 10 weeks ago that laid them off. Damage to their projects may be permanent, however, and ongoing restrictions on their research will harm lives, multiple HIV scientists at the CDC told KFF Health News on condition of anonymity because of fears of retaliation.

The researchers were laid off in early April, just before they put the finishing touches on in-depth, national surveys about HIV. Health officials across the country had interviewed tens of thousands of people at risk of acquiring HIV, or who are living with the virus, and compiled information from mountains of medical records.

States and cities were prepared to submit the information they collected to the CDC in April so the agency's statisticians could prepare the volumes of data for analysis.

Health officials and policymakers use the data to design HIV programs that more efficiently curb the spread of infections and save lives. For example, a [2023 survey](#) revealed that about half of adults under age 30 who were living with HIV weren't on treatment steadily enough to keep them healthy and prevent them from spreading the virus to others. Treatment rates were far higher for those over 50. As a result, health officials doubled down on outreach to younger generations.

However, in April, state and local health officials found themselves cut off from their CDC counterparts after the layoffs. Emails from the Department of Health and Human Services told staff their roles were "either unnecessary or virtually identical to duties being performed elsewhere in the agency."

Marti Merritt, a project coordinator at the Illinois state health department, was flabbergasted that she and other state employees had invested more than a year into the surveys only to have them

go dark in the final phase. “It’s like the data has gone into a black hole,” she said. “How do you set priorities if you don’t have data?”

Merritt worries that if the surveys don’t resume, limited budgets will be misspent — and that cases will rise. Data allows health departments to tailor their efforts to the populations at greatest risk of infection or disease progression.

Evidence shows that preventing HIV is far cheaper than treating people once they’re infected. Preventing one HIV infection results in [\\$466,000 in lifetime savings](#). Merritt was also dismayed to have wasted the time of thousands of people who opened up about intimate details of their lives in hopes of fighting the HIV epidemic.

A doctor and HIV expert reinstated at the CDC this week said the late termination of the surveys would waste millions of taxpayer dollars that have already been spent on data collection. Two large, long-standing efforts, the Medical Monitoring Project and the National HIV Behavioral Surveillance system, cost around \$72 million, he said.

“Two years’ worth of data from 30,000 participants will be unusable, and therefore wasted,” if the projects can’t be finished, he said.

To resume the surveys, he and other CDC researchers would need a green light from higher up because the grants covering these surveys ended while they were on administrative leave in May.

State health officials said they haven’t received the CDC notices that typically renew the surveys every June. Merritt has conducted interviews for the Medical Monitoring Project for about 20 years, she said, but the Illinois health department has now assigned her to other tasks. Other health departments have [laid off](#) or reassigned employees dedicated to HIV surveillance, too.

If HHS allows the reinstated researchers to resume the projects, they could try to account for the 10-week gap in their analysis. But it would take time, further delaying the next round of surveys — if those begin at all.

“These surveys aren’t lights that you turn on and off,” said John Brooks, a researcher who retired from the CDC’s Division of HIV Prevention last year. If the surveys resume, he said, “we can get some value out of all of the money spent.”

However, the surveys would be further impaired by actions related to Trump’s executive orders targeting words such as “gender” that researchers use to learn who has HIV, who is at risk, and why.

Experts at the CDC said they’ve already had to revise earlier surveys and recalculate results to not reference gender. This has meant altering data on two populations disproportionately affected by HIV: transgender people and men who have sex with men.

“To erase people from our data harms them,” said the researcher and doctor now reinstated at the

CDC. “I care about the transgender patients I see, and it’s so hurtful to see them treated this way by the government.”

The doctor said he has treated HIV patients since the beginning of the epidemic in the 1980s, and the sting he feels now is worse than under President Ronald Reagan, who never publicly mentioned HIV in his first term.

“There was a lack of funding,” he said, “but they didn’t censor science or try to control science like they’re doing now.”

Many HIV researchers have taken jobs outside the government or moved since the April layoffs. Some researchers returning to the agency called the reinstatements perplexing because the notices don’t say what they’ll be doing when they return and for how long.

A terse email to CDC employees from Tom Nagy, chief human capital officer at the Department of Health and Human Services, reviewed by KFF Health News, simply refers to the notice regarding the reduction in force and says, “That notice is hereby revoked.”

In an email response to queries, Andrew Nixon, HHS director of communications, wrote, “HHS is streamlining operations without compromising mission-critical work. Enhancing the health and well-being of all Americans remains our top priority.”

“We’ve been getting paid this whole time even though we’ve not been allowed to work, and that doesn’t feel good when you’re a dedicated civil servant,” said one reinstated employee.

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