Biden Rule Cleared Hurdles to Lifesaving HIV Prevention Drug, but in Georgia Barriers Remain

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Latonia Wilkins knows she needs to be on PrEP due to her non-monogamous lifestyle. But the 52-year-old Atlanta mother has faced repeated challenges getting the lifesaving drug that can prevent new HIV infections.

Years ago, Wilkins was dating a man newly diagnosed with HIV and went to get tested, she said, but was not offered PrEP.

Since then, Wilkins said, doctors either have told her she doesn't need the drug or were reluctant to prescribe it. Her insurance through work would not cover a long-acting injectable form that tends to have better results than the original pill form. Getting to appointments across Atlanta for the pills was a challenge. She is now enrolled in a drug trial for a promising PrEP injection but worries about future access and cost.

Preexposure prophylaxis, known as PrEP, reduces the risk of new HIV infections through sex by 99% and among injectable drug users by at least 74%, according to the Centers for Disease Control and Prevention.

Among states, Georgia has the highest rate of new HIV infections, but residents — especially women and Black patients like Wilkins — are often not getting PrEP, data shows.

A rule enacted by the Biden administration that took effect for many Affordable Care Act plans on January 1 should make it easier for people like Wilkins to get long-acting PrEP injectable drugs.

A new Trump administration adds an X factor to this and other federal health programs. On January 27, the White House announced a federal funding freeze, which sent shudders through health agencies and nonprofits. By January 29, it had reversed the order.

Federal initiatives like the Ryan White HIV/AIDS Program and HIV prevention funding seemed to be

affected — and “blocking access to PrEP would have deadly consequences,” said Wayne Turner, a senior attorney at the National Health Law Program.

Georgia has big racial and gender discrepancies in PrEP uptake, said Patrick Sullivan, who is an epidemiology professor at Emory University and leads AIDSVu and PrEPVu, which track HIV data and access to the drug — work that is backed by Gilead Sciences, a PrEP drug manufacturer.

Public health experts use what’s called a “PrEP-to-need ratio” to measure how many people at risk of HIV are getting the drug. A higher number is better. In Georgia for 2023, the statewide ratio was 6, while it was nearly 167 in Vermont, according to PrEPVu.

Kae Petrin/Healthbeat

While the ratio for white people in Georgia was roughly 22, it was about 3 for Black people and just over 3 for Hispanic people. And while it was 7 for men, it was just over 2 for women.

“Black people generally are underserved by PrEP, and women are underserved by PrEP relative to men,” Sullivan said.

Increasing PrEP uptake would help the state cut its new HIV diagnoses, said Dylan Baker, associate medical director at Grady Health’s HIV Prevention Program.

Georgia’s rate of new HIV diagnoses was 27 per 100,000 in 2022, according to the most recent available data. That’s second only to Washington, D.C., and more than double the national rate of 13 per 100,000. That amounts to about 2,500 new cases diagnosed in Georgia in a year.

Globally about 3.5 million people used PrEP in 2023, up from 200,000 in 2017 but short of the

United Nations' 2025 target of 21.2 million people, according to a 2024 report by the United Nations Program on HIV/AIDS.

PrEP users in Atlanta report many challenges in getting the drug, including cost, medical providers who don't prescribe it, stigma, a lack of inclusive marketing, and transportation. Wilkins said she has run up against all of those.

"Here I am telling you that I'm here to get tested because I have come into contact with someone who was living with HIV, and we had a sexual relationship, and you're not even mentioning PrEP to me," Wilkins said. "That was a disservice."

Insurers Now Required To Cover PrEP

Cost has long been a barrier. The Biden administration last fall issued guidance requiring most insurers to cover the full cost of all forms of PrEP, without prior authorization, along with certain lab work and other services. This includes pills as well as Apretude, an injection given every two months.

That means insured PrEP users should not face out-of-pocket costs, said Carl Schmid, executive director of the HIV+Hepatitis Policy Institute, which lobbied for the rule.

It applies to those on the federal marketplace plans and most large private health plans. A similar rule exists for Medicare and Medicare Advantage plans.

Schmid said he does not think the Trump administration will repeal the rule, but he is concerned the U.S. Supreme Court could end coverage for preventive services, including PrEP, when it issues a decision in Braidwood Management v. Becerra, anticipated this summer.

The rule will not help the uninsured. In Georgia, which did not expand Medicaid under the ACA, about 1 million adults under age 65 are uninsured.

"The cost is also a struggle, especially given different people are part of the gig economy, a lot of folks don't always have access to health insurance," said Maximillian Boykin, an Atlanta PrEP user.

Expanding Medicaid would help. States that have done so, Sullivan said, "have higher levels of PrEP uptake."

Winning the PrEP Lottery

Since getting on PrEP in 2019, Wilkins has encountered two doctors who did not want to prescribe it.

One female OB-GYN told her "'Girl, at our age, we should know better.'" Wilkins said she "fired" that doctor, telling her that such comments are stigmatizing.

When Wilkins moved, she looked for a nearby primary care provider so she would not have to pay

for transportation to get PrEP.

But the doctor she found, Wilkins said, told her to find an infectious disease specialist for PrEP.

"'You're not treating an infectious disease,' I say. 'This is preventive care,'" Wilkins recalled.

Wilkins' fortunes turned when she was selected to join a study for a twice-yearly injectable form of PrEP.

Lenacapavir, already approved for HIV treatment, showed promising results for HIV prevention in two earlier Gilead trials. Wilkins is part of a trial in Atlanta including about 250 cisgender women nationally who have sex with men.

It's much better than a daily pill or even a shot once every two months, Wilkins said.

She hopes to stay on the drug, but the U.S. list price for lenacapavir as an HIV treatment averages about $40,000 a year.

Gilead last year announced it signed royalty-free licensing agreements with six manufacturers to make generic lenacapavir for 120 primarily low- and lower-middle-income countries.

It's not clear where it falls with the Biden rule. "We believe it should be covered," Schmid said, "but want the federal government to state that clearly."

For many patients, challenges remain. Most people are willing to travel about 30 minutes for routine health care, Sullivan said, but in cities like Atlanta, those relying on public transportation may face longer commutes to PrEP providers. Some who need PrEP have unstable housing without firm mailing addresses.

Privacy is another concern. "Everybody should be able to find a place that's comfortable," Sullivan said. "More of that can go on in primary health care."

Others agree that public health messaging around PrEP services should target more diverse audiences. Dázon Dixon Diallo is the founder of SisterLove, an HIV, sexual, and reproductive health organization focused on Black women in the Southeast.

"You're not going to get to us by giving us a 3-second cameo in a commercial about PrEP," she said. "There's no story in there for me, right?"

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