"What is PrEP?"

How little blue pills that could save lives aren't reaching the people that need it most.

BY ALEX FURLIYA



PHOTO BY ALEX FURUYA

It's another busy day at the Uptown Neighborhood Health Center, located on 845 W Wilson, Chicago. Clients wait in long lines, parts of the building are under construction and receptionists are answering calls on every floor. Leticia Sustaita seems to float past the chaos to her clinic, nestled in a small corner of the health center.

"The office is usually quite busy," says Sustaita. "We have several programs and several offices and a small space. We have clinics, we have medical case management, we have HIV testing, mental health services for our clients as well..." She pauses to think, "I can't even remember what else."

As the program director of the University of Illinois Health Community Clinic Network, Sustaita is in charge of creating outreach programs to reach populations such as young men of color or low-income individuals that may be at risk of getting HIV but do not have resources, including basic healthcare. One of Sustaita's most important jobs is to answer questions her clients might have about the human immunodeficiency virus (HIV). Recently, however, many of her clients have been asking about preexposure prophylaxis (PrEP), a relatively new method of preventing HIV infections with a single blue pill.

"We are already offering PrEP at the FCID clinic and that's open to the general public," Sustaita says. "You don't have to have insurance for it. You do have to apply to the AIDS Drug Assistance Program, which does cover the PrEP treatment."

Sustaita's job is not an easy one. While PrEP is a great medical advancement in HIV prevention, getting the regimen to the people who need it has been a hurdle. There are a few explanation for this challenge. First, when the FDA first approved the regimen, misinformation about PrEP and the misconceptions surrounding it discouraged some people from seeking PrEP. Some people considered those who took PrEP to

be promiscuous, or even "Truvada Whores." The other big barrier is that certain people may not even know about intervention in the first place. Those who lack primary health care due to socioeconomic conditions often do not receive the information they need to access Truvada. Therefore, factors such as race and gender can affect one's access to PrEP or information about it. To top it off, the new presidential administration has caused many health care professionals to feel unprepared for upcoming cuts to healthcare.

PrEP is a pharmaceutical regimen that prevents HIV infections for HIV-negative people. HIV is the virus that lead to AIDS, or acquired immunodeficiency syndrome, a disease that attacks the immune system. Approximately 1.2 million people in the U.S. are living with HIV and there are about 50,000 new HIV infections every year, according to CDC. The virus attacks CD4 cells, also known as T-cells, which are an essential part of the body's immune system, according to the U.S. Department of Health and Human Services. After the virus destroys enough CD4 cells, the body becomes susceptible to infections and infectionrelated cancers. This can lead to serious health complications and even death. Fortunately, HIV is a fragile virus and can only be transmitted through bodily fluids such as blood, semen and breast milk but not saliva. The virus, therefore, can only spread through sexual intercourse or sharing injection drug equipment.

As of now, there are no known cures for HIV. Luckily, there are treatments called antiretroviral therapy (ART) that can control HIV. Today, people living with HIV can live nearly as long as someone who does not have HIV. That said, ART is expensive. In 2010, the average annual cost of HIV care for an individual was \$19,912, according to a study published in the *Journal of the International AIDS Society*. The number varies depending on how advanced one's disease is and whether there are other comorbidities, or other diseases, present.

Until recently, there were only a few ways to prevent HIV infections via sexual intercourse. People could use condoms or engage in sex that did not transfer fluids. If someone believed they had had risky sex, they could opt to seek post-exposure prophylaxis (PEP), a regimen similar to PrEP. However, PEP had two substantial limitations. First was that the person has to recognize they might've been exposed to the virus, and second is that they have to start the therapy within 72 hours after the potential exposure episode.

Then came PrEP, The regimen that consists of taking a drug called Truvada once a day. The drug, which includes emtricitabine and tenofovir disoproxil fumarate, tenofovir DF, lowers the chances of getting infected by HIV.

"Prophylaxis is prevention," says Dr. Peter Anderson, the director of the Pharmaceutical Sciences graduate program at University of Colorado Boulder and one of the researchers in the development of PrEP. "Both antiviral drugs inhibit the replication of virus."

The drugs act as agents that inhibit the virus from infecting the body. "If you've got the drugs on board before you're exposed to HIV at a high enough concentration, the virus can't replicate at all because the drugs are there to stop it and that essentially aborts the ability of the virus to infect the host," says Dr. Anderson.

Emtricitabine and tenofovir DF both belong to a class of HIV drugs called nucleoside reverse transcriptase inhibitors (NRTIs), according to the U.S. Department of Health and Human Services. These inhibitors block an enzyme, or a protein that starts a chemical reaction, in the virus. This particular enzyme is called reverse transcriptase and is responsible for the virus' ability to replicate. By blocking the enzymes, NRTIs essentially stop the virus from replicating. By taking Truvada everyday, the cells in the body are essentially protected by the NRTIs and block the virus from infecting the body.

Truvada, in theory, isn't the only drug that could be used for PrEP. There are other antiretroviral drugs that could potentially be used to prevent HIV infections. However, the specific drug was chosen, according to Dr. Anderson, because of its efficacy and general lack of serious side effects.

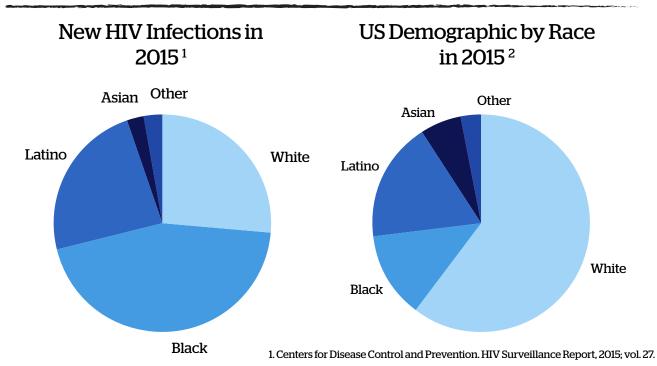
After the 2012 Preexposure Prophylaxis Initiative (iPrEx) trial which found that Truvada could prevent HIV infections among men who had sex with men (MSM), the FDA approved the regimen for HIV negative individuals.

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At first, PrEP was seen as groundbreaking. "Today's approval marks an important milestone in our fight against HIV," said FDA Commissioner Margaret A. Hamburg, M.D in an FDA news release. Soon thereafter, misconceptions about PrEP began to spread online and in conversation. Many

HIV Prevention Methods			
	Condoms	Post-Exposure Prophylaxis (PEP)	Pre-Exposure Prophylaxis (PrEP)
Relative Risk Reduction	80%	92%	92%
Benefits	Most accessible HIV prevention method.	Efficient in preventing HIV and is only a month-long treatment	Prevents possible HIV transmission before the risk episode happens.
Possible Challenges	Some people prefer not to use condoms and there are chances of breakage or slippage.	You must go on PEP within 72 hours after the risk episode and there some side-effects.	Must be taken everyday and also includes a routine check- up every three months. Also possible side-effects.

Disproportion in race between new HIV infections and US population in 2015



2. U.S. Census Bureau, "Table 10. Projections of the Population by Sex, Hispanic Origin, and Race for the United States: 2015 to 2060," Population Projections (2014).

believed that PrEP would simply enable men who had sex with men, or MSM, to practice unsafe sex and to forego condoms. Some believed that PrEP would encourage gay men to find more sexual partners, therefore putting them at a higher risk for HIV. In 2012, David Duran wrote in an articile in the Huffington Post titled, "Truvada Whores?" "Instead of educating and promoting safe sex practices," he writes, "the FDA is encouraging the continuation of unsafe sex and most likely contributing to the spread of other sexually transmitted infections."

Such concerns are reminiscent of old misconceptions about HIV from the 1980s, according to Amy Partridge, the senior lecturer in Gender & Sexuality Studies at Northwestern University. When the disease that we now know as autoimmune deficiency syndrome (AIDS) was first discovered, it was first described as a "gay cancer" and later known as "Gay-Related Immune Deficiency" (GRID).

"In those first four years or so, there were many hypothesis from epidemiologists and scientists, and from the gay community as well, as to what is causing HIV/AIDS," says Partridge. "Because they are working under the

rubric of a gay cancer or GRID, most of the hypotheses related to some aspect of gay life or gay male culture at the time."

At first, scientists believed that poppers, or chemicals called alkyl nitrites that were inhaled for sexual recreational purposes, were causing the disease. A popular theory as to what caused so many deaths among gay men at that time was that gay men had a viral "overload"

young adults, gay men of color as well as women who were also affected by AIDS.

"The earliest case reports were typically people who had access to medical care," says Prof. Aaron Norton, a visiting assistant professor in Gender & Sexuality Studies and Sociology at Northwestern University. "The gay men who had upper-middle class jobs were more likely to have medical care so they

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-Professor Aaron Norton

because they were so promiscuous.

"The theory of poppers and the theory of promiscuity both presuppose the fact that there's something fundamentally unnatural and something pathological that lead to disease in the gay male community," Partridge says.

The face of AIDS, at the time, was often the white gay man. This excluded

were more likely to make it into case reports. That wasn't intentional prejudice or discrimination on the part of the HIV clinicians, it was a product of larger social forces of structural conditions.

"Those framings of HIV still function today and how our laws operate and how people experience HIV stigma and so on," he says. Even today, MSM of color have a higher risk of getting HIV, according to Sustaita, who works with Latino MSM. In addition to encountering language and organize and plan outreach programs.

"Outreaching to [the undocumented] community is probably the best way to get a hold of that population," Sustaita

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cultural barriers, Latino MSM also face legal barriers if they are undocumented. In 2015, black gay and bisexual men accounted for almost 40 percent of HIV diagnoses in the United States, according to CDC. Black women, too, are also a population that is at high risk for HIV.

Just as HIV was codified as a "gay disease," stigma surround PrEP as well.

"PrEP gets coded as promiscuous," Dr. Norton says. "That's a negative stereotype that attaches to people who are on PrEP."

"On the flipside of that, I've experienced in sexual communication, someone saying, 'Oh you're not on PrEP? I don't want to have sex with you because you're not on PrEP.' So you can have stigma that moves in both directions."

In addition, some may not know their options to prevent HIV infections. If a person does not know about PrEP, says Norton, then he or she will not seek it.

That is where health professionals believe outreach can make an impact. Outreach, in terms of public health, is the act of reaching out to a population and providing services that they might not otherwise have. In this case, health professionals are attempting to reach out to MSM of color and provide information and even prescription for PrEP. Some health entities create signs or promotional content to advertise PrEP or HIV testing. Some, like Sustaita, says. "We can educate them and let them know that we're here and give them the knowledge about what PrEP is. A lot of people have misconceptions."

Health professionals, however, find that creating the perfect outreach programs to be challenging.

"Outreach is great in a whole of range of ways and it's a public health priority to make MSM have access to things like PrEP to avoid getting HIV because that's where we the highest rates currently," Partridge says. However, "There is always a question about being the target of a public health strategy. Individually it is great to have access to [treatment], but what does it mean to be on the receiving end of a public health strategy?"

New HIV Infections

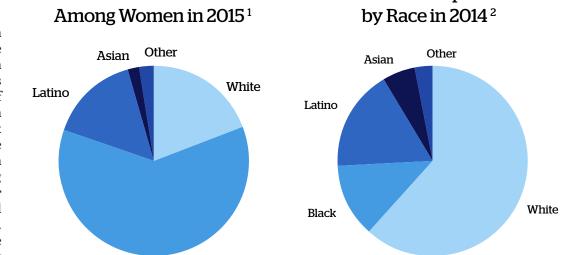
Black

Margaret Pollak, a lecturer in the Global Health Studies and Anthropology departments at Northwestern University, finds this to be particularly true in her research on diabetes intervention. Certain strategies that target a group of people can create pessimism. "With diabetes in Native communities, people feel really fatalistic," Pollak says. "A lot of people see that everybody in the community has it or has a family member with diabetes. Having posters with a Native face representing diabetes can have a detrimental effect because it makes it easier to say, 'Well, I'm going to get diabetes, so I'm not going to do anything about it or try to prevent it."

In HIV prevention, this issue is not new. "In general, what we've seen over the course of 25 years is that very vexed or complicated set of dimensions in reaching out to intervene and try to reduce people's risk of HIV," says Dr. Norton.

Say you have an initiative to have young black MSM use more condoms. "What kind of representation do you use?" asks Dr. Norton. "Do you use a person of color? Or does the person of color end up recapitulating or reaffirming the stereotypes of people of color of being more likely to be diseased which has been a long-time narrative for the past one-hundred years of history?"

Disproportion in race between new HIV infections and US population among women



1. Centers for Disease Control and Prevention. HIV Surveillance Report, 2015; vol. 27.

US Women Population

 U.S. Census Bureau, "Table 10. Projections of the Population by Sex, Hispanic Origin, and Race for the United States: 2015 to 2060," Population Projections (2014). In addition, these campaigns do not necessarily affect just the people targeted by these outreach programs. "Other people see these images, too, and that may kind of reinforce their idea of a person of color as the risky person that you might want to think twice about having sex with and so on," Dr. Norton says. "You're walking a fine line when you try to intervene and how you do that."

On the flipside, not having a representative from the target population in a public health intervention can be exclusive. Most mainstream promotional material about PrEP feature a very homogenous set of people, according to Camille Beredjick, a former employee at the HIV/AIDS community health center Harlem United, who now works at Joyful Heart Foundation, an organization that

However, after she clicked the off switch, she knew her clients, those who were from marginalized communities, were in trouble

With the new administration's promise to repeal ACA, limit Medicaid and target undocumented immigrants, Sustaita knew that there would be many questions she and her staff couldn't answer, and that scared her. These questions include, "What's going to happen to my insurance?" or "What's going to happen to my treatment?"

"I don't have answers for them," Sustaita says. "I think that's one of the more frustrating things my staff and I go through – We don't have answers for [our clients]."

While it is unclear whether or not access to PrEP will be directly affected

"Suddenly if there's fewer outreach initiatives because there's no longer grant money, then you can have fewer people knowing that PrEP is even an option for them."

"PrEP is most direly needed in communities that direly need healthcare and health insurance because they're least likely to have it," Beredjick says. "In the mainstream, middle and upper class white gays, HIV rates are generally going down, but for younger folks and folks of color, it's going up."

While this might seem bleak for the future of outreach programs, Partridge is still hopeful that those affected will prevail. She believes that early models of activism and organizing, including buyers clubs, can still be used today. Buyers clubs, made famous by the 2013 movie, Dallas Buyers Club, are groups that help individuals get access to HIV medication. Even if PrEP does become harder to access, Partridge believes that there would be ways to still get access to the drugs.

"It's important to go back to early AIDS organizing," Partridge says. "Buyers clubs were real and could certainly be put back in place if things really do become unavailable and overly expensive in the US and inaccessible. I don't think anyone should leap to that, we should fight to keep the institutions that we have and to keep them functioning for all of us, that should be our first priority. Should the worst case scenario happen with Trump, however, we have some pretty good models."

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works to eliminate sexual violence, domestic violence and child abuse. While working at Harlem United, Beredjick worked on a campaign called, "Swallow This," in order to have discussions surrounding HIV prevention and PrEP be more inclusive.

"In HIV prevention and also in PrEP, a lot of the ads you usually see depict an attractive couple holding each other and it says, 'I take it for us,'" Beredjick says. "There's also this whole demographic that aren't in monogamous relationship and these people don't sleep with one partner or a single gender.

"Harlem United has tried to go outside of the mainstream, sort of well-behaved narrative of HIV and say 'Hey, PrEP can work for you even if you don't look like this nice, married white gay couple in the ad," she says.

The current, biggest hurdle, however, is coming from the White House.

Leticia Sustaita remembers turning off her home television November 8, 2016, after seeing the states turning red. Usually not a political person, Sustaita was initially excited to watch the coverage of the 2016 presidential election.

by the new administration, outreach programs that are so crucial to reaching vulnerable populations including MSM of color can be affected. Many of these outreach programs are done by community clinics.

Currently, PrEP, in general, is free for anyone. "If you're a sexually active person and you get to the right clinician, they will prescribe it to you," Dr. Norton says.

"Anyone can get on PrEP," said Beredjick. "You just have to ask a doctor and it's covered by most insurances or Medicaid."

"We already see things budgetarily," says Partridge. "I do think a lot of those funds that are coming through Health and Human Services and National Institute of Science and so on— I think those have the possibility of really losing a lot of funds. A lot of programs and recruitment strategies are going to have to shut down."

If funding for outreach programs are scaled back, then some people who may be in need of PrEP might not learn about it. "Scaling back on that could have implications for people's access if there aren't also these other outreach peoples making people aware," Dr. Norton says.

The center is as busy as before. While

it might seem like any other day at the center, Sustaita is still worried about Trump.

"The rhetoric that Trump's campaign carried and what he continues to say about Mexicans, immigrants, Muslims – all of that makes me feel very uncomfortable," Sustaita says, wearily. "That's the population that we serve. It worries me."

However, Sustaita believes that HIV services will prevail.

"These services are still very, very necessary," says Sustaita. "HIV is still very prevalent, especially in low-income communities and individuals who are positive right now. They still need our support."