# PrEP: A Dream Deferred

The much-celebrated HIV prevention pill is failing to reach those at highest risk for the virus: Black men who have sex with men.

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The use of Truvada as PrEP—pre-exposure prophylaxis to prevent HIV—is going gangbusters.

By the end of 2015, likely well over 80,000 U.S. residents had filled at least one prescription for the daily tablet. And given the steadily increasing rate of new prescriptions registered each quarter, the population of HIV-negative people who have at least tried PrEP has probably swelled considerably by now. This is fantastic news for the effort to stem the tide of HIV infections among men who have sex with men (MSM), whom data suggest make up the vast majority of PrEP users. While it's still too early to determine Truvada's initial impact on infection trends—PrEP started gaining popularity only in late 2013—clinics with large populations of high-risk MSM on PrEP have reported very low HIV rates among them.

Indeed, this is fantastic news—for white MSM.

The picture has become increasingly clear: PrEP is largely failing to help those who need an HIV prevention game changer most desperately, namely Black MSM, in particular those younger than 25.

According to an estimate from Gilead Sciences, which manufactures Truvada, about three quarters of the men who have filled a PrEP prescription are white while just 9 percent are Black. Considering the racial breakdown of the epidemic among MSM, these figures are gravely lopsided.

Courtesy of Harlem United

“We’re not starting from a very good place,” says Eli Rosenberg, PhD, an assistant professor of public health at Emory University in Atlanta, reflecting on the initial demographic patterns of PrEP use.

During dozens of interviews with stakeholders in the PrEP field, including clinicians, social service workers, nonprofit leaders and researchers, many expressed concern that an unexpected downside of PrEP’s recent burst onto the scene is that the HIV prevention method is apparently on a path to widen already tragic racial disparities in infection rates among MSM.

In a nation facing a critical moment of reckoning with respect to race relations, the racial discrepancy in PrEP’s use thus far may result in yet another example of whites benefiting from a major societal advancement while African Americans are largely excluded.

“Honestly, I believe that if HIV rates are lowered in the white gay community, they will definitely lose interest in lowering rates in communities of color,” says Thomas Davis, a health education specialist at the Los Angeles LGBT Center who is African American. “They’ve been leaving us out since the start of the epidemic and still do to this day unless they’re called out for it.”

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“Unfortunately, right now, the government, our health care system and our society in general are not focusing enough on putting resources into increasing PrEP uptake among Black folks—it’s clear,” says Ashwini Hardikar, MPH, director of prevention and outreach at the LGBT-focused Callen-Lorde Community Health Center in the Chelsea neighborhood of Manhattan.

Callen-Lorde has the largest PrEP program—2,400 people strong—in New York state, of whom only 12 percent are Black. “We know that historically, Black lives have not mattered in this country,

and we need to turn that around, especially when it comes to PrEP," Hardikar says.

HIV among Black MSM remains a crisis in need of a response. An astonishing one quarter of the approximately 40,000 U.S. residents diagnosed with HIV annually are members of this minority within a minority. (MSM as a whole make up two thirds of new diagnoses.)

The Centers for Disease Control and Prevention (CDC) recently projected that if current trends persist, half of all Black MSM will contract HIV in their lifetime, compared with 1 in 11 (or 9 percent) of their white counterparts. And in a CDC study of MSM in 20 major U.S. cities, 30 percent of Blacks were living with HIV, compared with 14 percent of whites.

So for Truvada to make the greatest possible impact on HIV rates, its use as prevention would need to reach a critical mass among at-risk Black MSM. Instead, PrEP has increasingly found its niche among white MSM, a demographic that has already long benefited from a dropping HIV diagnosis rate, to the tune of an 18 percent decline between 2005 and 2014. During that time, diagnoses among Black MSM rose 22 percent, with an 87 percent surge among young Black MSM. (In promising news, however, the HIV rate among Black MSM, including youths, has leveled off in more recent years.)

The fact that PrEP is largely used by men older than 25 further limits Truvada's power to prevent new infections among Black MSM, since 45 percent of new cases among Black MSM are in 13- to 24-year-olds, compared with just 16 percent among their white counterparts. PrEP is not even approved for those younger than 18, and recent research suggests that teen MSM have trouble adhering to PrEP unless they are seen for monthly clinic visits, a considerable undertaking.

Regional disparities add yet another problematic layer. The South, with its high Black population and its woefully inadequate public health response to HIV, has become the hotbed of the epidemic among MSM.

Out of the top 25 so-called metropolitan statistical areas with the highest rates of diagnosed HIV among MSM, all but four are in the South, according to Rosenberg's research. Rosenberg also recently estimated that 11 percent of all young Black MSM in Atlanta contract HIV every year.

Unfortunately, PrEP has tended to make the greatest traction in major urban areas outside the South. And these cities are still often failing their local Black MSM populations with regard to PrEP.

In San Francisco and New York, which have undertaken concerted efforts to promote PrEP as a part of elaborate and costly epidemic-ending enterprises, reports from numerous sources show that use of Truvada among HIV-negative Black MSM remains disproportionately low compared with local infection rates among that demographic.

As HIV diagnosis rates continue an impressive fall in San Francisco, likely thanks in part to an estimated 12,500 residents going on PrEP, the number of diagnoses among African Americans has remained stable of late.

Surveys have also found that Black MSM lag behind whites in their awareness of PrEP and, at least by some accounts, their willingness to take it. In various real-world studies of PrEP among MSM, adherence to the daily Truvada regimen has been poorer among Blacks than whites. By the end of one yearlong study of very high-risk 18- to 22-year-old MSM, African-American participants had all but abandoned taking Truvada.

Courtesy of The Chicago PrEP Working Group

In addition, Black MSM may be less likely than whites to stick to the schedule of quarterly medical visits required to maintain a PrEP prescription.

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Harlem United, an HIV-focused community health center serving a largely Black community in Harlem and the South Bronx, has sunk $600,000 into a two-year promotional campaign to drive up local interest in Truvada as HIV prevention. Posters featuring PrEP tablets on the stuck-out tongues of grinning New Yorkers beckon with the flirty tagline SWALLOW THIS.

For all that money spent, few in real life have offered their own tongues in response, at least to Harlem United. A disappointing 60 to 90 people access PrEP from the organization at any given time.

From the way Jason Cianciotto, vice president of policy and advocacy for Harlem United, categorizes the challenge at hand, it's going to take a lot more than advertising to work against the societal forces impeding PrEP's success among Black MSM in New York City and across the country.

"Slow uptake is intrinsically linked to larger issues around why Black MSM have higher rates of HIV, experience higher rates of incarceration, lower education, domestic violence, higher unemployment and housing instability," Cianciotto says.

Raul Mejia, a PrEP specialist at Callen-Lorde, goes further. "In addition to how inaccessible PrEP is, Black MSM are still Black people and as such deal with life-threatening issues such as racism, internalized homophobia, homophobia, hyper-masculinity, violence and police brutality on a daily basis," he says. "This needs to be taken into account when attempting to serve this community."

A critical problem facing PrEP promotion among African Americans is their overall disenfranchisement from the health care system. Frequently a by-product of poverty and unemployment, this alienation from what many progressives argue is a basic American right is often compounded by an accident of geography. Those with very low incomes who live in the 19 states with governments that have refused to expand Medicaid under the Affordable Care Act (ACA, or Obamacare)—including almost all the states in the Republican-dominated South—have been summarily excluded from the recent mass expansion of the health care rolls.

If the Trump administration succeeds in its pledge to roll back Obamacare, African Americans would be particularly vulnerable to the wave of medical disenfranchisement that would devastate the country unless Congress passes robust legislation to properly replace the outgoing president's crowning achievement.

In addition, the insidious legacy of the Tuskegee syphilis experiment continues to wreak havoc on the overall health of African Americans more than 40 years after the sadistic, decades-long

program was finally exposed. An inherited culture of mistrust of the medical establishment and propensity for medical conspiracy theories may leave Black MSM wary of HIV prevention that comes in a pill and requires routine medical care. Furthermore, many African Americans are raised with a strong bias against going to the doctor for anything but serious illness.

Chivas Michael, a PrEP navigator at CrescentCare Health in New Orleans, recalls the chilling words of an African-American client whose grandmother picked cotton as a sharecropper: “He said, ‘My grandmother told me that when you were sick, you were taken out to the back like a mule and shot.’

“It’s something in the water in the community that’s become cultural: ‘My arm isn’t falling off, so I shouldn’t go to the doctor,’” Michael says.

Experts believe that Black MSM may also shy away from seeking out PrEP for fear that having a Truvada prescription would expose them to scorn from homophobic family members. Black MSM considering PrEP may face further internal conflicts if they don’t identify as gay. Fears that physicians holding the keys to a PrEP prescription may be yet another source of stigma and sex shaming could be quite justified in some cases, given the pervasive ignorance about PrEP in the medical field. And even though there are often ways to access PrEP for free, Black MSM may automatically assume that such an expensive drug is out of their reach financially and not even explore payment options.

Michael, who is on PrEP, doesn’t mince words when addressing the larger societal context into which PrEP has arrived. “There is something very imperialistic about the way that PrEP has been rolled out,” he says, “because you can’t get a young man of color to care about whether or not he contracts HIV when he doesn’t feel good enough about himself to care about whether or not he lives or dies.

“And so it is a very—pardon the pun—tough pill to swallow,” Michael continues. “The public health community, we have to address helping people feel comfortable doing simple things like leaving their turning signal on too long,” he says, alluding to Black men’s fear of aggressive policing.

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Many of the impediments to PrEP’s uptake among Black MSM have also long plagued efforts to engage HIV-positive African Americans in care for the virus. Such parallels raise the question of whether the leadership behind PrEP’s introduction failed to rely on basic intuition to anticipate PrEP’s anemic rollout among Black MSM.

Courtesy of The New York City Health Department

According to LaRon Nelson, PhD, FNP, an assistant professor of nursing at the University of Rochester, the structure of the major studies responsible for the advent of PrEP did not prioritize investigating how Truvada could most successfully address the pressing needs of Black MSM.

Of course, the initial clinical trials among MSM were first and foremost charged with proving that PrEP worked for MSM as a whole, rather than answering more nuanced questions about promoting uptake and adherence among a particularly high-risk subgroup.

Still, the fact remains that the MSM study populations of the global iPrEx study of PrEP and its open-label extension (OLE) phase, as well as the subsequent U.S.-based PrEP Demonstration Project, were all made up of less than 10 percent African Americans.

As for the leadership of these three pivotal studies, out of the more than 50 authors of the associated published papers, none were African-American men. Neither of the iPrEx studies had a single Black author, while just two Black women are listed among the PrEP Demo Project paper's authors.

"In this world, skin color is a category that shapes your experience," says Nelson, who is one of the four Black researchers at the helm of a recent study that, promisingly, has had initial success

supporting PrEP uptake and adherence among African-American MSM. “When you don’t have diversity on your scientific team, those kinds of experiences are never brought to the table to form study designs, what questions you can ask, how questions get asked.”

The head of iPrEx, Robert M. Grant, MD, MPH, a professor at the University of California, San Francisco, School of Medicine, all but acknowledges that his team was indeed ill suited to determine how to help PrEP succeed among Black MSM. Asked over email whether more research is needed into how better to promote PrEP uptake and adherence among Black MSM, he replies, “No, not in my opinion and not in the way that research is usually funded. Does anyone really need white research network chairs and NIH leaders deciding what Black people want or need to know?”

A second wave of research has risen up to answer such questions, just as workers in clinics, nonprofits and the more progressive public health departments around the country have undertaken an extensive process of trial and error to see just what might be the magic formula needed to help PrEP succeed among Black MSM.

The solutions with the greatest promise tend to share a theme familiar from HIV care strategies for African Americans: taking care of the whole person. This means seeking to address the many life challenges, or so-called structural barriers, standing in the way of Black MSM using PrEP successfully, including accessing food, housing and employment, coping with racism and homophobia, and obtaining health insurance.

“We’re not just interested in them as a possible risk for HIV infection,” says Nelson of his researchers’ method of giving referrals to mental health services or other groups that could help study participants with myriad needs. “We’re interested in them as a human being. We’re trying to help them figure out a way to live in this world.”

Of course, wraparound services and other forms of PrEP outreach aren’t necessarily cheap; widespread use of PrEP among Black MSM will likely come with a much higher overall price tag than for their white peers.

The CDC, for one, is stepping up to the plate. PrEP promotion among Black MSM is a central focus of two major multiyear awards exceeding $300 million that the CDC has granted to health departments and social service groups in high-impact cities nationwide.

Hyman Scott, MD, MPH, medical director of Bridge HIV at the San Francisco Department of Public Health, is optimistic that the ever-scrappy national HIV prevention community will find a way to harness the power of PrEP among Black MSM.

“I think that we will reach a tipping point in the next few years,” Scott says. “But the faster we can reach this, the better. The racial and ethnic disparities in HIV infections among Black MSM necessitate a rapid approach.”

“This could be a pivotal moment,” says Callen-Lorde’s Mejia, “to transform health care to work with and for Black communities and be able to limit the historical marginalization that has existed

in this community in relationship to health care.”

The stakes couldn’t be higher. The health and well-being of tens of thousands of the most marginalized members of society hang in the balance, as does the promise that Black lives really do matter.

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