PrEP IN BLACK AMERICA

A Master Plan for HIV Prevention in Black America

For Us By Us: PrEP in Black America:
A Master Plan for HIV Prevention in Black America

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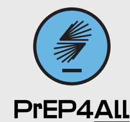

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Introduction

In the spirit of seeking change to ameliorate the devastating impact of HIV in Black communities through biomedical HIV prevention, Black leaders convened the "PrEP in Black America (PIBA) Summit" virtually and in person on September 13, 2022, in Atlanta, Georgia, at the Offices of ThriveSS, a community-based organization and PIBA partner, dedicated to achieving health equity for Black same gender loving men.

On the heels of the 10th anniversary of the approval of the first biomedical HIV prevention strategy by the United States Food and Drug Administration, in partnership with local communities, stakeholders, advocates, and policy makers, the PIBA Summit aimed to:

1. identify factors that contribute to the systematic underutilization of biomedical HIV prevention strategies among Black communities, and
2. develop a Black people centered framework or "roadmap" for PrEP in Black communities.

PrEP in Black America continues a legacy of "For Us By Us" social and political activism in Black communities to fight for equity.

And you can always hear this long sob story: "You know it takes time." For three hundred years, we've given them time. And I've been tired so long, now I am sick and tired of being sick and tired, and we want a change.
— Fannie Lou Hamer

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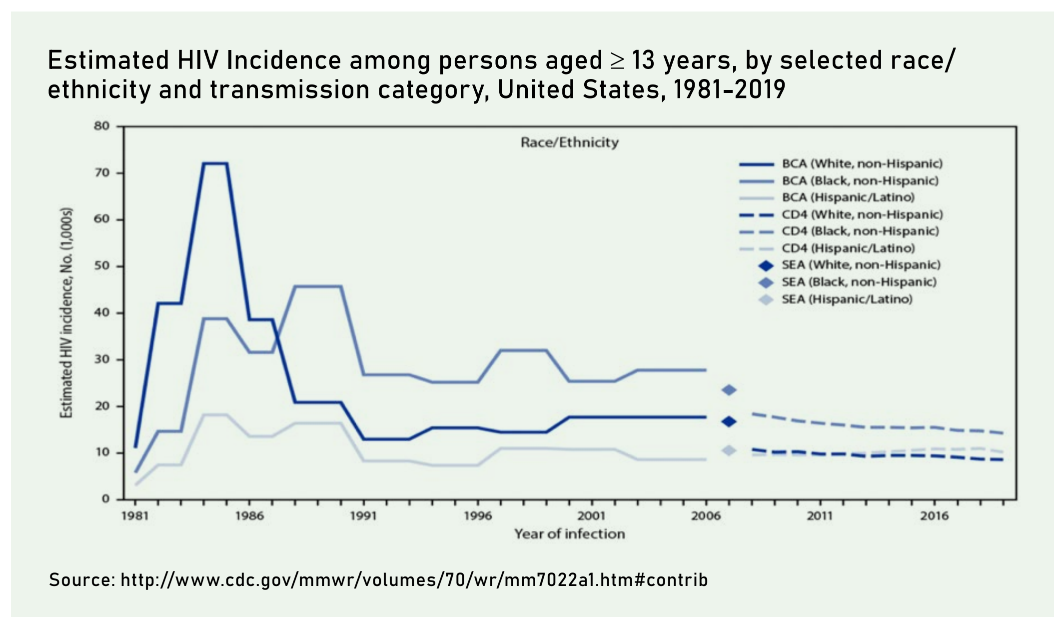
HIV in the Black Community: An Epidemiologic Snapshot

In the US, Black people have been historically disproportionately impacted by HIV. Between 1981-2019, an estimated 2.2 million people have been diagnosed with HIV; an overwhelming number of whom have been Black.[1] According to data from the Centers for Disease Control and Prevention, HIV diagnoses among Black people have increased over time; from 29% in 1981 to 42% in 2019 when Black people represented 17%[2] and 14% of the US population respectively. In 2019, Black same gender loving men comprised 25% of incident diagnoses while Black women represented 55% of diagnoses among women.[3] Similarly, Black transgender women were overrepresented among incident HIV diagnoses; representing 46% of all diagnoses among transgender women whereas Black transgender men comprised 19% of all diagnoses among transgender men.



Estimated HIV Incidence among persons aged ≥ 13 years, by selected race/ethnicity and transmission category, United States, 1981–2019

Source: http://www.cdc.gov/mmwr/volumes/70/wr/mm7022a1.htm#contrib

The year 2022 marks the 41st anniversary since the first Centers for Disease Control and Prevention published the *Morbidity and Mortality Weekly Report* of five cases of a type of pneumonia among previously healthy men in Los Angeles, California, effectively marking the beginning of the HIV pandemic in US.[4]

Strategies for Biomedical HIV Prevention

The year 2022 also marked the 10th anniversary of the Food and Drug Administration's approval of the first biomedical HIV prevention strategy, oral tenofovir disoproxil fumarate with emtricitabine as pre-exposure prophylaxis (PrEP).[5] PrEP involves a person without HIV being prescribed an oral (pill), an injection, or vaginal ring (not presently available in the US) of HIV antiretroviral medication to reduce their risk of HIV acquisition by up to 99% when taken as prescribed. Several key research studies have demonstrated the safety and effectiveness of PrEP.[6]

PrEP efficacy trial results

Study	Population	Locations	Regimen / Results
iPrEx Phase III trial that evaluated the safety and efficacy of once-daily oral Truvada to prevent HIV infection in gay men, other men who have sex with men (MSM) and transgender women. For more information: www.avac.org/trial/iprex	2,499 gay men, other MSM, transgender women	• Brazil • Ecuador • Peru • South Africa • Thailand • US	• Daily oral Truvada showed 44% efficacy
TDF2 Study Phase II/III trial that evaluated the safety of once-daily oral Truvada in heterosexual men and women. For more information: www.avac.org/trial/tdf2	1,200 men and women	• Botswana	• Daily oral Truvada showed 62% efficacy
Partners PrEP Study Phase III trial that evaluated the safety and efficacy of two different strategies to prevent HIV transmission in HIV-serodiscordant couples: once-daily oral tenofovir and once-daily oral Truvada. For more information: www.avac.org/trial/partners-prep	4,758 serodiscordant heterosexual couples	• Kenya • Uganda	• Daily oral Truvada showed 75% efficacy • Daily oral tenofovir showed 67% efficacy
Bangkok Tenofovir Study (CDC 4370) Phase II/III trial that evaluated the safety and efficacy of once-daily oral tenofovir to prevent HIV infection in people who inject drugs. For more information: www.avac.org/trial/cdc-4370-bangkok-tenofovir-study	2,400 people who inject drugs	• Thailand	• Daily oral tenofovir showed 49% efficacy
FEM-PrEP Phase III trial that evaluated the safety and effectiveness of once-daily oral Truvada for HIV prevention in women. For more information: www.avac.org/trial/fem-prep	1,950 women	• Kenya • South Africa • Tanzania	• Daily oral Truvada showed no effect
VOICE (MTN 003) Phase IIb trial that evaluated the safety and effectiveness of three different strategies to prevent HIV in women: once-daily oral tenofovir, oral Truvada, and vaginal tenofovir gel. For more information: www.avac.org/trial/mtn-003-voice	5,029 women	• South Africa • Uganda • Zimbabwe	• Daily oral tenofovir showed no effect • Daily oral Truvada showed no effect • Daily vaginal tenofovir gel showed no effect

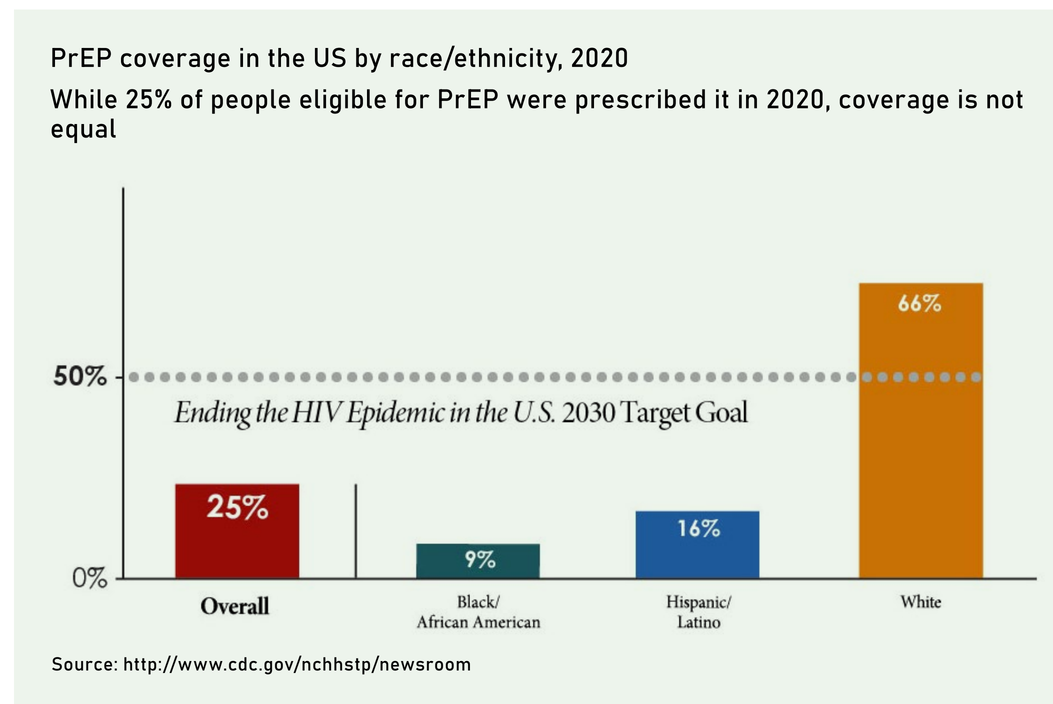
Source: https://www.prepwatch.org/wp-content/uploads/2017/05/PrEP_efficacy_results.pdf

PrEP Use Remains Unequal

Leisha McKinley-Beach, a nationally-recognized HIV consultant and advocate based in Atlanta, Georgia, says, "According to data from the CDC, 91% of Black Americans who can benefit from PrEP have not received a prescription. We can't say PrEP is a success until Black America benefits from it."

PrEP has been touted as a "gamer changer" for its ability as a user controlled systemic option for HIV prevention. The US Preventive Services Task force gave PrEP an A grade and recommends that PrEP for individuals at high risk for HIV.[7] PrEP has received additional endorsements by expert federal scientific panels and professional associations including the Panel on Treatment of HIV During Pregnancy and Prevention of Perinatal Transmission,[8] the American College of Obstetricians and Gynecologists.[9] Biomedical HIV prevention is included as part of the 'Prevent' Pillar of the US Ending the HIV Epidemic Plan for America, a federal initiative aimed to reduce HIV diagnoses in the US by 90% in 2030.[10]

Despite its wide endorsement, rigorous research to demonstrate safety and effectiveness, and potential promise to bend the curve of HIV in communities at highest risk for HIV, disparities in oral PrEP utilization remain. Of the nearly 469,000 Black people with an indication for PrEP use, only 9% (42,372) have received a prescription.[11] When considering the overall burden of HIV among Black people in comparison to rates of PrEP coverage, there is an obvious need to further examine factors that affect PrEP utilization. As such mobilization efforts like the PIBA Summit have critical relevance.

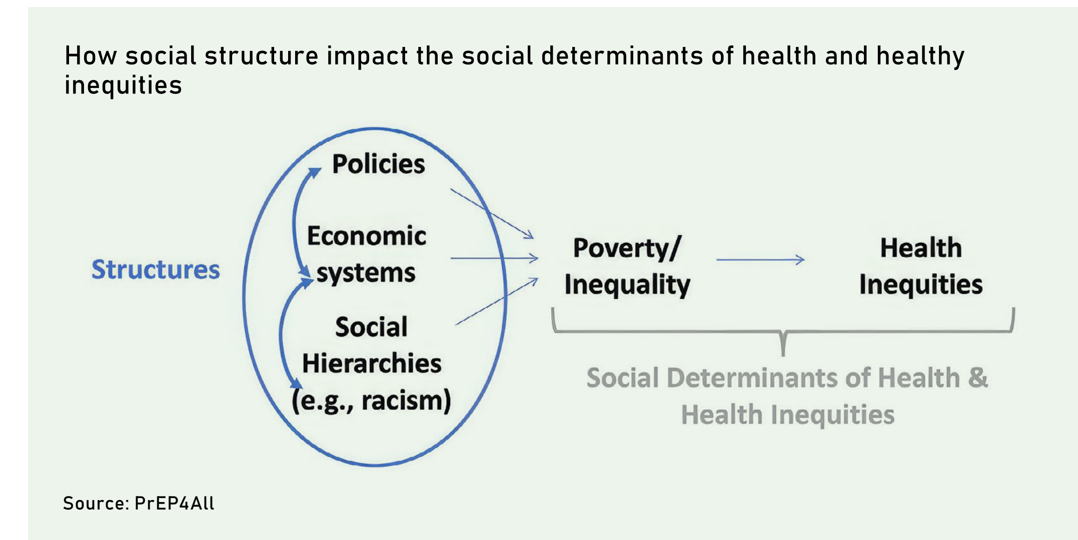


Sankofa: Remembering the Past to Forge a Way Forward

Widely accepted social and structural factors that negatively affect PrEP use include lack of knowledge and awareness,[12] HIV related stigma, provider bias,[13] and cost.[14]

For Black people, we must acknowledge that the absence of positive HIV-related health (prevention and treatment), and furthermore health overall, is rooted in more than 400 years of raced-based systemic oppression or structural racism; defined as "macrolevel systems, social forces, institutions, ideologies, and processes that interact with one another to generate and reinforce inequities among racial and ethnic groups."[15] Recently, increased attention has been paid to addressing racism as a threat to public health as part of the National HIV/AIDS Strategy to reduce HIV-related disparities and health inequities.[16]

In her presentation at the PIBA Summit, Dr. Oni Blackstock, Primary Care and HIV Physician, Researcher, and Founder and Executive Director at Health Justice[17] outlined the following contextual factors that affect PrEP in Black America: 1) Policies: redlining and racial segregation, divestment of financial and healthcare resources from Black communities, 2) Economic Systems: occupational segregation that trap Black people into low-income work and generational poverty, over policing of Black bodies which fuels mass incarceration of Black people, criminalizing of sex work, internalized homophobia and HIV stigma, and 3) Social Hierarchies: inherent racial biases among healthcare providers, who are less likely to prescribe PrEP. Strategies to advance HIV prevention among Black Americans must fully consider intersectionality and how systems of oppression affect Black health.



Deliberations at the PIBA Summit informed the development of a Black people centered framework or "roadmap" to address PrEP disparities in Black communities. Recommendations are as follows:

1. Efforts to address HIV prevention in Black communities must be led by Black people at all levels
2. A well-resourced multi-pronged effort to educate Black people about PrEP is needed
3. Support for a federally-funded National PrEP Program

For Us By Us: A Model for Effective Mobilizing Black People to Prevent HIV

"It is widely believed that we now have all the tools necessary to end the HIV epidemic. The approval of oral PrEP in 2012 as a tool to prevent HIV was an extraordinary gamechanger that should have been scaled up exponentially, particularly to reach populations that carry the disproportionate burden of the epidemic. But shamefully, that has not been the case," says Riko Boone, HIV Project Director of Treatment Action Group.

Recommendation 1

Energize the Black public health workforce to lead the HIV prevention response.

PIBA attendees stressed the need for the reinvigoration of the current of HIV leadership to be reflective of those individuals disproportionately affected by HIV at all levels.

In his 2021 article written in *TheBodyPro,* Juan Michael Porter, II highlighted the lack of diversity in key leadership positions at the National Institutes of Health, where 19 of its 23 Deputy and Associate Directors and 23 of its 27 Institute and Center Directors are White.[18] A near 30-year veteran in the fight against HIV, elder and PIBA leader, Leisha McKinley-Beach reminded attendees that the HIV epidemic would not change until its leadership changes.

PIBA is the first step in building allegiance among Black leaders across health sectors to challenge the status quo. The fact is Black people not strangers to leveraging social collectivism to advocate for policy and social change.

The PIBA Organizing Committee works to amplify the efforts of other Black Focused Organizations that include but are not limited to the Black Public Health Academy, Thrive SS, United We Rise, UBtheCure, Black Women's Health Imperative, Sister Love, Guiding Right, Inc., Us Helping Us, BLAQ Out, The Counter Narrative, and the National Black Justice Coalition.

The clarion call for increased representation of Black leaders extends to HIV research. The HIV research industrial complex has benefitted immensely from the contributions of the Black body globally as participants of HIV research. However, Black scientists have not equally benefitted. Nearly a decade before then NIH Director Francis Collins's 2021 apology on behalf of NIH for maintaining systems supported systemic and structural racism,[19] 2011 and 2019 analyses of NIH grant success demonstrated that applications submitted by US Black principal investigators were least likely to be funded than those submitted by White investigators.[20] PIBA attendees called for reciprocity in funding paradigms and supported Black scientists as being experts best suited to critically examine Black public health issues.

Recommendation 2

Educate Black masses on the science and effectiveness of PrEP.

The following exemplar quotes are from PIBA attendees who responded to the question, "What does PrEP in Black America look like for you?" during a small group breakout discussion exercise aimed at defining a framework for PrEP in Black America.

> "The current state of PrEP on Black America looks like a lack of knowledge and information. Some still don't know what PrEP is, many in the Black community have misperceptions of who the medication is for, and others who know about it sometimes don't know how to access it."—A035

> "PrEP in Black America looks like a significant number of Black people being educated, and more people being comfortable about discussing HIV without stigma" —A011

Attendees re-iterated the need for strengths-based approaches to reframe PrEP as a tool of sexual liberation and not one focused on shaming and blaming Black people for our sexual practices, sexual identities, or sexual pleasures and desires. Exemplar quotes included the following:

> "PrEP in Black America should be easily accessible, de-stigmatized, and an integral part of sexual health for all who are eligible."—A021

> "Centering activities in the entire Black community"—A082

> "Marketing and social media that advertises to the Black community in a way that removes stigma" —A055

> "Effective communication and marketing around optimal sexual health and general well-being. Intentional and impactful strategies around misconceptions and misinformation."—A71

Recommendation 3

Support a Federally-Funded National PrEP Program.

PIBA attendees supported "Universal access to essential benefits without judicial, legal or financial impediments." A061 Three main criteria were of a federally-funded National PrEP program were identified:

1. PrEP should be available as a standard component of routine sexual health services,
2. Inexpensive or no cost to users, including medication and labs, and
3. Explore strategies to expand the pool of racially reflective providers who prescribe PrEP.

PIBA organizers amplify the efforts of PrEP4All and other grassroots organizing efforts in support of a National PrEP program. In its report, PrEP4All identifies seven key steps to ending racial disparities in the PrEP utilization in the US.

1. **Mobilize civil society** to increase public-private partnerships with the goal of developing strategies to increase PrEP utilization.
2. **Develop media awareness campaigns** that include representation from populations of people affected by HIV to reduce HIV stigma normalize PrEP.
3. **Fund Tele-PrEP** with non-HIV providers among communities that experience increased exposure to social and structural barriers, e.g., people in rural geographies, poverty, lack of transportation.
4. **Support current PrEP providers and HIV organizations.**
5. **Galvanize primary care providers** around PrEP.
6. **Center peer support** with peer navigation services from racial and gender reflective peers.
7. **Increase PrEP science literacy** through evidence based educational training programs.

Conclusion

While Black people are seemingly disproportionately impacted by just about every chronic illness in the US, we are collectively sick and tired of being sick and tired. Black leaders are gathering and organizing en masse in solidarity to confront and dismantle historical systems of oppression that negatively impact Black health. It is time for change; communities affected by illnesses that sit at the juncture of social chaos, must be allowed to lead efforts at ameliorating health. PIBA organizers are committed to continuing the effort to define and promote a Plan for PrEP in Black America for Black people by Black people.

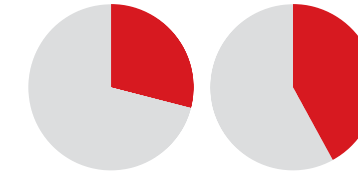
Phill Wilson says it well. “We were greater than the middle passage. We were greater than slavery. We were greater than Reconstruction. We were greater than Jim Crow. We were greater than the war on drugs, and we are greater than HIV/AIDS!”

FORUSBYUS PrEP in Black America: A Master Plan for HIV Prevention in Black America

EPIDEMIOLOGY

2.2 million

An **overwhelming number** of the 2.2 million HIV diagnoses in the US in the years 1981–2019 were Black.

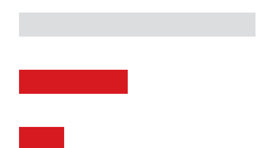


In 1981 Black people represented **17%** of the US population but comprised **29%** of new HIV diagnoses. By contrast, in 2019, Black people represented **14%** of the US population and **42%** of new HIV diagnoses.

In 2019 in the US, Black women accounted for **55%** of all new HIV diagnoses among women while Black MSM represented **25%** of all new HIV diagnoses among men.

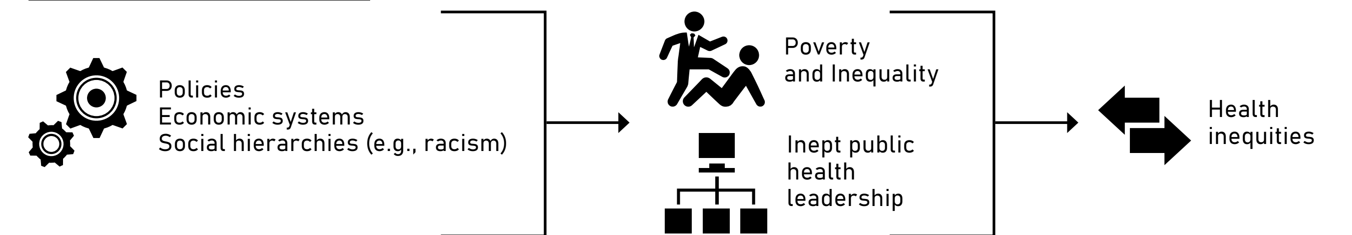
PrEP reduces risk of HIV infection by **99%** when taken as prescribed.

Unequal use of PrEP. Of people eligible for PrEP, **9%** of Blacks have received prescriptions, while the number for Whites is **66%**.



In 2019 in the US, Black trans women accounted for **46%** of all new HIV diagnoses among trans women while Black trans men accounted for **19%** among trans men.

STRUCTURAL ISSUES



MASTER PLAN

Energize the Black public health workforce to lead the HIV prevention response.

Educate Black masses on the science and effectiveness of PrEP.

Federally-Funded National PrEP Program
Mobilize civil society
Develop awareness campaigns
Fund Tele-PrEP
Support current providers
Galvanize primary care providers
Center peer support
Increase PrEP science literacy

Source: Center for Disease Control and Prevention HIV diagnoses | HIV and African American people | Race/Ethnicity | HIV by group | HIV/AIDS | CDC, 2023

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