



BIG IDEAS

**ENDING THE HIV EPIDEMIC —
SUPPORTING ALL PEOPLE LIVING WITH HIV AND REDUCING NEW TRANSMISSIONS**

SEIZING THE MOMENT: ELEVATING BLACK WOMEN IN THE HIV RESPONSE

IN RECENT YEARS, significant progress has been made in lowering rates of HIV transmission among U.S. women, including U.S. Black women. This progress is now at risk. It is crucial to take more focused and strategic actions to protect and enhance this progress by recognizing and empowering Black women as visible and valuable partners in the fight to end the HIV epidemic.

Black women often have had to shoulder a disproportionate share of the burdens from generations of racism, economic injustice, and the social impacts of the harm visited on Black people and Black families. When we speak of Black women, we mean African American women and others of the African diaspora in all of their diversity, including cisgender and transgender women. In some cases, the needs, experiences, and preferences of transgender and cisgender women may differ, and where appropriate, we highlight unique considerations for transgender Black women in a way that seeks to respect and honor all Black women.

By focusing on Black women now, 2024 can be a year that produces results. By naming and responding to their needs, it can be a turning

POLICY ACTION IS NEEDED IN 2024 AND BEYOND TO END HIV AMONG BLACK WOMEN

CONCRETE STEPS CAN BE TAKEN TO STRENGTHEN THE RESPONSE TO HIV AMONG BLACK WOMEN:

LEARN: The NIH should fund modeling studies to identify the resource needs and priority actions to end HIV among Black women

CDC's Medical Monitoring Project should analyze factors driving declines at each stage of the care continuum for cisgender and transgender Black women with HIV

INVEST: CDC, HRSA, SAMHSA, and HHS should use Minority AIDS Initiative (MAI) funds to support Black women-led organizations with the community trust to effectively serve Black women

HRSA, CDC, and SAMHSA should expand their investments in organizations led by and for Black transgender women

REFINE: CDC and HRSA should develop an action plan for improving outcomes for Black women along the prevention and care continua that highlights evidence-based interventions, with a special focus on greater use of PrEP to prevent HIV diagnoses in Black women

To integrate interventions to overcome social, structural, institutional, and behavioral barriers to HIV prevention and care, the NIH HIV Prevention Trials Network (HPTN) should conduct a study of Black women analogous to its landmark study overcoming these barriers for Black gay men.

CDC should disseminate tools for state and local jurisdictions to offer guidance on the proper prioritization of funding for different elements of a comprehensive prevention and care strategy for Black women.

BLACK WOMEN COMPRISE A SIGNIFICANT SHARE OF THE HIV EPIDEMIC IN THE UNITED STATES, YET OFTEN FEEL OVERLOOKED IN BROAD NATIONAL RESPONSES TO THE EPIDEMIC.

point for accelerated progress if policymakers at the federal, state, and local levels: 1) **learn more** to set concrete targets, 2) **make strategic investments** to support Black women-led organizations and initiatives, and 3) **refine** current programs to maximize their impact.

1. CONDUCTING RESEARCH TO SET PRIORITIES AND ESTABLISH MEANINGFUL TARGETS

The United States has made great progress at increasing outcomes for people with HIV and reducing new transmissions, such that it is possible to envision the end of HIV in the U.S. Ending HIV entails supporting all people with HIV to maintain their health and lead a high quality of life and reducing new transmissions so that HIV is no longer a sustained public health threat. The path there, however, is not uniform. Some places in the U.S. have a lower burden of HIV and could achieve this critical milestone before others. Furthermore, the strategies and interventions needed to end HIV differ by population. Ending HIV among Black women would be a signal milestone toward ending HIV in all populations because Black women are an important part of our epidemic and success could stimulate sustained commitment to doing so for all. To get there, we need a greater understanding of the resources needed, the most critical interventions, and we need to set targets and milestones to monitor our progress.

POLICY ACTION: The NIH should fund modeling studies to identify the resource needs and priority actions to end HIV among Black women.

What will it cost and what must we do to end HIV among Black women? While research and programmatic experience has provided many lessons, more research is needed in the form of modeling studies to help policymakers to estimate what it would cost to end HIV among Black women. We need to move from an amorphous goal in a time of perennially tight budgets to a defined target for Congress, the Administration, and state and local policymakers to rally behind. Furthermore, how resources are spent matters to the impact they achieve. Therefore, the NIH should fund studies that examine relative needs for various services to prevent and treat HIV, overcome structural barriers such as housing insecurity, and improve quality of life.

POLICY ACTION: CDC's Medical Monitoring Project (MMP) should analyze factors driving declines at each stage of the care continuum for cisgender and transgender Black women with HIV.

The HIV care continuum monitors population-level progress at successive steps from HIV diagnosis to ART initiation to viral suppression and has proven to be an important tool for spotlighting areas where individuals are most likely to stop engaging in care in ways that can lead to policy action.¹ CDC's MMP is a critical surveillance resource that provides nationally representative information on the care experience of people living with HIV.² CDC should task the MMP team to analyze where fall-offs occur in the HIV care continuum for Black women, explore factors that explain these declines, and offer evidence-based recommendations for improving outcomes at each stage of the continuum. Importantly, such analyses should be specific to Black women who may have unique barriers to sustained engagement in care. Beyond MMP, CDC also should examine the role of sexual trauma and intimate partner violence as factors that could explain some of these outcomes and also point to effective policy responses. Where feasible, analyses should differentiate between cisgender and transgender Black women, and if the MMP dataset is not suitable for such delineation, CDC should conduct tailored quantitative or qualitative analyses to offer a more precise roadmap for how to make progress.

2. INVESTING IN BLACK WOMEN LEADERS AND INSTITUTIONS TO BETTER RESPOND TO HIV

Due to persistent racism and discrimination, it can be difficult to examine disparities and inequities in health and other spheres of life that provide more evidence of the burdens and challenges facing Black women and Black communities. Alternatively, it can be uplifting to consider the resilience of Black communities and identify their assets. This includes Black women who are often the center of families and communities. It is an oversimplification that resonates with truth to say that it is Black women who look out for everyone else. They take care of the children, they push men to seek health care, and they often serve as the glue that holds communities together. This recognition points to a critical strategy of investing in Black women and supporting Black women-led organizations and

initiatives to improve health and strengthen Black communities. But, first, we need to create more opportunities for Black women to lead in taking care of themselves. We need to make sure that the diversity of Black women is at the proverbial table at all levels of policymaking to ensure that their experiences and voices are reflected in official action. And, we need to make greater investments in the institutions that often can be uniquely effective at reaching Black women not currently engaged in services.

POLICY ACTION: CDC, HRSA, SAMHSA, and HHS should use Minority AIDS Initiative (MAI) funds to support Black women-led organizations with the community trust to effectively serve Black women.

Notwithstanding Supreme Court precedents related to affirmative action in university admissions and the use of race in governmental funding decisions, it is lawful to prioritize funding for Black women-led organizations.³ There are several ways that the MAI and other programs could more effectively bolster Black women-led institutions. We have previously offered recommendations for overcoming structural barriers to sustaining strong Black-led organizations.⁴ Solutions could include making MAI formula funds more flexible to maximize the capacity and ability of Black-led community-based organizations (CBOs) to respond to change by allowing for a more diverse use of funds and to provide enhanced CBO administrative supports to strengthen core functions such as accounting, grant administration, personnel development, etc. The Minority AIDS Fund, a part of the MAI, could support a network of Black women CBO leaders to exchange information and offer social support. The Ryan White HIV/AIDS Program (RWHP) Special Projects of National Significance (SPNS) could fund a demonstration program to bolster Black women-led CBOs. All of these agencies, as well as state and local

health departments, should be tasked with identifying strategies for bolstering Black women institutions that can more effectively serve their communities than larger health centers or other programs with a broader mission and client population.

POLICY ACTION: HRSA, CDC, and SAMHSA should expand their investments in organizations led by and for Black transgender women

A CDC study in seven U.S. cities found that nearly two in three Black transgender women are living with HIV (see page 5).⁵ This is an alarming rate that is likely to be exacerbated by the high level of hate being directed to transgender people through laws and official actions that demonize transgender people, restrict access to health care and public facilities, and that create a climate that is leading to violence, with growing rates of murders of Black transgender women.

To respond, our collective actions need to bolster efforts to reinforce Black transgender people and expand the capacity to provide welcoming and culturally appropriate services. In many parts of the U.S., this capacity often does not exist. Federal agencies and state and local health departments should be tasked with assessing how their current programs and activities prioritize Black transgender women and develop actionable plans for expanding research and services to meet the needs of these communities.

3. MAXIMIZING THE IMPACT OF CURRENT EFFORTS

Many Black women recognize the progress made nationally at preventing HIV and caring for people with HIV, yet this progress is often uneven with disparities in outcomes and inequities in access

VIRAL SUPPRESSION IS A CRITICAL HIV OUTCOME

Sustained viral suppression is the ultimate clinical outcome of consistent high quality health care. Along with quality-of-life metrics, it is a way to measure whether the health system is meeting the needs of people with HIV. Whereas women are typically diagnosed with HIV sooner than other groups, they also typically have lower rates of viral suppression, suggesting that the current mix

of services and supports does not fully meet their needs. Yet, progress is being made.

COMPARED TO ALL PEOPLE WITH HIV IN THE U.S.

In 2019, **62.4% of cisgender Black women** were suppressed and **67.2% of Black transgender people** (both female and male) were suppressed compared to

64.1% of all cisgender women and 66% of all people.

AMONG RYAN WHITE HIV/AIDS PROGRAM CLIENTS

In 2021, **89% of cisgender Black women** Ryan White clients were suppressed and **85.8% of all transgender people** (female and male of all races) were suppressed compared to 89.7% of all clients.

Sources: <https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-report-vol-26-no-2.pdf> and <https://ryanwhite.hrsa.gov/sites/default/files/ryanwhite/data/rwhap-annual-client-level-data-report-2021.pdf>.

for Black women increasing. This comes on top of decades of their needs being neglected and overlooked. Therefore, there is a need to better refine programs and services in ways that speak to the needs of Black women and that explicitly recognize some of the unique circumstances facing transgender and cisgender Black women.

POLICY ACTION: CDC and HRSA should develop an action plan for improving outcomes for Black women along the prevention and care continua that highlights evidence-based interventions, with a special focus on greater use of PrEP to prevent HIV diagnoses in Black women.

To celebrate Black women and elevate their role in the HIV response entails both doing more to prevent HIV and doing more to improve quality of life and clinical outcomes in women living with HIV. More guidance can be helpful in terms of where to focus and how to intervene. By law, RWHAP resources are largely restricted to services for people with HIV and should not be diverted to achieve prevention goals. Given this dual commitment to Black women who are both positive and negative, however, new efforts are needed to integrate prevention and care strategies. Researchers have developed an HIV prevention continuum that is analogous to the care continuum.⁶ It starts with a negative HIV test and flows to linkage to prevention services, retention in prevention services, and ultimately to the sustained offering of prevention adherence supports. CDC and HRSA should collaborate to develop an integrated prevention and care continuum for Black women that both shows where the most women are stopping engagement in services and that offers the evidence for the most effective interventions at each stage. In some cases, interventions or suites of interventions can be effective for improving both prevention and care outcomes.

Expanding awareness of, access to, and use of PrEP by Black women is a particularly urgent priority. Too many women are unaware of PrEP, do not believe they could benefit from it, or have questions and concerns about it that go unaddressed. Because the majority of new HIV diagnoses in women are among Black women, more focused efforts to partner with Black women to ensure that they benefit from this effective prevention intervention is warranted. Marketing of PrEP often leaves cisgender Black women feeling ignored. More work is needed to engage Black women and their providers in dialogues about the relevance of PrEP and how to expand community-based capacity to educate about and deliver PrEP services to both cisgender and transgender Black women. Examples of needed interventions include more widespread access to PrEP education and medication at the places where Black women regularly engage in health and wellness care, such as ob/gyn, and fitness and holistic wellness centers. Further, the availability

of injectable longer-acting forms of PrEP may create new opportunities to reduce barriers to accessing PrEP and to minimize disparities in access.

POLICY ACTION: To integrate interventions to overcome social, structural, institutional, and behavioral barriers to HIV prevention and care, the NIH HIV Prevention Trials Network (HPTN) should conduct a study of Black women analogous to its landmark study overcoming these barriers for Black gay men.

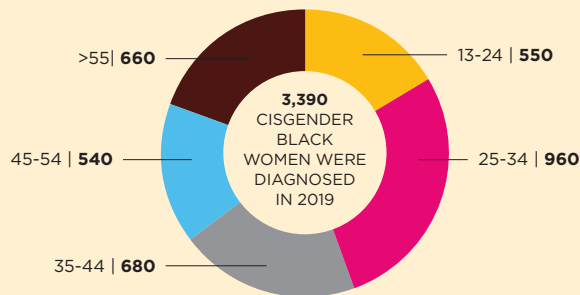
Communities heavily impacted by HIV are often heavily impacted by sexually transmitted infections (STIs), substance use disorders (SUD), poverty, trauma, violence, and other challenges that can magnify poor HIV-related prevention and care outcomes.^{7,8} Further, many factors that can impede engagement in services are outside of the health system and HIV does not exist in isolation. Therefore, to improve the effectiveness of government programs and other interventions, more attention is needed to translate these insights into policy change to address needs of Black women across the lifespan. In 2019, for example, one in five new cases of HIV in Black women were in women over age 55 and fully one in three were in women over age 45 (see page 5).⁹ Many of these women are sexually active and at risk for HIV, yet too few attempts have been made to understand their views and desires, and their health care providers often fail to screen their patients or take sexual histories due to biases that suggest that they could not be sexually active.¹⁰ Younger Black women also have unique issues that must be considered. Previously, the NIH supported the HPTN 096 study that sought to assess an integrated, HIV status-neutral, population-based approach designed to reduce HIV incidence among Black men who have sex with men (MSM) in the U.S.¹¹ The study includes a package of four interventions which simultaneously address social, structural, institutional, and behavioral barriers to HIV prevention and care. The NIH should develop and fund a study that seeks to achieve comparable goals for Black women as HPTN 096. In designing such a study, careful consideration must be given to ensuring that it is inclusive of all Black women while including adequate representation and participation of transgender women. Also, it must be designed to meet the needs of women with specific barriers such as those who engage in sex work and those with a history of incarceration.

POLICY ACTION: CDC should disseminate tools for state and local jurisdictions to offer guidance on the proper prioritization of funding for different elements of a comprehensive prevention and care strategy for Black women.

THE EPIDEMIOLOGICAL STORY OF BLACK WOMEN AND HIV

The following is a data snapshot that illustrates the impact of HIV on both cisgender and transgender Black women. Comparable data do not exist to provide the same data points for these two populations.

CISGENDER BLACK WOMEN



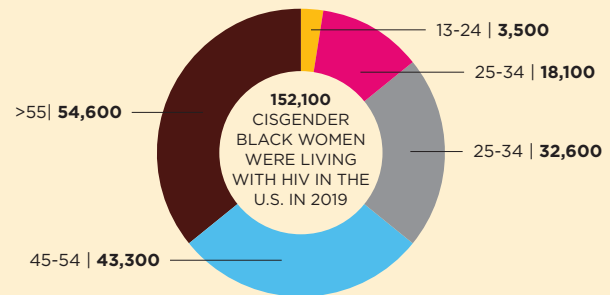
HIV INCIDENCE

BY AGE, COMPARED TO 2010

In 2019, **1,930 fewer** cisgender Black women acquired HIV, compared to 2010 (3,390 vs. 5,320)

In 2019, cisgender Black women accounted for **23.7% of all Black people who acquired HIV** in that year, compared to 28.3% in 2010

In 2019, cisgender Black women accounted for **9.7% of all people of all races who acquired HIV** in that year, compared to 12.7% in 2010



HIV PREVALENCE

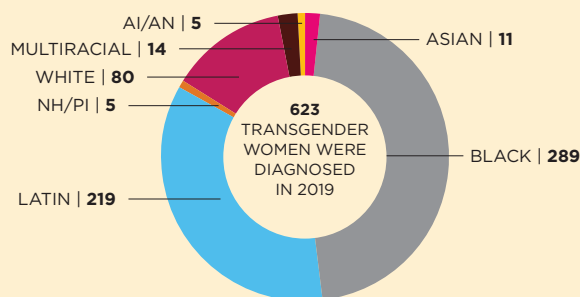
BY AGE, COMPARED TO 2010

In 2019, **9,000 more** cisgender Black women were living with HIV compared to 2010 (152,100 vs. 143,100)

In 2019, cisgender Black women accounted for **31.7% of all Black people with HIV**, compared to 34.0% in 2010

In 2019, cisgender Black women accounted for **12.8% of all people of all races with HIV**, compared to 14.2% in 2010.

TRANSGENDER BLACK WOMEN

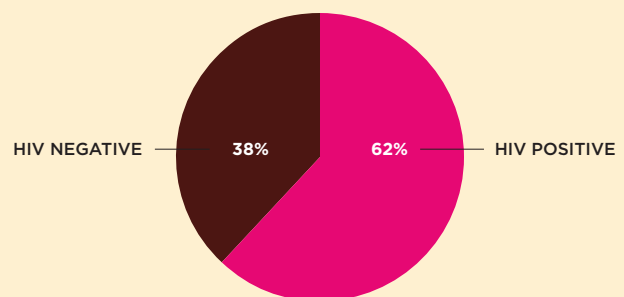


HIV DIAGNOSES

IN THE U.S., 2019, BY RACE

In 2019, 2% of all HIV diagnoses in the U.S. were in transgender people. **93% were in transgender women.**

In 2019, **46.4% of new diagnoses** among transgender women were in Black women.



HIV PREVALENCE

IN 7 U.S. CITIES, 2019-2020

In 2019-2020, in 7 U.S. cities, **62% of Black transgender women had HIV**, compared to 42% overall (35% for transgender Latinas and 17% of white transgender women).

In 2019-2020, in 7 U.S. cities, Black transgender women accounted for **51.4% of all transgender women with HIV.**

Sources: 1) CDC, Estimated HIV Incidence and prevalence in the United States, 2017-2021. *HIV Surveillance Supplemental Report*, 2023; 28(No. 3), accessed on August 1, 2023. 2) CDC, Estimated HIV incidence and prevalence in the United States, 2010-2015. *HIV Surveillance Supplemental Report* 2018;23(No. 1), accessed on August 1, 2023. 3) CDC, *HIV Surveillance Report*, 2019; vol. 32, accessed on August 1, 2023. 4) CDC, *HIV Infection, Risk, Prevention, and Testing Behaviors Among Transgender Women—National HIV Behavioral Surveillance*, 7 U.S. Cities, 2019-2020. *HIV Surveillance Special Report* 27, accessed on August 1, 2023. All CDC Surveillance reports can be accessed at <https://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>.

When there are so many unmet needs and so many potential ways to improve the health of Black women, how do policymakers set priorities to have the biggest impact? This has implications for federal, state, and local policy.

Previously, CDC worked to develop resource allocation models to guide the allocation of CDC prevention resources at the health department level.¹² CDC should work with health departments and planning councils to update and refine these models for Black women and provide technical assistance on how to use them effectively when dividing up limited financial resources. In considering the overlapping burden of HIV, STIs, Hepatitis C and other infectious diseases, many have advocated for greater services integration at the federal and local levels. One way this can be achieved, for example, is to integrate screening for infectious diseases so that such tests all can be performed at one visit, ideally stretching resources to serve greater numbers of people.

THE TIME IS NOW

Success leads to success. Coming through decades of despair since HIV appeared, it is inspiring to believe that we can end HIV in the United States. This will not happen automatically. But, by taking strong action in 2024 and charting a course to end HIV among Black women, we can leap forward to our goal of ending it for everyone.

*“It’s time to make Black women a priority
It’s time that we’re recognized
It’s time for great change
It’s time that what we need is realized
Things are not forthcoming
It’s frustrating quite naturally
We are a part of this epidemic
And that, others need to see
There are many things in motion
It makes no sense to me
What is happening and why are women
not a priority”*

POETIC EXCERPT WRITTEN BY STACY JENNINGS

ENDNOTES

- Centers for Disease Control and Prevention. (2019, July). *Understanding the HIV Care Continuum*. <https://www.cdc.gov/hiv/pdf/library/factsheets/cdc-hiv-care-continuum.pdf>
- Centers for Disease Control and Prevention. (2023, August 22). *Medical Monitoring Project (MMP)*. <https://www.cdc.gov/hiv/statistics/systems/mmp/index.html>.
- Myers, L., & Crowley, J.S. (2023, August). *Minority AIDS Initiative (MAI) After Affirmative Action*. https://oneill.law.georgetown.edu/wp-content/uploads/2023/08/ONL_QT21_Minority_AIDS_Initiative_P3-1.pdf
- Myers, L. & Crowley, J.S. (2023, January). *The Minority AIDS Initiative (MAI) Is An Essential Tool For Fighting HIV*. https://oneill.law.georgetown.edu/wp-content/uploads/2023/01/ONL_QT17_Minority_AIDS_Initiative_P5-Final-Version.pdf.
- Centers for Disease Control and Prevention. *(HIV Infection, Risk, Prevention, and Testing Behaviors Among Transgender Women—National HIV Behavioral Surveillance, 7 U.S. Cities, 2019–2020*. HIV Surveillance Special Report 27. <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Accessed on August 1, 2023.
- McNairy, M. L., & El-Sadr, W. M. (2014). A paradigm shift: focus on the HIV prevention continuum. *Clinical infectious diseases* : an official publication of the Infectious Diseases Society of America, 59 Suppl 1(Suppl 1), S12–S15. <https://doi.org/10.1093/cid/ciu251>.
- Smith, L.R., et al. *Integrating Intersectional and Syndemic Frameworks for Ending the US HIV Epidemic*. *American Journal of Public Health* 112, no. S4 (June 1, 2022): pp. S340–S343. <https://doi.org/10.2105/AJPH.2021.306634>.
- Teixeira da Silva, D., Bouris, A., Voisin, D. et al. *Social Networks Moderate the Syndemic Effect of Psychosocial and Structural Factors on HIV Risk Among Young Black Transgender Women and Men who have Sex with Men*. *AIDS Behav* 24, 192–205 (2020). <https://doi.org/10.1007/s10461-019-02575-9>.
- Centers for Disease Control and Prevention, Estimated HIV Incidence and Prevalence in the United States, 2017–2021. *HIV Surveillance Supplemental Report*, 2023; 28(No. 3), <https://www.cdc.gov/hiv/library/reports/hiv-surveillance/vol-28-no-3/index.html>. Accessed on August 1, 2023.
- Durvasula R. (2014). *HIV/AIDS in older women: unique challenges, unmet needs*. *Behavioral medicine (Washington, D.C.)*, 40(3), 85–98. <https://doi.org/10.1080/08964289.2014.893983>.
- HIV Prevention Trials Network (HPTN). (n.d.). *Getting to Zero Among Black MSM in the American South: Testing the Efficacy of an Integrated Intervention Strategy*. Accessed August 1, 2023 from <https://www.hptn.org/research/stu>.
- Yaylali, Emine et al. (2016). From Theory to Practice: Implementation of a Resource Allocation Model in Health Departments. 22(6). Accessed August 1, 2023 from <https://stacks.cdc.gov/view/cdc/39781>.