

How Long Will We Allow Intersectional Stigma (+ Invisibility) to Beget Inaccessible Miracles for HIV Prevention, Treatment & Cure?

Riko A. Boone, MSW, MPH, MA
HIV Project Director - Treatment Action Group



Ph.D. Candidate
Applied Social Psychology
George Washington University

November 30, 2023
Yale University School of Public Health
Center for Interdisciplinary Research on AIDS
AIDS Science Day



1

TAG

Treatment Action Group

Treatment Action Group (TAG) is an independent, activist, and community-based research and policy think tank committed to racial, gender, and LGBTQ+ equity; social justice; and liberation, fighting to end HIV, tuberculosis (TB), and hepatitis C virus (HCV).

TAG catalyzes open collective action by affected communities, scientists, and policymakers to ensure that all people living with or impacted by HIV, TB, or HCV — especially communities of color and other marginalized communities experiencing inequities — receive life-saving prevention, diagnosis, treatment, care, and information.

We are science-based activists working to expand and accelerate vital research and effective community engagement with research and policy institutions for an end to the HIV, TB, and HCV pandemics.

2

Monitoring Intersectional Stigma: A Key Strategy to Ending the HIV Epidemic in the United States

Cristina Rodríguez-Hart, PhD, MPH, Cheriko A. Boone, MSW, MPH, MA, Ana María del Río-González, PhD, Bryan A. Kutner, PhD, MPH, Stefan Baral, MD, Paul A. Burns, PhD, Danielle German, PhD, MPH, Lisa Eaton, PhD, Lisa Lucas, MSc, Robert H. Remien, PhD, Marcia Ellis, MA, and Sannisha K. Dale, PhD

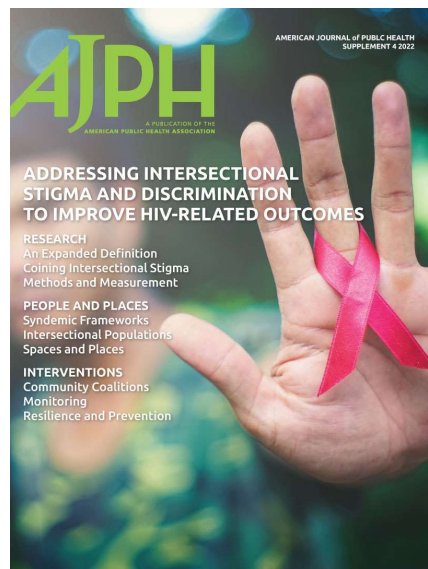
strategies for successful monitoring, which we believe will lead to more comprehensive, equitable, and ethical EHE interventions in the United States.

INTERSECTIONAL STIGMA IN PUBLIC HEALTH PRACTICE

This section describes how select data sources can better address intersectional stigma at multiple levels of public health practice (federal, state, local, and

Stigmatizing Spaces and Places as Axes of Intersectional Stigma Among Sexual Minority Men in HIV Prevention Research

Tamara Taggart, PhD, MPH, H. Jonathon Rendina, PhD, MPH, Cheriko A. Boone, MSW, MPH, MA, Paul Burns, PhD, MS, Joseph Carter, MA, Devin English, PhD, Shaunika Hull, PhD, Jenné S. Massie, DrPH, MS, Mary Mbatia, MPH, MA, Leandro Mena, MD, MPH, Ana María del Río-González, PhD, MA, Ore Shalhav, MPH, Ali J. Talan, DrPH, Carly Wolfer, MA, and Lisa Bowleg, PhD, MA



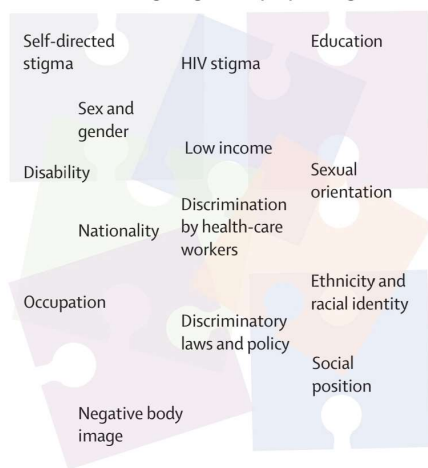
3

Ageism: the -ism affecting the lives of older people living with HIV



Giovanni Guaraldi, Jovana Milic, Mario Cascio, Cristina Mussini, Esteban Martinez, Jules Levin, Daniele Calzavara, Rebecca Mbewe, Julian Falutz, Chloe Orkin, Matteo Cesari, Jeffrey V Lazarus

Factors contributing to ageism in people living with HIV



Interventions to fight ageism



The Lancet. Nov. 28, 2023

4

JOURNAL OF Research on Adolescence

JOURNAL OF RESEARCH ON ADOLESCENCE, ***(*) 1-18

Black Lives Matter!: Systems of Oppression Affecting Black Youth

Special Series: Dismantling Systems of Racism and Oppression during Adolescence

Intersecting Structural Oppression and Suicidality Among Black Sexual Minority Male Adolescents and Emerging Adults

Devin English
Rutgers School of Public Health

Joseph A. Carter
The Graduate Center of the City University of New York (CUNY)

Danielle R. Busby
University of Texas Medical Branch

Diamond J. Cunningham
Tulane School of Public Health and Tropical Medicine

H. Jonathon Rendina
The George Washington University and Whitman-Walker Institute

Cheriko A. Boone
The George Washington University

Ali J. Talan
Whitman-Walker Institute

Raymond L. Moody
Columbia University

Lisa Bowleg
The George Washington University

STRUCTURAL OPPRESSION AND SMM SUICIDALITY 9

FIGURE 1 National distribution of participants in the analytic sample. Note: Numbers within states correspond to the State Racism Index Score. Participants in Puerto Rico and Washington DC not included in the analytic sample.

5

American Journal of Preventive Medicine

RESEARCH ARTICLE

Intersecting Structural Oppression and Black Sexual Minority Men's Health

Devin English, PhD,¹ Joseph A. Carter, MA,^{2,3} Cheriko A. Boone, MSW, MPH,⁴ Nicola Forbes, BA,⁵ Lisa Bowleg, PhD,⁶ David J. Malebranche, MD, MPH, Ali J. Talan, DrPH,² H. Jonathon Rendina, PhD, MPH^{2,3}

Black Participants

Structural Racism: 0.20* (Anxiety Symptoms), 0.17 (Depress Symptoms), 0.42*** (Perceived Burden), 0.13 (Heavy Drinking), 0.11 (HIV Testing)

Racism x Anti-LGBTQ: 0.23** (Anxiety Symptoms), -0.18 (Depress Symptoms), 0.38*** (Perceived Burden), 0.22** (Heavy Drinking), -0.21 (HIV Testing)

Anti-LGBTQ Policies: 0.08* (Anxiety Symptoms), 0.06 (Depress Symptoms), 0.20** (Perceived Burden), 0.10* (Heavy Drinking), -0.14* (HIV Testing)

White Participants

Structural Racism: 0.01 (Anxiety Symptoms), 0.01 (Depress Symptoms), -0.09 (Perceived Burden), 0.03 (Heavy Drinking), 0.01 (HIV Testing)

Racism x Anti-LGBTQ: 0.02 (Anxiety Symptoms), 0.04 (Depress Symptoms), -0.06 (Perceived Burden), 0.03 (Heavy Drinking), 0.05 (HIV Testing)

Anti-LGBTQ Policies: 0.02 (Anxiety Symptoms), 0.01 (Depress Symptoms), -0.02 (Perceived Burden), 0.00 (Heavy Drinking), 0.00 (HIV Testing)

6



7

AJPH OPEN-THEMED RESEARCH

Negative Police Encounters and Police Avoidance as Pathways to Depressive Symptoms Among US Black Men, 2015–2016

Lisa Bowleg, PhD, MA, Ana María del Río-González, PhD, MA, MS, Mary Mbaba, MPH, Cheriko A. Boone, MSW, MPH, and Sidney L. Holt, MA

RESEARCH ARTICLE

HSR Health Services Research

A mixed-methods assessment of off-duty police shootings in a media-curated database

Emmanuella Ngozi Asabor MPhil^{1,2} | Elle Lett MBiostat MA PhD^{3,4} | Brein Mosely MS^{5,6,7} | Cheriko A. Boone MSW, MPH, MA⁸ | Saahil Sundaresan³ | Tian An Wong PhD⁹ | Maimuna S. Majumder MPH, SM, PhD^{3,10}

8

JAMA Network
Johns Hopkins University

☰ JAMA®
🔗
🔍

PAST

Article

October 8, 1910

THE NEGRO AS A HEALTH PROBLEM

H. M. FOLKES, M.D.

» [Author Affiliations](#)

JAMA. 1910;55(15):1246-1247.

doi:10.1001/jama.1910.04330150006002

9

“[Harriet A. Washington] has unearthed an enormous amount of shocking information and shaped it into a riveting, carefully documented book.”
—NEW YORK TIMES

MEDICAL APARTHEID

The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present

HARRIET A. WASHINGTON

NATIONAL
BOOK CRITICS
CIRCLE AWARD
WINNER

“ Researchers who exploit African Americans were the norm for much of our nation’s history ...

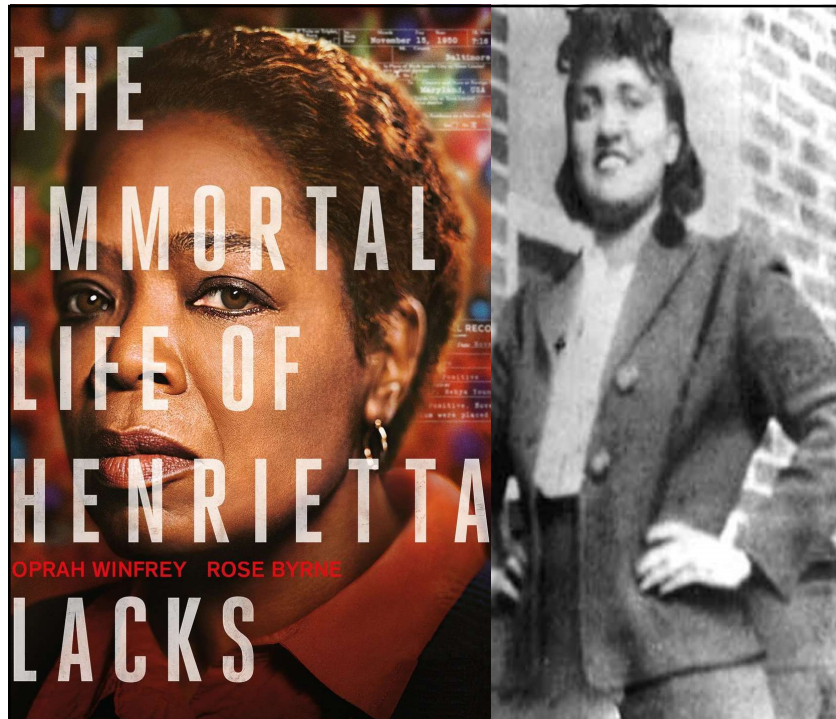
... understanding the true extent of unethical medical research with African Americans [is] more than idle curiosity or an academic exercise:

...

... It [is] key to removing barriers between African Americans and the bounty of the American health-care system. ”

-- Harriet A. Washington

10



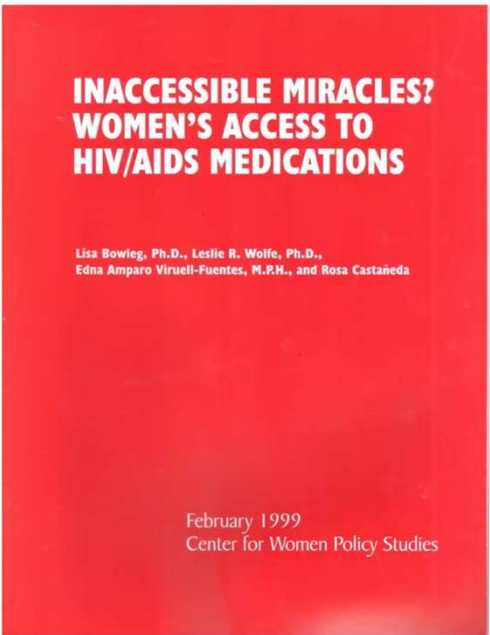
THE IMMORTAL LIFE OF HENRIETTA LACKS
OPRAH WINFREY ROSE BYRNE

This is Henrietta Lacks. Before her death in 1951, her doctor took and saved several tissue samples from her cervix without her permission or knowledge.

From these cells came the world's first "immortal cell line". Her cells have been used to develop everything from cloning to the polio vaccine. They have been used to develop cancer drugs, drugs to treat HIV, herpes, Parkinson's disease, and hundreds of others.

Scientists have grown more than 20 tons of her cells, and they're involved in more than 11,000 patents.

11



**INACCESSIBLE MIRACLES?
WOMEN'S ACCESS TO
HIV/AIDS MEDICATIONS**

Lisa Bowleg, Ph.D., Leslie R. Wolfe, Ph.D.,
Edna Amparo Viruell-Fuentes, M.P.H., and Rosa Castañeda

February 1999
Center for Women Policy Studies

“Historically, women of all racial/ethnic backgrounds, men of color and injection drug users have been underrepresented in clinical trials for HIV/AIDS drugs (Stone et al., 1997). **Women, and men of color, are less likely to know about new HIV/AIDS drugs or to be informed that they are eligible to participate in clinical trials** (Stone et al., 1997).

...As protease inhibitors began to show promise in clinical trials, AIDS activists continued to advocate for expedited and expanded access to medications prior to approval by the Food and Drug Administration (Gavaghan, 1995). Yet, **most of the knowledge about protease inhibitors has been based on clinical trials conducted on men.**”

12

PRESENT



13

◆ AIDS Research and Human Retroviruses > Vol. 38, No. 1 > Socio-Behavioral

Considerations for Increasing Racial, Ethnic, Gender, and Sexual Diversity in HIV Cure-Related Research with Analytical Treatment Interruptions: A Qualitative Inquiry

Karine Dubé , John Kanazawa , Chadwick Campbell , Cheriko A. Boone, Allysha C. Maragh-Bass, Danielle M. Campbell, Moisés Agosto-Rosario, Jamila K. Stockman, Dázon Dixon Diallo, Tonia Poteat , Mallory Johnson, Parya Saberi, and John A. Saucedo

- Women remain dramatically underrepresented in all HIV research (including HIV cure research)
- Data suggests that disparities in representation are not due to screening failure
- Data on race and ethnicity is under-reported, and when reported, diversity is suboptimal

AIDS RESEARCH AND HUMAN RETROVIRUSES
 Program, January 12, 2022
 © 2022 Mary Ann Liebert, Inc., publishers
 https://doi.org/10.1089/aids.2021.0127

Mary Ann Liebert, Inc., a publishers

Population Representation in HIV Cure Research: A Review of Diversity Within HIV Cure Studies Based in the United States

Carly Roberts¹*, Emma Creamer²*, Chenko A. Boone³, A. Toni Young^{2,†}, and Many Magnus ^{1,†}

Abstract

HIV is experienced across diverse populations, with gender and racial/ethnic minority populations bearing a significant proportion of disease. With National Institutes of Health (NIH) placing a priority on the enrollment of women and racial/ethnic minorities into studies, it is important to understand the diversity of participants in research. We sought to characterize how HIV cure research studies report data on diversity. A sampling frame of publications with funding provided by the Martin Delaney Collaboratories for HIV Research in 2019 was reviewed for reporting of demographic data. Of 55 publications that included research on humans human specimens, only 51% provided any demographic description. There often is insufficient consideration of diversity of populations in HIV¹ cure research. Ameliorating gaps in this regard will require recruitment of diverse populations specimens and specifications to report demographic data in articles. This will ensure inclusion of diverse participants in HIV cure research from earliest laboratory to eventual phase III studies.

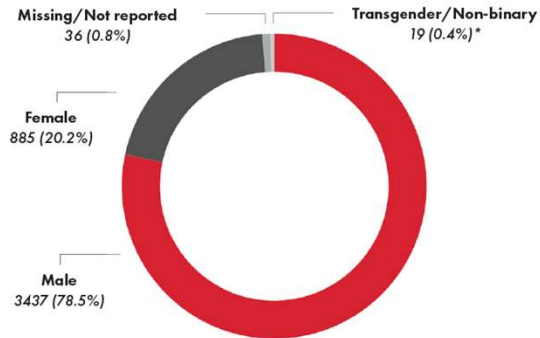
Keywords: diversity, generalizability, representation, HIV cure research

14

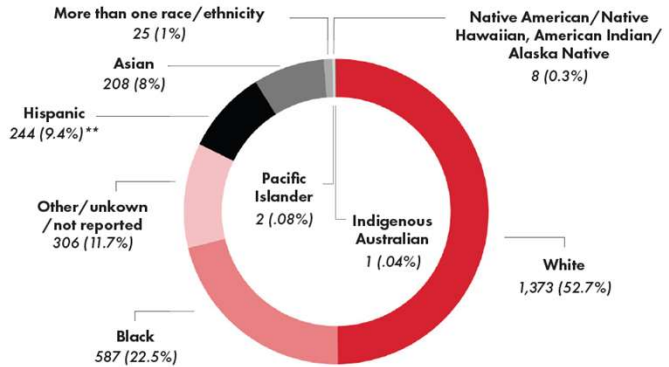
HIV Cure Research Demographic

Demographics of participation in HIV cure-related clinical studies with results presented or published from 2018 to October 2022. Total of 122 clinical trials or observational studies (115 adult, seven pediatric/adolescent), with five providing no sex, gender or race/ethnicity information and 36 providing no race/ethnicity information. Total number of participants: 4475.

Total from studies reporting sex and gender (Total=4375)



Total from studies reporting race/ethnicity (Total=2607)



Unpublished data, as of November 2022. Treatment Action Group

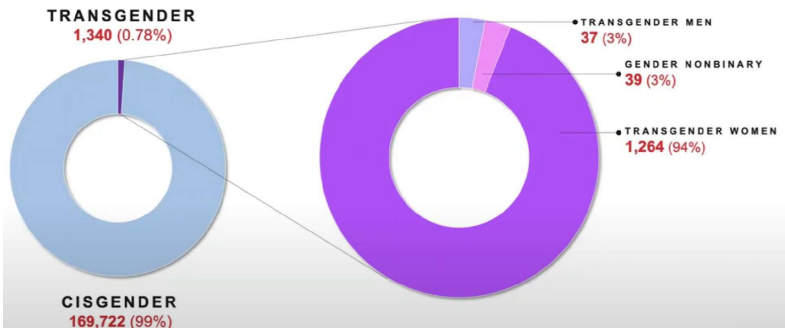
15

TRANS PEOPLE ARE UNDERREPRESENTED IN HIV CURE-RELATED RESEARCH, MAKING UP LESS THAN 1% OF PARTICIPANTS IN STUDIES WE'VE TRACKED SINCE 2018.

To be effective, research must be more inclusive of affected communities. TAG tracks demographic participation in HIV cure-related clinical trials. Learn more at www.treatmentactiongroup.org.



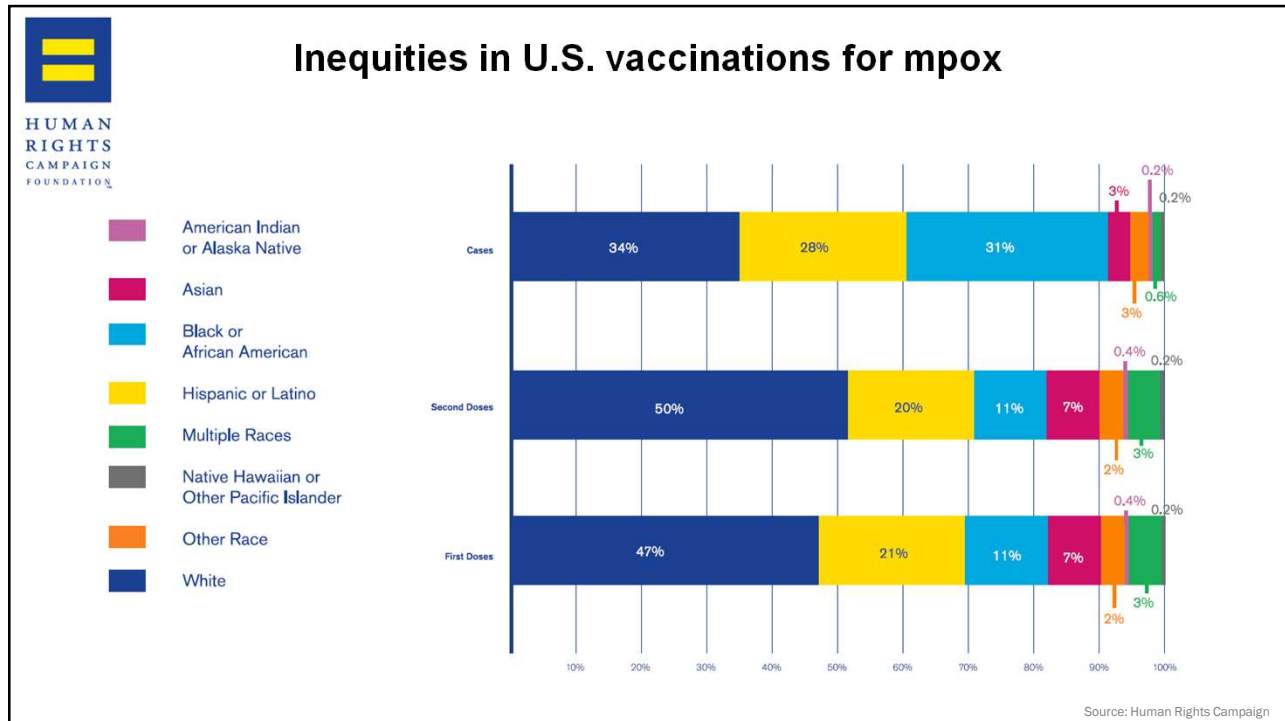
Representation in Milestone HIV Clinical Trials



Preliminary Findings



16



17



18

HEALTH EQUITY

By Michael Sun, Tomasz Oliwa, Monica E. Peek, and Elizabeth L. Tung

Negative Patient Descriptors: Documenting Racial Bias In The Electronic Health Record

(2022) *Health Affairs*

“Compared with White patients, Black patients had 2.54 times the odds of having at least one negative descriptor in the history and physical notes. Our findings raise concerns about stigmatizing language in the EHR and its potential to exacerbate racial and ethnic health care disparities.”



Original Investigation | Health Policy

Examination of Stigmatizing Language in the Electronic Health Record

Gracie Himmelstein, MD; David Bates, MD, MS; Li Zhou, MD, PhD

(2022) *JAMA Network Open*, 5(1), e2144967-e2144967.

“Across all medical conditions studied, stigmatizing language appeared more frequently in notes written about non-Hispanic Black patients.”

19

SCOTUS affirmative action ruling was 'blow' to Black students, but it put 'spotlight' on HBCUs: Advocates

"This provides an opportunity," one educator said.

By [Arthur Jones II](#)

Video by [Julian Kim](#) and [Nam Cho](#)

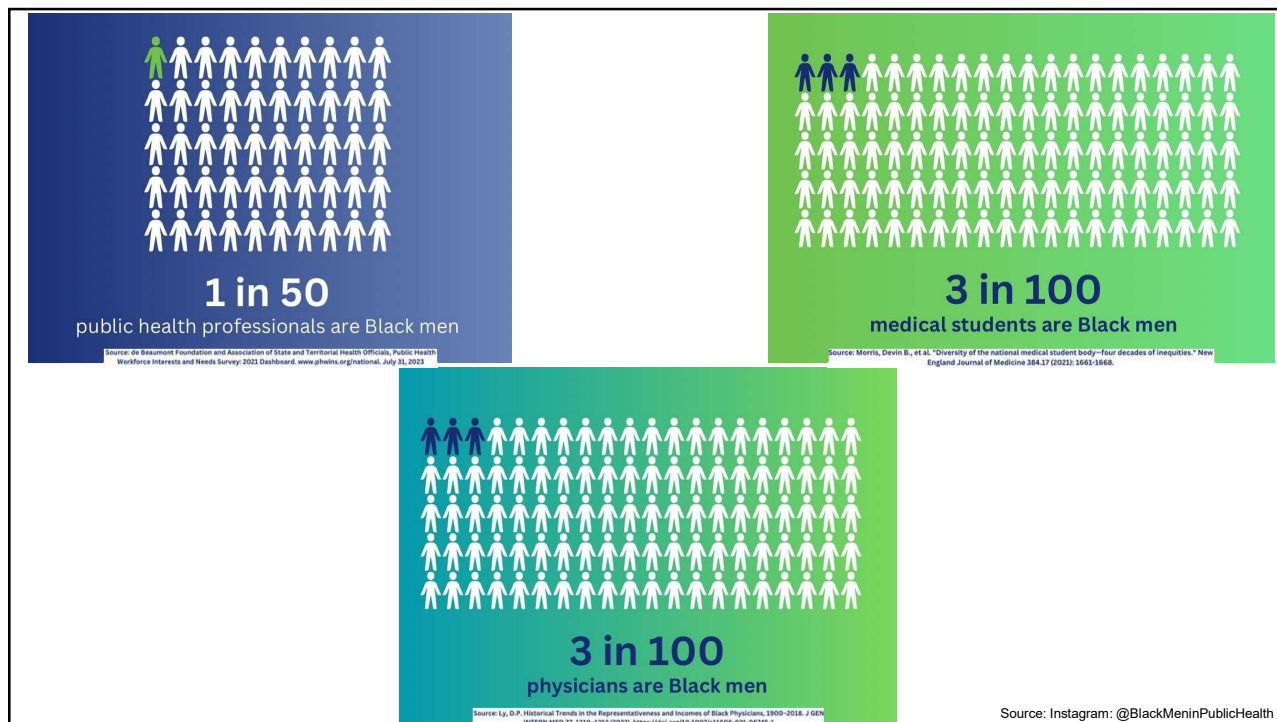
October 24, 2023, 7:07 PM



FUTURE



20




21

The PrEP in Black America Initiative — Key Recommendations

FORUSBYUS
PrEP IN BLACK AMERICA
A Master Plan for HIV
Prevention in Black America

Energize	Energize the Black public health workforce to lead the HIV prevention response.
Educate	Educate Black masses on the science and effectiveness of PrEP.
Support	Support a Federally-Funded National PrEP Program.



22

23

tagline Vol. 29, No. 1, November 2022

COMMUNITY REPRESENTATION IN HIV RESEARCH: FROM STUDY VOLUNTEERS TO INVESTIGATORS

By Cheriko A. Boone, Abraham Johnson, and Richard Jefferys

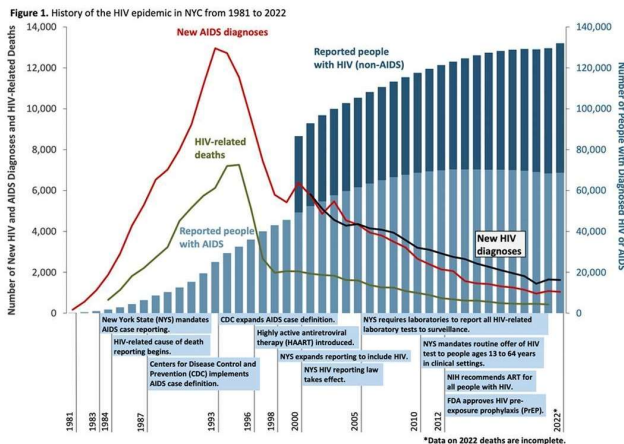
1. Underrepresentation still presents key points for continued advocacy.
2. Meaningful and inclusive community engagement drives **ALL** aspects of research endeavors.
3. Equitable enrollment of affected communities is achievable when there are adequate resources and an established commitment to doing so.

"Ending HIV . . . will require us to lean in and learn from those closest to the epidemic. We need data that tells the whole story — research that captures the full spectrum of experiences and communities impacted by HIV. We have to make things more accessible and remove the mystery around people gaining access to research, resources, and opportunities."

-- Dafina Ward
Executive Director, Southern AIDS Coalition

24

New HIV diagnoses in New York City declined 2% from 2021 to 2022 — a 72% decrease since 2001.



GEORGE W. BUSH
 PRESIDENTIAL CENTER

TWENTY YEARS LATER, THE RESULTS ARE CLEAR: PEPFAR HAS SAVED MORE THAN 25 MILLION LIVES AND PREVENTED MILLIONS OF HIV INFECTIONS. MEMBERS OF CONGRESS AND AMERICAN CITIZENS FROM BOTH PARTIES SHOULD BE PROUD.

— President George W. Bush
 The Washington Post, September 13, 2023

25

Braidwood v. Becerra

- Judge Reed O'Connor: Appointed by George W. Bush
- U.S. Preventive Services Task Force (USPSTF) was unconstitutional
- The judge ruled that because the USPSTF was unconstitutionally appointed any preventative care procedure they rated as A or B from March 23, 2010 onward is void.
- Poses a threat to a range of preventive services, including PrEP, cancer screenings, STIs, diabetes, etc.

No. 23-10326

**United States Court of Appeals
for the
Fifth Circuit**

Braidwood Management, Incorporated, John Scott Kelley, Kelley Orthodontics, Ashley Maxwell, Zach Maxwell, Joel Starnes,
Plaintiffs—Appellants/Cross-Appellants,
Joel Miller, Gregory Schodeman,
Defendants—Appellees/Cross-Appellees,
versus
Xavier Becerra, Secretary, U.S. Department of Health and Human Services, in his official capacity as Secretary of Health and Human Services, United States of America, Janet Yellen, Secretary, U.S. Department of Treasury, in her official capacity as Secretary of the Treasury, Julie A. Su, Acting Secretary, U.S. Department of Labor, in her official capacity as Secretary of Labor.
Defendants—Appellants/Cross-Appellees.

ON APPEAL FROM THE UNITED STATES DISTRICT COURT FOR THE
NORTHERN DISTRICT OF TEXAS, FORT WORTH DIVISION

UNOPPOSED MOTION FOR LEAVE TO FILE BRIEF OF AMICI CURIAE HIV AND
HEPATITIS POLICY INSTITUTE, AIDS ALABAMA, AIDS FOUNDATION OF
CHICAGO, AIDS UNITED, ADDITIONAL AMICI LISTED ON INSIDE COVER IN
SUPPORT OF APPELLANTS/CROSS-APPELLEES

The Braidwood Management v. Becerra case could become a major barrier to access preventive services. Any decision that affirms the plaintiff (Braidwood) threatens to jeopardize public health, exacerbate racial disparities in HIV prevention, and undo our progress toward ending the HIV epidemic.

RIKO BOONE
HIV Project Director
Treatment Action Group

TAG
Treatment Action Group

26

POLITICO

'An extreme response': Republicans move to kill Trump's HIV-fighting program

The GOP-controlled House has proposed a deep cut to the former president's AIDS-fighting program.



'Don't Say Gay' bills nationwide





The Washington Post

SOCIAL ISSUES

Anti-trans bills have doubled since 2022. Our map shows where states stand.

Since January, state legislators have introduced more than 400 anti-trans bills — more than the number introduced in the previous four years combined

By Annys Shin, N. Kirkepatrick and Anne Branjein
Updated May 19, 2023 at 7:01 a.m. EDT | Published April 17, 2023 at 6:00 a.m. EDT

27

2

Policy Threats to HIV Prevention & Research

In 2023, the Republican-led House Labor, Health and Human Services, Education, and Related Agencies (L-HHS) proposed \$767 million in cuts and eliminations to domestic HIV funding:

- **Eliminates** funding for the *Ending the HIV Epidemic Initiative* within the Centers for Disease Control and Prevention (**-\$220 million**), the Ryan White HIV/AIDS Program (**-\$165 million**), and Community Health Centers Program (**-\$157 million**)
- **Eliminates** funding for Part F of the Ryan White HIV/AIDS Programs which includes:
 - Dental Programs (**-\$13.6 million**)
 - AIDS Education and Training Centers (**-\$34.9 million**)
 - Special Projects of National Significance (**-\$25 million**)
- **Eliminates** funding for Minority AIDS Initiative activities within the Substance Abuse and Mental Health Services Administration (**-\$119.3 million**)
- **Cuts** funding for the Minority HIV/AIDS Fund by 53% (**-\$32 million**)

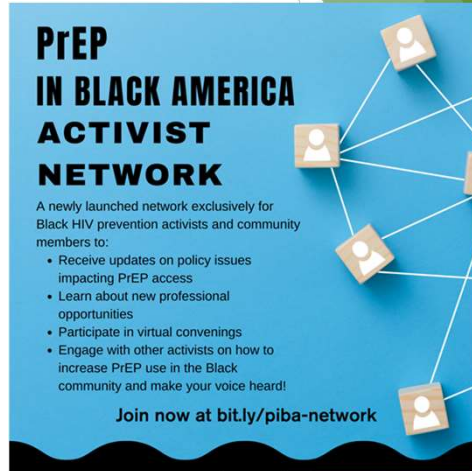
28

Slide 28

- 2 Can we do animation on thi page so each bullet come up seperately?
John Meade, 11/11/2023
- 2 This may be easier to set up in PowerPoint. I don't know how to give each individual bullet its own animation in Google Slides.
Riko Boone, 11/11/2023

Get Involved!

Tell Congress to #SaveHIVFunding

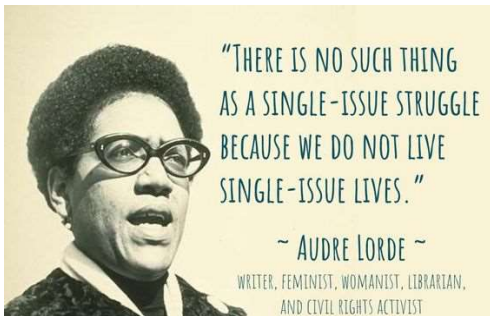
A blue graphic with a network of person icons connected by lines. The text reads: **PrEP IN BLACK AMERICA ACTIVIST NETWORK**. Below this, it says: "A newly launched network exclusively for Black HIV prevention activists and community members to:" followed by a bulleted list:

- Receive updates on policy issues impacting PrEP access
- Learn about new professional opportunities
- Participate in virtual convenings
- Engage with other activists on how to increase PrEP use in the Black community and make your voice heard!

 At the bottom, it says "Join now at bit.ly/piba-network".

29

THANK YOU!



@TAGTeam_Tweets

@RikoAmour

Riko@treatmentactiongroup.org

RikoBoone@gwu.edu

30