CONGRESS PROCEDINGS:

Strategies and Urgent Research Priorities to End the HIV Epidemic in Black Communities





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MISSION

The HIV Implementation Science to Optimize Research Impact (HISTORI) Scientific Congress aims to help Black communities in the United States end the HIV epidemic by providing an inclusive, self-directed platform for Black investigators to connect, learn and engage in collective advocacy.

SUMMARY

Introduction

The 2022 HISTORI Scientific Congress was a multi-culturally affirming forum for Black investigators involved in research that contributes to ending the HIV epidemic in Black communities. A group of thirteen leaders in the fight against HIV in Black communities convened the event, which took place in June 2022 in Dallas, Texas. The congress brought together investigators from across the country to engage in priority-setting, knowledge exchange, research methods capacity-building, and science generation. This document serves to synthesize insights shared by Black investigators in the HISTORI network regarding research priorities and strategies to end the HIV epidemic in Black communities in the United States.

Methods

Individuals were invited to register for the congress meeting because they 1) were actively engaged in research contributing to ending the HIV epidemic in Black communities and 2) identified as Black. Before the meeting, registrants were asked to identify the most urgent research priorities for ending the HIV epidemic in Black communities through an online questionnaire. These responses were summarized and presented back to participants for feedback and discussion during the congress meeting. Participants were also invited to share their views on barriers, facilitators and next steps for putting identified priorities into action and addressing the epidemic in Black communities more broadly. Detailed notes were taken during discussions and all data collected was analyzed for key themes.

SUMMARY

Participants

A total of 73 individuals completed the questionnaire, 55 of whom also took part in the group discussions. Participants represented 18 different states and were involved with HIV research in a variety of ways including living with HIV. The primary affiliation of most participants was a university (49%), followed by a non-profit or community-based organization (23%), and a research institute (12%). Others were affiliated with healthcare organizations, industry, or government. Participants served a variety of roles at their institutions including professors or research scientists (38%), directors (25%), and managers (15%). Peer navigators/liaisons and other research support staff were also present.





Reimagine Research Leadership & Resource Access

Optimize funding structures to provide more opportunities for Black-led and community-led research. Increase the proportion of HIV research funding intended for Black communities that is directed by investigators whose identities and experiences reflect the make-up of these communities.



Equity in Funding Opportunities: Provide strategic funding opportunities for Black investigators within existing governmental and academic funding institutions. Prepare structured pipelines within such funding institutions that are accessible to early- and mid-career Black investigators and trainees.

В

Equity in Funding Decision-Making: Create opportunities for Black investigators and community members to make (and contribute to making) funding decisions for projects focused on addressing HIV in Black communities within existing governmental and academic funding institutions.



New Funding Streams: Develop innovative, alternative funding mechanisms for Black-led and community-led research including by way of partnerships with philanthropic and private-sector institutions.

If they don't give you a seat at the table, bring a folding chair

-Shirley Chisholm



Reimagine Scholarly Collaboration

Establish productive networks of support, mentorship and collaboration among Black investigators, community-based experts and researchers, and interdisciplinary professionals.



Build Capacity: Support Black investigators and trainees through professional development opportunities including mentorship, training, grant peer review networks, and resourcesharing.

В

Empower Community-Based Experts: Value community advocates and individuals with lived experience of HIV as knowledge-creators and researchers in their own right through fostering equal partnerships and providing opportunities to engage in priority-setting. Develop leadership training and research capacity-building opportunities for community members.



Embrace Interdisciplinarity: Develop training initiatives for researchers that prioritize interdisciplinary approaches to combating the HIV epidemic including collaboration with storytellers, visionaries, artists, writers and performers. Break down silos because the epidemic cannot come to an end through research alone.



Reimagine Implementation Science

Advance implementation science approaches that center the experiences of Black communities and place value on modes of interpretation and intervention that align with community-identified priorities, strengths and needs.



Devise New Models: Develop implementation science theories, frameworks and models with, by and for Black communities and researchers. Apply strengths-based, rights-based and anti-racist approaches to implementation science that incorporate creativity, imagination and other ways of knowing that have been embraced by Black communities.



Adapt or Discard Inappropriate Models: Identify and document shortcomings of existing implementation science tools that fail to meet the needs of Black communities including by way of pathologizing communities and devaluing ways of knowing and doing that are central to experiences of Black communities.



Effectively Engage IRBs: Provide resources and training for IRB committees on reviewing community-based and participatory research. Provide resources and training for community-based researchers on navigating IRB processes.

For the master's tools will never dismantle the master's house

- Audre Lorde



Reimagine Solidarity

Build research infrastructures that actively work against anti-Black racism and other forms of oppression including transphobia, homophobia, ableism, and anti-indigenous racism while addressing the detrimental effects of these realities on the minds and bodies of Black populations and Black investigators.



Create Space for Healing: Provide accessible spaces for healing, reflection, imagination, and addressing the cumulative trauma faced by Black researchers and community members. Provide support systems and resources for navigating violent research spaces in order to promote collective sustainability.



Address Systemic Anti-Black Racism: Transform culture, governance structures, funding structures and priorities in public, private and civil sector institutions involved in HIV research development and implementation to be anti-racist.



Build Inclusive Community: Create research spaces that are welcoming to individuals of diverse classes, genders, sexualities, and lived experiences. Work in solidarity towards addressing common (i.e. anti-Black racism) and unique (e.g. transphobia, homophobia, sexism) influences on the experience of HIV vulnerability and infection that Black populations face.

Caring for myself is not selfindulgence, it is self-preservation, and that is an act of political warfare

- Audre Lorde



Reimagine Community Accountability

Hold institutions engaged in sponsoring and conducting research intended to address the HIV epidemic in Black communities accountable to these communities.



Sustainable Impact: Use modes of measuring research success that focus on meeting community-identified goals, promoting sustainability, and addressing holistic health concerns beyond only sexual health rather than research output in the form of publications.



Responsible Community Engagement: Produce and adhere to community-directed and community-informed guidelines and protocols for ethical, restorative and healing engagements with Black communities.



Systems of Redress: Develop effective systems of redress for institutions that fail to serve, support and protect Black communities in the course of research pertaining to HIV.

Justice is what love looks like in public

-Cornel West

URGENT RESEARCH PRIORITIES

Impact of anti-Black racism and other social determinants of health on access and uptake of HIV prevention, treatment, care and support services

- Culturally appropriate interventions
- Healthcare and health insurance access
- Housing
- Poverty

- Provider bias
- Social justice and health equity
- Structural inequalities and structural interventions
- Transportation

Community-based interventions

- Building trust
- Capacity-building of community-based organizations
- Community engagement
- Implementation science
- New models of implementation science
- Participatory action research

HIV-related stigma and discrimination

- HIV stigma
- Intersectional stigma
- Power and pleasure
- PrEP stigma
- Religious underpinnings of HIV stigma
- Resilience and strength-focused research
- Stigma among LGBTQ+ populations
- Stigma in healthcare
- Stigma management

URGENT RESEARCH PRIORITIES

PrEP (and other prevention) technologies, implementation, access and uptake

- Behavioral prevention research
- Behavioral research
- Biomedical and clinical prevention research
- Improve PrEP adherence
- Injectable PrEP
- PrEP costs
- PrEP education and screening

- PrEP for:
 - Black men who have sex with men
 - Black women
 - Trans individuals undergoing hormone therapy
 - Young Black men
- PrEP implementation and scale-up

HIV care access and adherence

- Care coordination
- Care re-engagement
- Engagement strategies for adolescents
- HIV testing
- Improving healthcare provider and patient relationships
- Improving service delivery models in Black communities
- Viral suppression

HIV education and communication

- Culturally-appropriate communication
- HIV education for adolescents and young adults
- HIV education for Black women
- HIV education on college campuses
- Mainstream media
- Non-stigmatizing communication
- Sexual health education in grade school
- Sexually transmitted infections education
- Tailoring communication strategies for different demographics

URGENT RESEARCH PRIORITIES

Populations of Interest

- Black adolescents
- Black cis heterosexual men
- Black families
- Black gay, bisexual and other men who have sex with men
- Black gender non-conforming and non-binary individuals

- Black girls
- Black lesbian women
- Black LGBTQ+ youth
- Black residents of the South
- Black rural populations
- Black trans men
- Black trans women

Research Infrastructure and Workforce

- Alternative models of HIV research funding
- Anti-Black racism in resource allocation and access
- Black-led research
- Data ownership
- Dedicated funding pipelines for Black researchers
- Effective academic-community partnerships
- Global North-South collaborations and knowledge sharing
- HIV and public health funding allocation practices
- Impact of past HIV research spending
- Leadership development of people living with HIV
- Limitations of existing frameworks and models

Comorbidities

- Mental health
- Neurocognitive disorders
- Sexual trauma
- Sexually transmitted infections
- Substance use disorders
- Syndemics frameworks
- Tracking co-infections

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- Yale Center for Methods in Implementation and Prevention Science (CMIPS)
- Yale Rigorous, Rapid and Relevant Evidence Adaptation and Implementation to Ending the HIV Epidemic (R3EDI) Hub















R3EDI: Rigorous, Rapid and Relevant Evidence Implementation to Ending

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Kyle Gordon

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