



EXPANDING OUR LEGACY:  
ENGAGING BLACK HIV  
ADVOCATES IN CLINICAL  
RESEARCH

Authors:

Maximillian Boykin, Jeremiah Johnson, Abraham Johnson,  
Myriam Johnstone, Louis Shackelford, Stephaun Wallace

Presenters:

Maximillian Boykin, Abraham Johnson, Myriam Johnstone,  
David “Jax” Kelly, Louis Shackelford

# PRESENTATION OUTLINE

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- History of Research Cohort Formation
- Context for Course
- Summary of Curriculum
- Future of Research Cohort
- Statistical Findings
- Recommendations
- Q&A



# HISTORY OF RESEARCH COHORT FORMATION

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- Treatment Action Group, Black AIDS Institute, and HIV Trials Network
- Curriculum development
- Recruitment process
  - Black AIDS Institute – Black Treatment Advocates Network (BTAN)

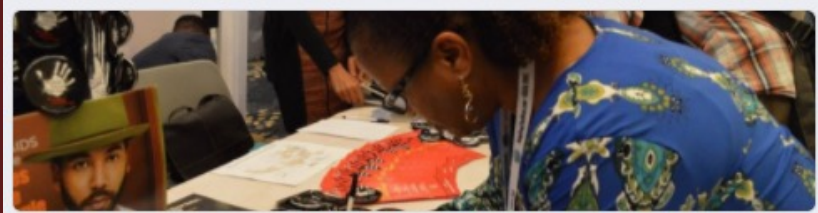


# TRAINING THE WE THE PEOPLE RESEARCH ADVOCATES

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## Five Phases of Work in 2020:

1. Community survey and report
2. HIV Prevention Research  
Webinar Series  
(Spring/Summer)
3. Cohort Application Process  
(August)\*
4. Virtual Training (Sept – Dec)
5. Cohort Convening/ Advocacy  
Opportunities



## We the People Research Cohort Application

Following our conversation on the Call on the 6th please fill this out by the Noon ET on a Thursday August September 3rd.

\* Required

Email address \*

Your email

Name \*

Your answer

BTAN Chapter or Affiliate or Not Apart of BTAN \*

Your answer

What makes you interested in joining the We the People Research Cohort? \*

Your answer

What has been your connection to HIV Vaccine or prevention research? This could be a personal story, a connection through employment, volunteering or you could have had no connection at all in the past



# HIV PREVENTION RESEARCH ADVOCATE CERTIFICATION PROGRAM

The HIV Prevention Research Advocacy Certification Program is unique in that it:

- Provides a robust curriculum around HIV sciences and biomedical interventions.
- Addresses these topics using a framework which centers the needs of Black people, and the relationship Black people have to these topics.
- The certification program builds capacity around how to address structural barriers and other barriers to research and advocacy that marginalized folks may experience.
- Our certification program addresses the co-occurrences of HIV, and how relationships to them morph according to different identities that people hold.
- All content created and presented from a uniquely and unapologetically Black point-of-view.

This certification program is for anyone who is interested in understanding more about HIV prevention clinical trials, research advocacy, and the unique experiences of Black communities in this space.

# CONTEXT: ADVOCACY IN RESEARCH

- HIV in Black America
- Racial disparities in HIV-related health since HAART therapy (1996)
- Studies of HIV treatment adherence
  - Disparate outcomes due to social determinants of health, which adversely impact the care that Black people access



# CONTEXT: ADVOCACY IN RESEARCH (continued)



- Origins of medical mistrust in Black communities
- Tactics for moving beyond medical mistrust
  - Ex. Recruit and hire Black researchers, recruiters, and community engagement officers
- Lack of participation in clinical trial development and research
- Role of Community Advisory Boards

# SUMMARY OF CURRICULUM

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Each module included: a recorded presentation, survey, and expert call

- **Module 1:** Background - HIV surveillance, social/structural barriers in research, medical mistrust
- **Module 2:** Current State of HIV Science
- **Module 3:** Changes in HIV Prevention Research
- **Module 4:** Opportunities for Advocacy



SUMMARY OF  
CURRICULUM  
(continued)

Expert Calls Guest included:

- Dr. Vivian Carter, Tuskegee University
- Tori Cooper, Human Rights Campaign
- Larry Scott-Walker, THRIVESS
- Dr. Stephaun Wallace, HVTN & CoVPN
- Dr. LaRon Nelson, Yale University
- Keita Mutepfa, Merck Inc.

# FUTURE OF RESEARCH COHORT

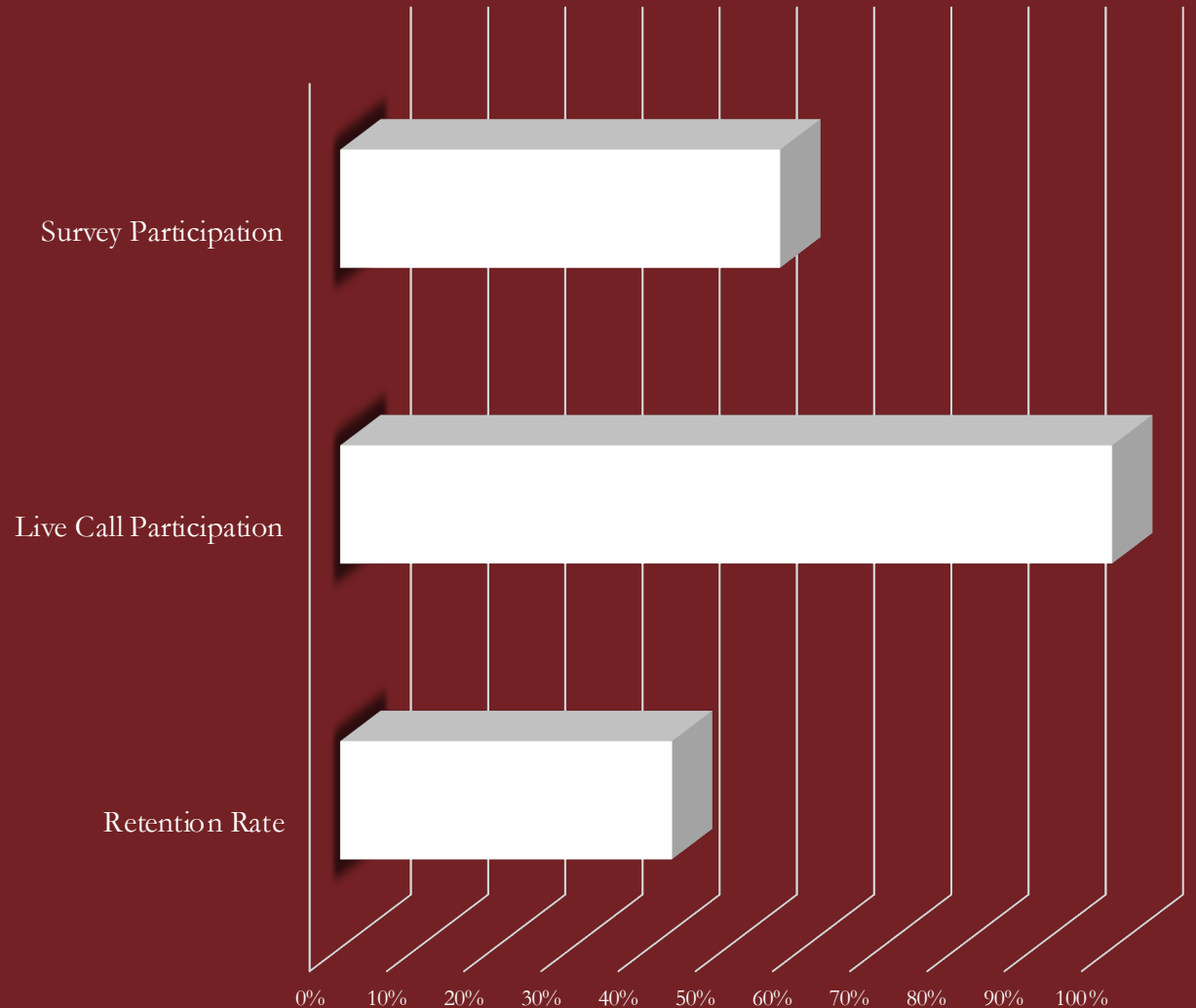
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- Collaborative training event
- Linkage to further educational opportunities
  - AVAC Trial Design Academy
  - Research advocacy event notifications
- Alumni mentorship for future 2021 cohort
  - Recruitment plans for 2021 cohort

# STATISTICAL FINDINGS

- Member retention rate: 43%
  - 13 course graduates
- Live call participation from active cohort members: 100%
- Survey participation from active cohort members: 57%

## 2020 Research Cohort



# RECOMMENDATIONS

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- Increase diversity of the cohort ( i.e., age, gender, and orientation)
- Cohort member retention strategies
- Develop a robust recruitment strategy for recruiting new members
- Develop a pre and post evaluation survey to measure process outcomes
- Develop a more streamlined approach for administering pre and post surveys







QUESTIONS?