



**Lincoln University - Legacy Project Partnership**

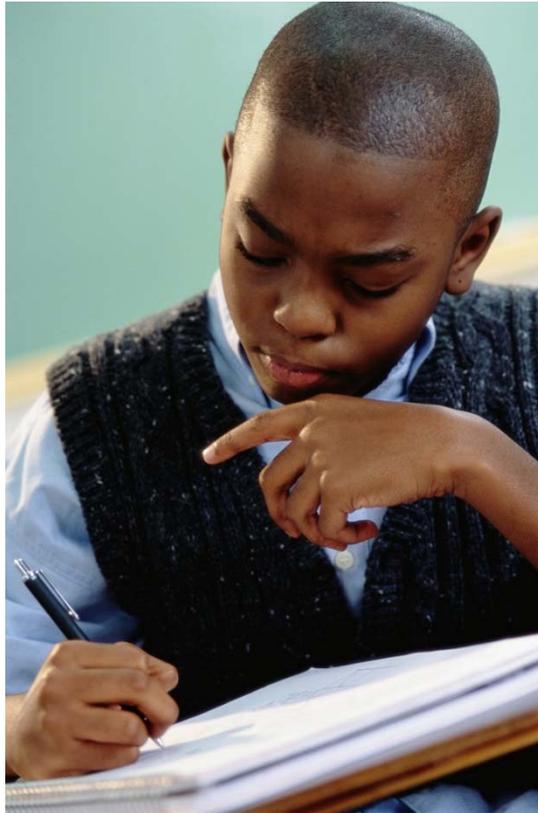
***Examining Innovative Research  
Methodologies in Community and  
Academic Settings: A Closer Look at  
CBPR in Mobilizing Historical Black  
Colleges and Universities around  
Preventive and Therapeutic HIV Clinical  
Research***

# Overview

- Purpose
- Objectives
- Background
- Study Rationale
- Methods & Design
- Key Findings
- What's Ahead
- Research Team
- Questions



# Purpose



- To address the lack of representation of African Americans involved in HIV/AIDS research and clinical trial participation
- To contribute toward improving the quality of life for African American college students who attend Historically Black Colleges and Universities (HBCUs)
- To improve the quality and effectiveness of prevention, care, and support activities as they relate to HIV/AIDS

# Study Objective

- Primary:
  - to assess the level of HIV/AIDS knowledge, attitudes and beliefs in African American college students who attend or have attended HBCUs
- Secondary:
  - to prevent the transmission of HIV and to mitigate the consequences of AIDS through care, support, and treatment
  - to explore participants' responses as they relate to biomedical research





# Background

- African Americans face the most severe burden of HIV in the US. The prevalence of HIV/AIDS has reached epidemic proportions among African Americans, particularly among African American youth and young adults (aged 13-24).
- African Americans represent approximately 14% of the total US population.
- In 2010, HIV incidence among African Americans was almost 8x higher than that of Whites, and African Americans accounted for almost half (44%) of people in the U.S. living with HIV.

(Centers for Disease Control and Prevention, 2012)

# Background

- African Americans have historically been, and are currently, underrepresented in HIV clinical research trials
  - “The National Medical Association has long recognized that the lack of involvement by African Americans and other people of color in clinical trials have contributed to health disparities”. Clinical trials are fundamental to our understanding of the proper diagnosis and treatment of disease and quality of life. (National Medical Association, 2008)
- HBCUs have provided a vehicle for the development and education of over 5 million students, most of whom are African American. (National Association for Equal Opportunity in Higher Education, 2014)
- HBCUs: (United States Environmental Protection Agency, 2014)
  - matriculated 24% of all African American students enrolled in four-year colleges
  - awarded masters degrees and first-professional degrees to about one in six African American men and women
  - awarded 24% of all baccalaureate degrees earned by African Americans nationwide”



# Study Rationale

- Large numbers of African Americans enrolled at HBCUs
- High HIV incidence rates among African Americans, particularly African American youth and young adults
- HBCUs are a primary point of focus for intervention, prevention and treatment programming, and research

# Methods & Design

- Qualitative
  - 24 semi-structured interviews with faculty across 7 different HBCU campuses
  - 2 focus groups with 35 students across 2 HBCU campuses (Lincoln and Cheyney)
- Quantitative
  - 543 online surveys of HBCU students across 17 different HBCU campuses





# Student Focus Groups & Faculty Interviews

- Held On-campus (FGs) and (FIs) via Phone
- Snowball Sampling
- 1.5-2 hrs in Length
- Audio Recorded & Transcribed
- Facilitated by HBCU staff and Legacy Project staff
- Compensation (Focus Group Recruiters)
- Discussion Questions:
  - HIV/AIDS on HBCU Campuses
  - Existing HIV Programs and Services
  - Involvement with HIV Clinical Research
  - HIV Messaging
  - Awareness and Support of HIV Clinical Research



# Online Student Survey

- Flyers and Advertisements
- Gift Card Raffle
- Survey Questions
  - Demographics (n=15)
  - HIV/AIDS Knowledge (n=24)
  - HIV/AIDS Clinical Trials Research (n=4)
  - Career Planning (n=7)



# RESULTS



# Survey Demographics

- 62.6% - Female
- 72% - Aged 18-22
- 94.5% - Identified as AA/Black
- 86.4% - Heterosexual-identified
- 64.3% - Single
- 68.8% - Full time student
- 69.8% - Live on campus
- 40.9% - Attend Lincoln University

# PERCEPTION OF HIV RISK AND TRANSMISSION

- Interviewed **faculty stated factors such as multiple sexual partners, inconsistent condom use, substance use, and lack of awareness as factors increasing student risk for HIV.** Many faculty members could not provide an accurate answer.
- **Students in focus groups** noted the common ways to contract HIV but there were still **some incorrect answers regarding myths of HIV transmission.**
- Many **students surveyed indicated accurate knowledge in response to questions regarding HIV risk and transmission.**
- **96.7%** of students reported that you don't have to look sick to spread HIV, most (**91.4%**) agree that condoms reduce the risk of contracting HIV, and **93%** agreed that one encounter of unprotected sexual intercourse can result in HIV transmission.
- **97.5%** of students noted that a woman can contract HIV if she has unprotected vaginal sex with a man who has HIV. Similarly most (**88.1%**) agreed that anal sex without a condom can result in HIV infection.

# WILLINGNESS TO PARTICIPATE IN HIV CLINICAL TRIALS

- **Both students in focus groups and faculty interviewed knew very little about HIV clinical trials, with popular myths brought up several times.**
- Faculty attitudes towards clinical research were mostly positive and **most faculty would support students interested in participating in an HIV clinical research trial.**
- Survey results:
  - **65.4% were not willing to participate** in an HIV clinical trial.
  - **57.1% reported never hearing anything about HIV clinical trials (57.1%).**
  - **48% agreed that students on their campus are rarely informed** about the results of HIV clinical trials, even when studies are done among the student body.
  - **36.8% agreed that they have a professor on campus that discusses advances in HIV clinical research.**

# IMPRESSIONS OF HIV CLINICAL RESEARCH

- Students in focus groups showed **significant cynicism towards HIV clinical research because of distrust in medical research and stigma.**
- **The topic of distrust of medical research was brought up several times during focus groups and faculty interviews.**
- The impressions of HIV Clinical research by the survey participants were overall positive.
  - The majority **agreed (73.9%) that clinical researchers would protect them from harm**, and that HIV clinical researchers respect the concerns of the communities (56.1%).
  - **45.4% were concerned that their privacy would be invaded** if they participated in an HIV clinical trial.
  - 52.7% agreed that they would feel comfortable telling their family and friends about their participation in an HIV clinical trial
  - 41.2% agreed that they know where to get accurate information about HIV clinical research study results in their community.



# HIV PROGRAMS AND INTERVENTIONS ON HBCUs

- **Lack of knowledge and awareness of programs and resources on HBCUs is significant among faculty and students.**
- There is a disconnect between faculty and focus group students in perceptions of available HIV testing programs: Students in focus groups report a lack of HIV testing, where faculty report plenty of opportunities for HIV testing.
- Faculty and students suggested in-class programs with incentives, such as extra credit, as a tool to increase knowledge and awareness of HIV and HIV clinical research.
- Faculty and students report a lack of HIV messaging and HIV research messaging on HBCUs.
- The most commonly suggested messaging idea included social media, Internet, and in classroom programs.
- More study participants disagreed (38.7%), than agreed (32.7%) that HIV clinical researchers ask for their thoughts and ideas about the trial designed in their community (off campus).
- The majority agreed (78%) that **they would feel good if they could help people who were infected with HIV.**



# PROFESIONAL OPPORTUNITIES AND DEVELOPMENT

- Survey Results:
  - 57.2% agreed that the faculty at their schools would provide the necessary support and mentorship for a career in HIV clinical research.
  - 69% agreed that their family and friends would support them if they decided to devote their professional life treating and caring for people with HIV/AIDS.
  - Many participants noted that they either weren't (41.3%) or did not know (37.5%) if there were opportunities to work at HIV clinical research sites, health clinics, and/or AIDS-service community based organizations at the career fair.



# Summary

- Overall students and faculty lack awareness of available HIV programs and HIV clinical research.
- Students and faculty report a lack of importance of HIV on HBCUs since HIV is currently viewed as a treatable disease by younger generations who have experienced HIV post HAART.
- Faculty and students report a lack of available HBCU resources, services, and programs to support the prevention of HIV/AIDS.
- In addition, there is very little knowledge of HIV clinical trials, with a mix of both positive and negative attitudes.

# What's Ahead



# Research Assistants



# Research Team

- **Stephaun Wallace, MS**
  - Co-Principal Investigator; Legacy Project, Seattle, WA
- **Denise Gaither-Hardy, MA**
  - Co-Principal Investigator; Lincoln University, Lincoln University, PA
- **Shelley Johnson**
  - Project Manager; Lincoln University, Lincoln University, PA
- **Nubia Chong, BS**
  - Research Associate, HIV Vaccine Trials Network, Seattle, WA
- **Vera Okolo**
  - Research Assistant, HIV Vaccine Trials Network, Seattle, WA
- **Logan Wahl**
  - Research Assistant, HIV Vaccine Trials Network, Seattle, WA
- **Michele Andrasik, PhD**
  - Co-Investigator, HIV Vaccine Trials Network/Legacy Project, Seattle, WA

This project is funded in whole or in part with Federal funds from the Division of AIDS, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Department of Health and Human Services, grant number UMI AI068614, entitled Leadership Group for a Global HIV Vaccine Clinical Trials (Office of HIV/AIDS Network Coordination) with additional support from the National Institute of Mental Health.

# Questions?

Presenters:

Denise Gaither-Hardy, MA  
Lincoln University

Nubia Chong  
SUNY Downstate  
MD Candidate 2015  
HIV Vaccine Trials Network

“There is no such thing as a single-issue struggle because we do not live single-issue lives.”

— [Audre Lorde](#)

***Thank you for attending!!***

