

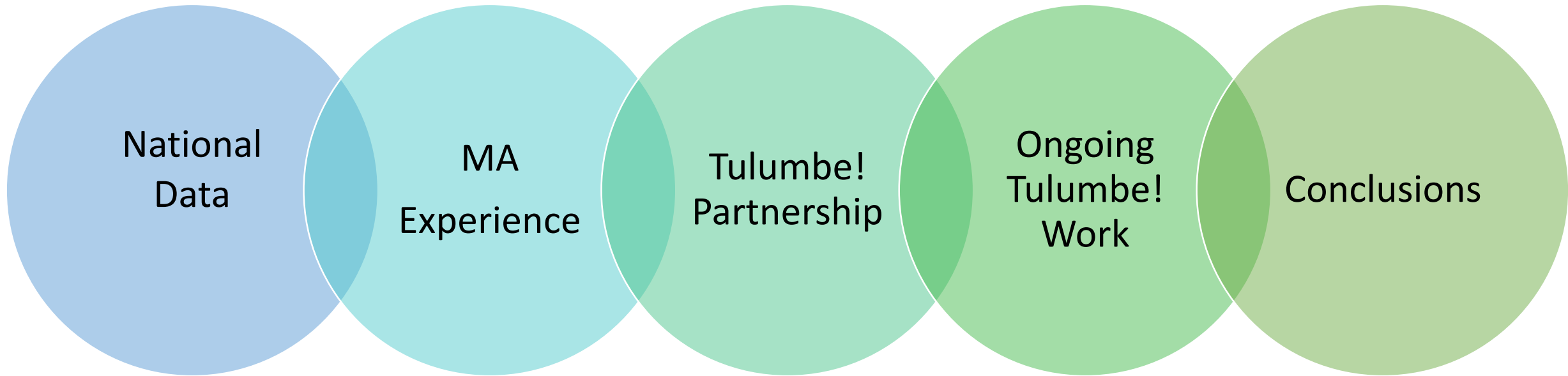
# The Tulumbe! Project

*Developing a Community-Led Research Agenda to Address HIV among  
African Immigrants*

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Chioma Nnaji, MPH, Med, Senior Program Director  
Multicultural AIDS Coalition

# Overview



# A hidden epidemic?


> J Acquir Immune Defic Syndr. 2008 Sep 1;49(1):102-6. doi: 10.1097/QAI.0b013e3181831806.

## HIV among African-born persons in the United States: a hidden epidemic?

Roxanne P Kerani<sup>1</sup>, James B Kent, Tracy Sides, Greg Dennis, Abdel R Ibrahim, Helene Cross, Ellen W Wiewel, Robert W Wood, Matthew R Golden

Research

### The Epidemiology of HIV Among People Born Outside the United States, 2010-2017

Roxanne P. Kerani, PhD, MPH<sup>1,2,3</sup> ; Anna Satcher Johnson<sup>2,3</sup>; Deepa Rao, PhD, MA<sup>5</sup>; Matthew R. Golden, MD and H. Irene Hall, PhD<sup>4</sup>

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ONLINE FIRST

## HIV in Persons Born Outside the United States, 2007-2010

Adria Tassy Prosser, PhD

Tian Tang, MS

H. Irene Hall, PhD



**HHS Public Access**

Author manuscript

*J Immigr Minor Health*. Author manuscript; available in PMC 2020 February 01.

Published in final edited form as:

*J Immigr Minor Health*. 2019 February ; 21(1): 30–38. doi:10.1007/s10903-018-0699-4.

### Differences Between U.S.-Born and Non-U.S.-Born Black Adults Reported with Diagnosed HIV Infection: United States, 2008–2014

Hanna B. Demeke<sup>1</sup>, Anna S. Johnson<sup>2</sup>, Baohua Wu<sup>3</sup>, Ndidi Nwangwu-Ike<sup>3</sup>, Hope King<sup>4</sup>, and Hazel D. Dean<sup>5</sup>

Video Interview

**Context** Persons born outside the United States comprise about 13 % of the US population, and the challenges these persons face in accessing health care may lead to poorer human immunodeficiency virus (HIV) disease outcomes.

**Objective** To describe the epidemiology of HIV among persons born outside the United

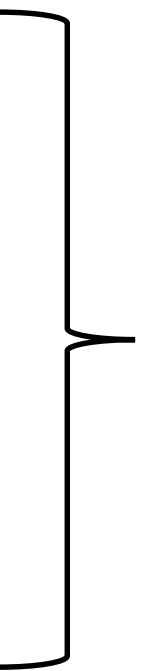
# National Data: HIV Among Black Individuals in the US US versus Non-US Born

	US Born	Non-US Born
Gender (new diagnoses)	>Male	>Female
Risk Category (Men)	Majority MSM	Majority Heterosexual
Highest Annual Rate (2008-2014)	MSM	African Women
Diagnoses Trend	Largest decline among women	Smallest decline among women
Late Diagnoses*	26%	37%

\*AIDS classification  $\leq$  3 months after HIV diagnosis

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**Annual HIV Diagnosis Rates, 2014  
per 100,000 Population**

African-born women	100.5	 5x
US-born Black men	72.8	
African-born men	51.3	
Caribbean-born men	40.6	
Caribbean-born women	31.8	
US-born Black women	19.1	

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## *What We Know:*

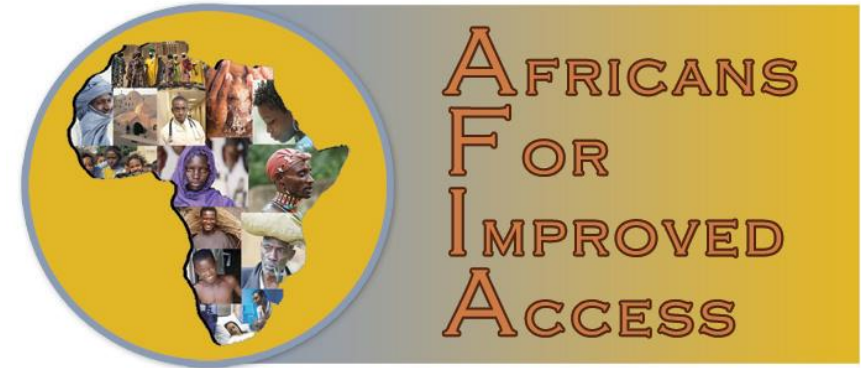
# National data on HIV among African Immigrants

- present with an AIDS diagnosis and more advanced disease
- experience greater HIV-related stigma
- experience barriers to testing and care in home country and the US
- significant proportion of HIV infection among individuals occurs post-immigration in the US
- epidemiology of HIV in African immigrants is different than U.S. epidemic as a whole
- ongoing risk of co-infection with hepatitis B, malaria and tuberculosis

# Africans For Improved Access (AFIA) Program

*A program of the Multicultural AIDS Coalition*

- In 1994, the State convened a group of African immigrant professionals
- In 2000, Office of HIV/AIDS (OHA) conducted an HIV needs assessment
- In 2000, MAC, funded through CDC, included the African immigrant sub-coalition as part of the Black HIV/AIDS Coalition
- In 2003, OHA funded AFIA and subcontractors to provided HIV/AIDS services



[www.mac-boston.org](http://www.mac-boston.org)

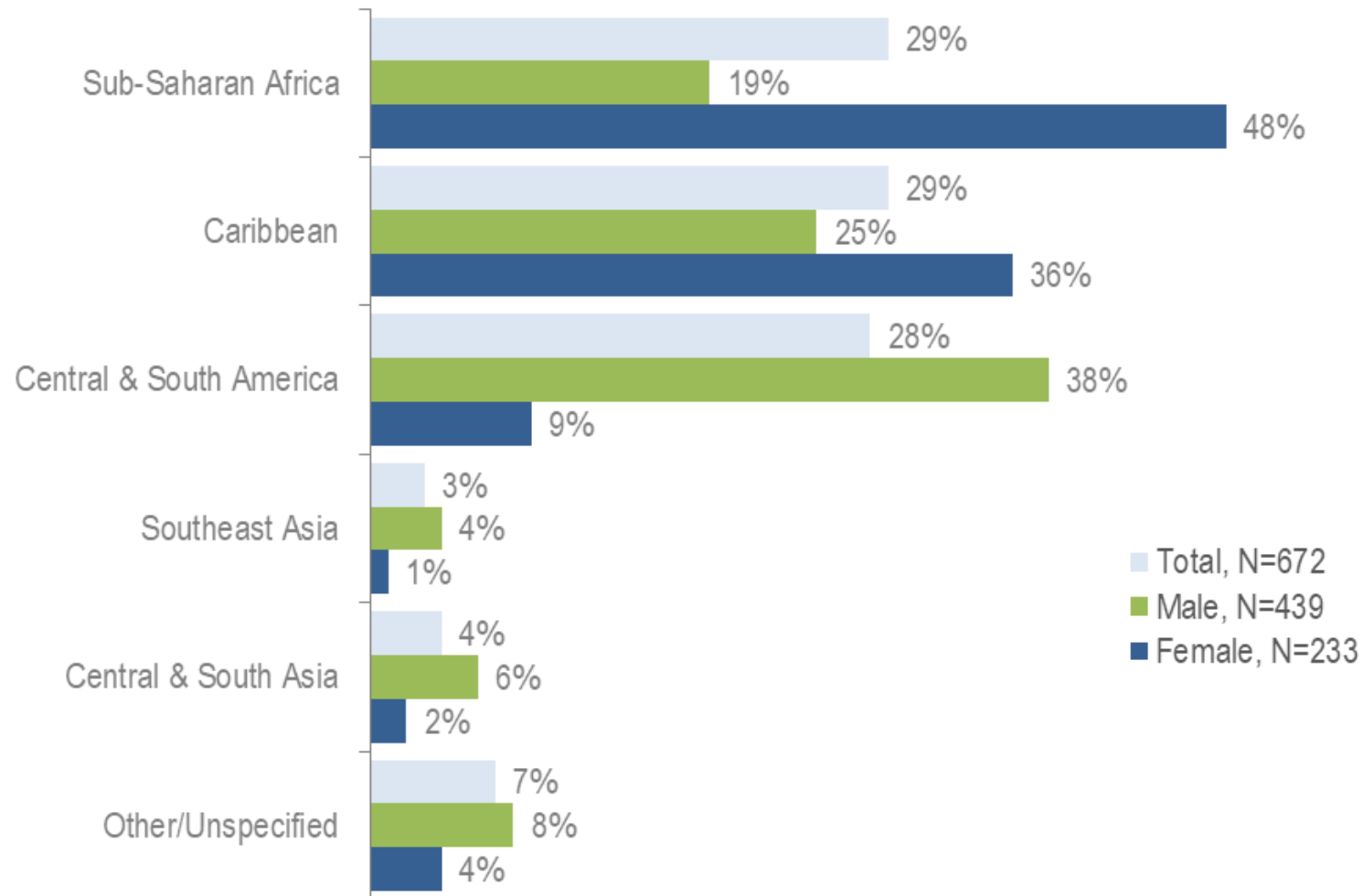
# Four Programmatic Principles

1. Nurture a community-led process in all activities.
2. Build long-lasting bridges in the community
3. Incorporate African-centered social and cultural values and practices
4. Maintain strong linkages with other needed services and overarching issues





# HIV diagnoses among people born outside the United States by sex assigned at birth and world region of birth: Massachusetts, 2016–2018



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# TULUMBE!

... a Luganda (language spoken in Uganda) word that means “to engage”.

*It is a call upon all partners, stakeholders and the general community to come together and engage in coming up with solutions that will address ending the HIV epidemic among the African Immigrant community.*

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# Tulumbe! Partners

- **Carol Bova**, PhD, RN, ANP, Nurse and Academic Researcher at the University of Massachusetts Medical School
- **Lorraine Anyango**, African Community Member
- **Bisola Ojikutu**, MD, MPH, Physician and Academic Researcher at Brigham & Women's Hospital
- **Mbita Mbao**, Licensed Clinical Social Worker
- **Dara Oloyede**, African Community Member
- **Chioma Nnaji**, Program Director at Africans For Improved Access (AFIA) Program
- **Ayomide Omotola**, African Community Member
- **Khady Diouf**, M.D., AAHIVS, OB-GYN and Academic Researcher at Brigham & Women's Hospital



**THE TULUMBE! PROJECT**

TULUMBE IS A LUGANDA (LANGUAGE SPOKEN IN UGANDA) WORD THAT MEANS, **"LET US ENGAGE!"**

**OUR MISSION**

...is to co-create a robust, sustainable partnership that considers the unique contributions of patients, community members, stakeholders, and researchers.

**WE FOCUS ON**

...developing solutions to end the HIV epidemic among the African immigrant community through:

- Learning more about what is happening in the community
- Eliminating the stigma around HIV and related topics
- Building cultural awareness
- Engaging African immigrants into care and services

Join us in improving the health of the African immigrant community!

**Contact Info:**  
Lorraine Anyango  
Tulumbe! Project Coordinator  
Phone: 617-840-2611  
Email: lorismallz@gmail.com



[www.tulumbe.org](http://www.tulumbe.org)

# Patient-Centered Outcomes Research Institute (PCORI)

- patient-centeredness: rely on patient perspectives and values to guide and improve the work
- research teams that include patients, caregivers, clinicians, and other healthcare stakeholders, as well as researchers
- funding specifically focused on engagement and building capacity



# PCORI Pipeline to Proposal (P2P)

Supports the development of health-related research ideas and proposals designed by partnerships of patients, caregivers, and other key stakeholders.

Tier 1:  
Partnership  
Development and  
Engage Stakeholders for  
Research Ideas

Tier 2:  
Develop Research  
Questions

Tier 3:  
PCORI Proposal  
Development



# What We Accomplished

## Tier 1: Partnership Development and Engage Stakeholders

- Governance document
- Member skills and assets matrix
- Name of partnership
- Provider survey
- Community forums
- Development of research topics

## Tier 2: Develop CER Research Questions

- Stakeholder report back event
- Research 101 workshop
- Community survey to prioritize topics and research questions
- Dissemination

## Tier 3: Proposal Development

*Sunset in 2017*

# Tier 1 Community Forums

- Lowell and Boston, Massachusetts
- 61 participants attended
- 40-49 age group
- 59% women
- Most were from Eritrea, Uganda, Liberia, Zambia, Zimbabwe, Kenya, Nigeria and Cameroon



## Tier 1

# Themes from Community Forums

## Barriers

- Shame, death and isolation associated with HIV
- Lack of visibility of Africans living with HIV
- Lack of HIV messaging
- Not communicating about sex to children
- Family secrets
- State of denial about HIV infection
- Gender dynamics and lack of personal agency for women
- Lack of motivation to access information despite many programs
- People do not think they are at risk

## Strategies

- Mobilize the community to have regular discussions
- Need representatives in the African immigrant community that can share their experiences with HIV or other related diseases
- Engage community leaders
- Normalizing the sex conversation

Reflection from Partnership: Lack of HIV education



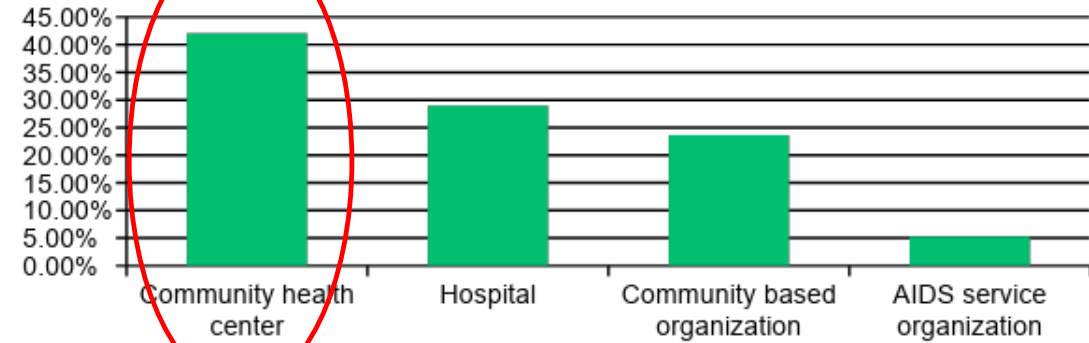
## Tier 1

# Provider Survey (n=53)

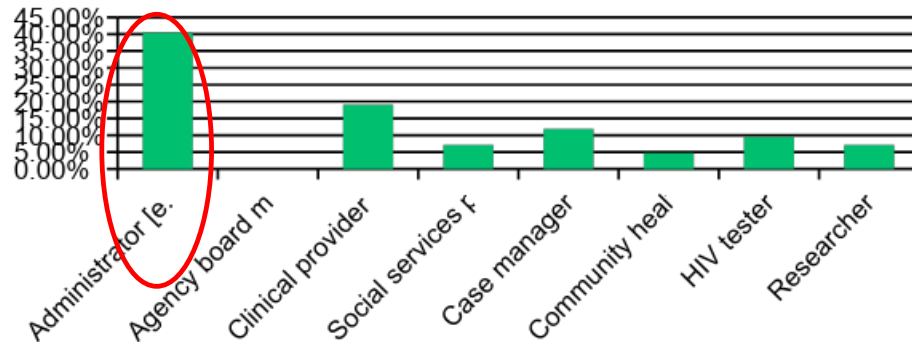
In which state are you located?



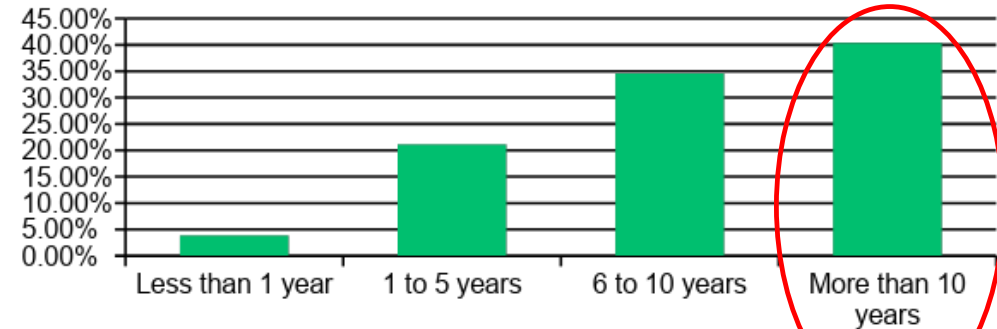
I work at a:



What is your primary function at your organization?



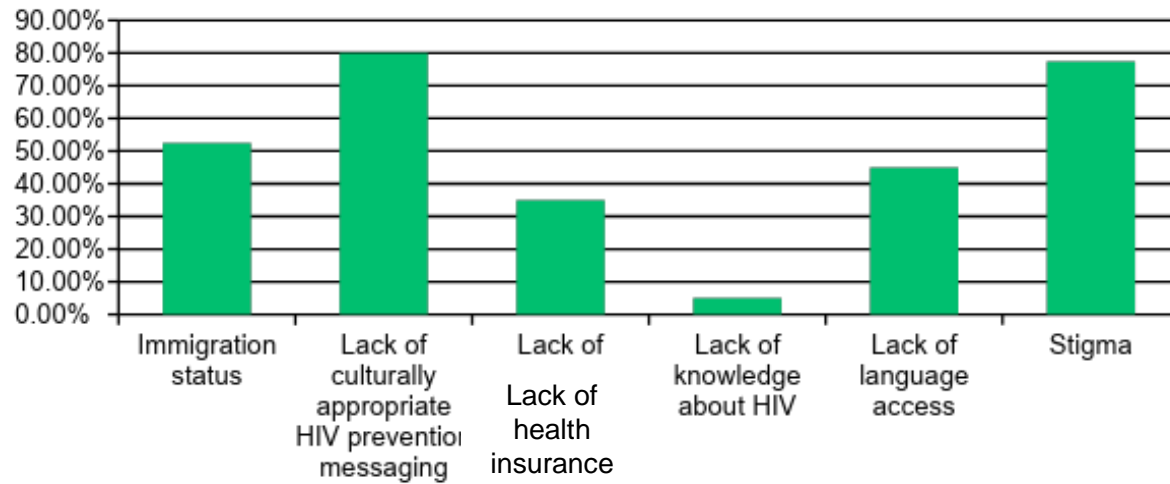
How long have you provided services to African immigrants?



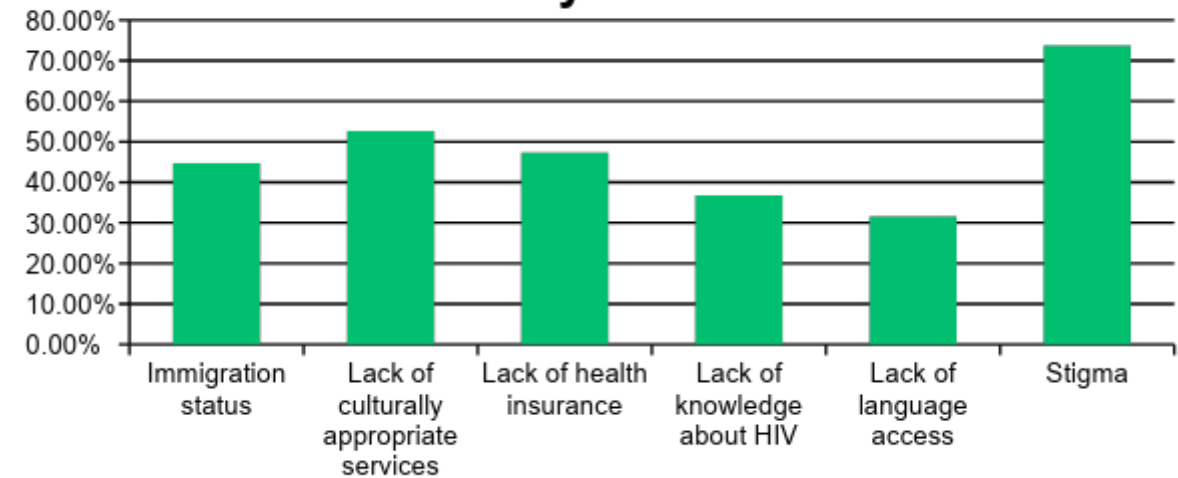
## Tier 1

# Barriers Experienced by Providers

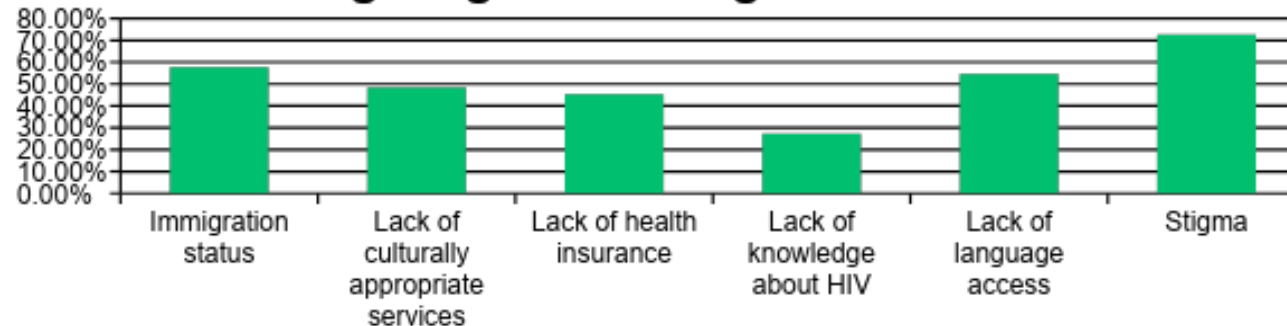
### Primary HIV Prevention



### Secondary HIV Prevention



### Navigating and Linkage to Care



## Tier 1

# Experiences of Providers

### **Interventions that work**

- Education and assurance of confidentiality
- Open access to publicly funded free services and medication
- Hiring and training African immigrants (i.e. CHWs, case managers)
- Outreach to local African immigrants owned businesses
- Bringing testing to the community
- Coordination and integration of services (i.e. test and treat)
- Meeting with the clients one-on-one and addressing other issues first

### **Interventions that do not work**

- Current evidence-based group and individual level interventions
- Treating African immigrants as if they respond to the same messaging as African American or African Caribbean immigrants
- Aggressive messaging related to HIV, or only focusing on HIV
- Peer support groups
- Hiring and training African immigrants
- English only campaigns



# TULUMBE! PROJECT:

[www.tulumbe.org](http://www.tulumbe.org)

Come together, engage and develop solutions  
that will end the HIV epidemic among  
African immigrant communities

1

## INCREASE SAFER SEX AND HIV/STI TESTING AMONG AFRICAN IMMIGRANT YOUTH



YOUTH ARE UNABLE TO TALK TO THEIR PARENTS AND RECEIVE WRONG INFORMATION FROM OTHER SOURCES. THERE IS A NEED FOR YOUTH-FRIENDLY PREVENTION SERVICES AND EDUCATION TAILORED TO AFRICAN IMMIGRANT YOUTH SO THEY FULLY UNDERSTAND HIV/STI PREVENTION AND WILL ENGAGE IN SAFE SEX PRACTICES.



MORE THAN

150

AFRICAN IMMIGRANT COMMUNITY  
MEMBERS AND OVER

50

HEALTHCARE PROVIDERS AND  
RESEARCHERS IDENTIFIED

6 HEALTH  
TOPICS

2

## INCREASE SELF-EMPOWERMENT AMONG AFRICAN IMMIGRANT WOMEN



AFRICAN CULTURAL AND SOCIETAL NORMS DICTATE A HARMFUL POWER IMBALANCE BETWEEN MEN AND WOMEN. IT LIMITS WOMEN'S ABILITY TO NEGOTIATE SAFER SEX AND MAKE DECISIONS ABOUT THEIR BODIES.

WOMEN NEED TO BE INFORMED ABOUT THEIR SEXUAL HEALTH, AND ALSO BE EMPOWERED TO CHALLENGE GENDER NORMS IN ORDER TO PROTECT THEMSELVES FROM HIV/STI.

HIGH LEVELS OF STIGMA WITHIN THE COMMUNITY LEAD TO POOR HEALTH FOR EVERYONE.

NOT TALKING ABOUT RISKY BEHAVIORS, NOT USING CONDOMS, AND NOT TESTING INCREASES THE RISK OF HIV/STI INFECTIONS. HIV-POSITIVE AFRICAN IMMIGRANTS LIVE IN ISOLATION, FEARING TO DISCLOSE AND SEEK CARE.



## REDUCE HIV STIGMA IN THE AFRICAN IMMIGRANT COMMUNITY

3

DISCUSSIONS ABOUT HIV/STI AND OTHER TOPICS ARE NOT COMMON AMONG AFRICAN IMMIGRANT FAMILIES. THERE IS NO DIALOGUE BETWEEN PARENTS OR BETWEEN PARENTS AND CHILDREN ABOUT SEX, SEXUALITY, DRUGS, PREVENTIVE PRACTICES AND THE NEED FOR HIV/STI TESTING.

TALKING ABOUT THESE TOPICS IS SEEN AS TABOO.



## IMPROVE FAMILY COMMUNICATION ABOUT SEXUAL HEALTH

4

MALE DOMINANCE PUTS MEN AS HEAD OF THE HOUSEHOLD, WITH WOMEN EXPECTED TO BE SUBMISSIVE TO THEM.



THIS LIMITS PARTNER COMMUNICATION ABOUT SEXUAL BEHAVIOR, INCLUDING DISCUSSION OF CONDOM USE. MASCULINITY NORMS ALSO ARE A BARRIER TO MEN ACCESSING HEALTH AND HIV SERVICES.

## REDUCE THE NEGATIVE INFLUENCE OF MALE DOMINANCE

5

AFRICAN IMMIGRANTS OFTEN COME TO THE U.S. WITH DIFFERENT HEALTH CARE EXPERIENCES. THERE IS A COMMUNICATION BARRIER BETWEEN PROVIDERS AND PATIENTS, RESULTING IN DIFFICULTY NAVIGATING THE HEALTH SYSTEM.

BEING ABLE TO OBTAIN, PROCESS UNDERSTAND, AND COMMUNICATE HEALTH-RELATED INFORMATION HELPS IMPROVE HEALTH KNOWLEDGE AND ALLOWS BETTER ACCESS TO SERVICES.



## INCREASE HEALTH LITERACY AMONG AFRICAN IMMIGRANTS

6



## Tier 2

# Stakeholder Report Back

40 attendees

### Prioritized Health Topics:

- Reducing HIV stigma in the community
- Increasing safer sex and testing among African youth
- Improving family communication about sexual health



## Tier 2

# Develop Research Questions

- Held a research 101 workshop for the partnership
- Implemented a community survey (n=42)
- Dissemination / Feedback
  - Conferences
  - Provider meetings
  - African immigrant events
  - National HIV-related webinars
  - Online via facebook and twitter
  - Tulumbe listserv

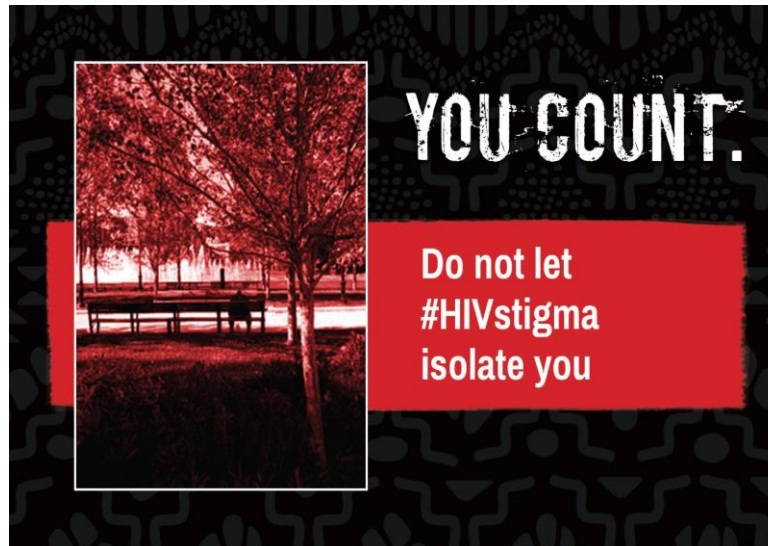
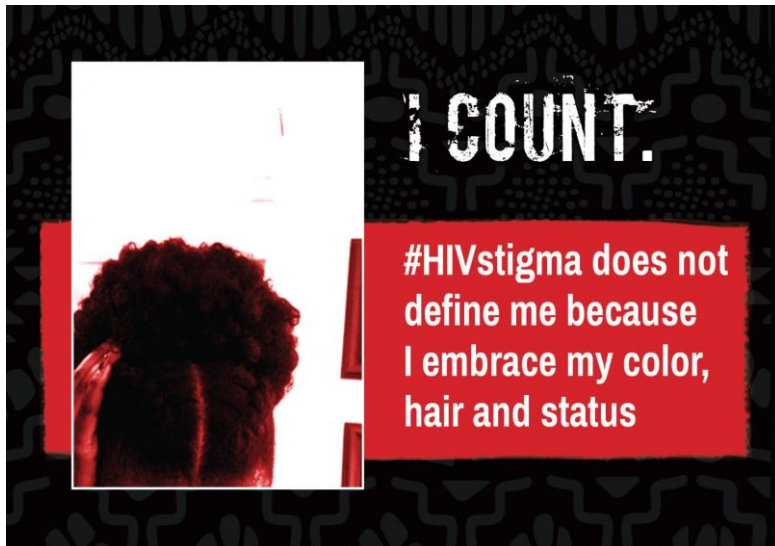




# Ongoing Tulumbe! Work

## Getting to Zero: HIV Stigma Among African Immigrants

- Engage African immigrants in addressing HIV related stigma among the community
- Recruited 8 African immigrants to participate in a photovoice research project
- Developed a campaign



# Ongoing Tulumbe! Work, cont'd

## Comparative Effectiveness of Individual versus Group-Level Interventions to Reduce HIV Risk among African Immigrant Women

- To **culturally adapt** two widely utilized, evidence-based HIV and sexually transmitted infection (STI) prevention interventions originally designed for US-born Black women—Sister-to-Sister or S2S, and Sisters Informing Sisters about Topics on AIDS or SISTA—for use by culturally diverse populations of African-born Black women, and
- To **conduct a randomized controlled comparative effectiveness trial** to determine the effects of adapted versions of Sister-to-Sister versus SISTA on increasing condom use and PrEP uptake.



# Tulumbe!: What worked

- Having a diverse representation of partners from different countries
- Having partners who are passionate about working with African immigrants
- Ongoing engagement of African immigrants
- Building partnerships requires time, flexible funding, and trust
- Building a deeper understanding of the issues and developing effective clinical and non-clinical interventions
- Providing incentives for community members to actively participate
- Supporting African community members in participating in local HIV advocacy and education activities

# Tulumbe!: What has been challenging

- Recruitment and retention of community members
- Access to adequate funding to carry out the projects
- Finding a time for meetings that worked for everyone
- Maintaining engagement of partners
- Diverse representation




National African Immigrant and Refugee HIV and  
Hepatitis Awareness (NAIRHHA) Day  
September 9th

# Contact Information

Tulumbe! Partnership  
[www.tulumbe.org](http://www.tulumbe.org)

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[cnnaji@mac-boston.org](mailto:cnnaji@mac-boston.org)  
857.325.1489




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