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# ENGAGING AFRICAN IMMIGRANTS IN ADDRESSING HIV DISPARITIES WITHIN THE POPULATION

8<sup>th</sup> Annual UMCCTS Community Engagement and Research Symposium  
March 22, 2019

Lorraine Anyango: Tulumbe! Project Coordinator  
Mbita Mbao, LICSW: Tulumbe! Member  
Dara Oloyede, MPH: Tulumbe! Member

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# OBJECTIVES

- To describe the Tulumbe! partnership
- To explain the planning, implementation, and evaluation of two Tulumbe! projects
- To discuss the challenges and successes of the Tulumbe! partnership

# TODAY'S AGENDA

- Introductions
- Overview of Tulumbe!
- Development of Our Research Topics
- Photovoice Activity
- HIV Stigma Photovoice Project
- Lessons Learned
- Next Steps
- Q&A

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# ROLL CALL



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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**, Advocate and Tulumbe! Project Coordinator
  - **Eduardo E. Nettle**, Population Health Program Manager for the Office of HIV/AIDS (OHA), Bureau of Infectious Disease at the Massachusetts Department of Public Health
  - **Bisola Ojikutu**, MD, MPH, Physician and Academic Researcher at Brigham & Women's Hospital
  - **Siede Slopadoe**, Program Coordinator at AFIA
  - **Frederick Kiggundu**, Program Coordinator at AFIA
  - **Mbita Mbao**, Licensed Independent Clinical Social Worker
  - **Sekou Kaba**, African Community Leader
  - **Dara Oloyede**, MPH, African Youth Community Member
  - **Chioma Nnaji**, Program Director at AFIA
  - **Ayomide Omotola**, MPH, African Youth Community Member
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# OVERVIEW OF FUNDING

**Patient-Centered Outcomes Research Institute (PCORI)** is an independent nonprofit, non-governmental organization in Washington, DC, was authorized by Congress in 2010 to answer many of the questions patients and their clinicians face daily.

**Massachusetts Getting to Zero Coalition and Gilead Pharmaceuticals:** Led by the AIDS Action Committee and Fenway Health, the Coalition is made up of 35 community-based organizations and health centers statewide working to eliminate the transmission of HIV.

# PCORI (2017 AND 2018)

- PCORI Tier I:
  - Partnership Development
  - Provider survey
  - Community forums
  - Development of research topics
- PCORI Tier 2:
  - Stakeholder report back event
  - Feedback from Massachusetts Integrated Prevention and Planning Council (MIPPC)
  - Research 101 workshop
  - Community survey to prioritize topics and research questions
  - Dissemination

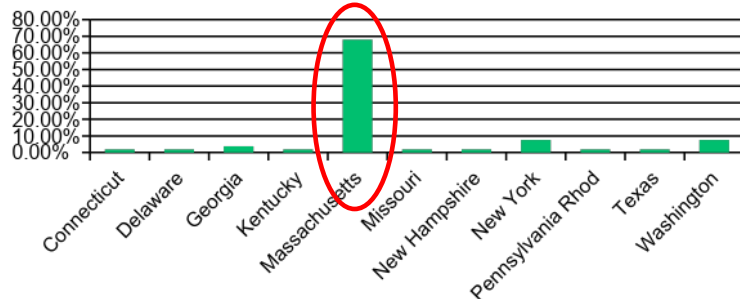


# PROVIDER SURVEY

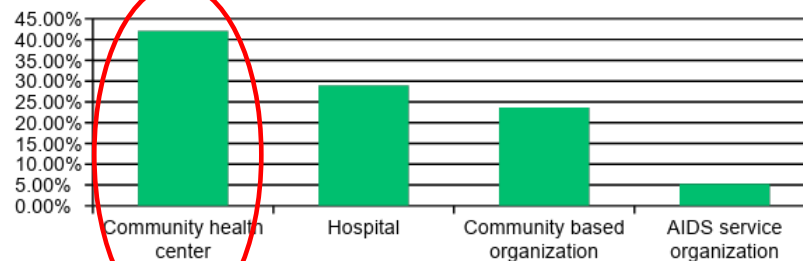
- Demographic Information
- Barriers and Successes to HIV Services for African Immigrants
  - Primary HIV Prevention
  - Secondary HIV Prevention
  - Navigation and Linkage to Care
- More Information
  - Marketing Strategies
  - Recommendations for someone to interview
  - Increased interest in getting more information about the project

# PROVIDER SURVEY (53 RESPONDENTS)

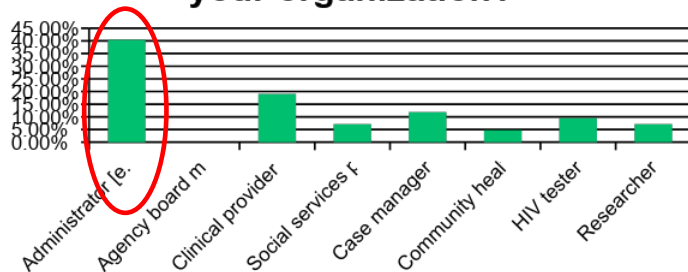
**In which state are you located?**



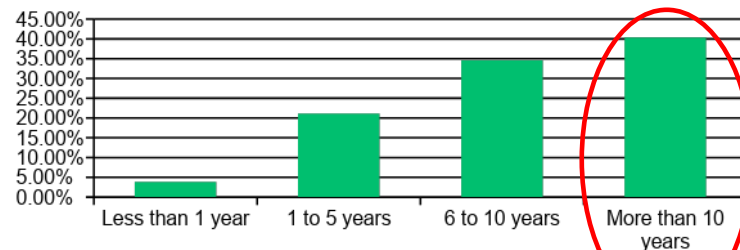
**I work at a:**



**What is your primary function at your organization?**

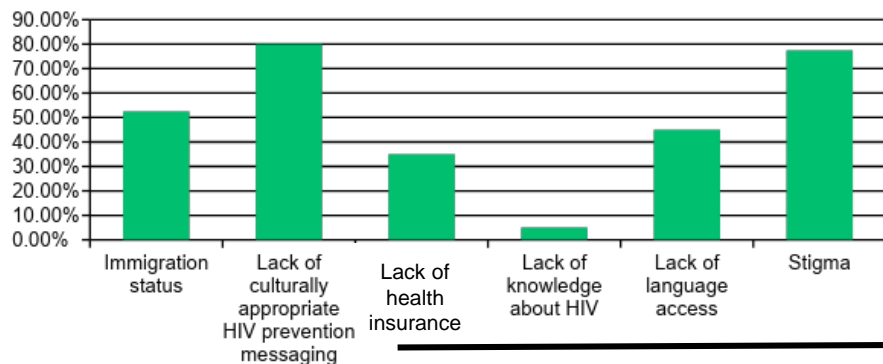


**How long have you provided services to African immigrants?**

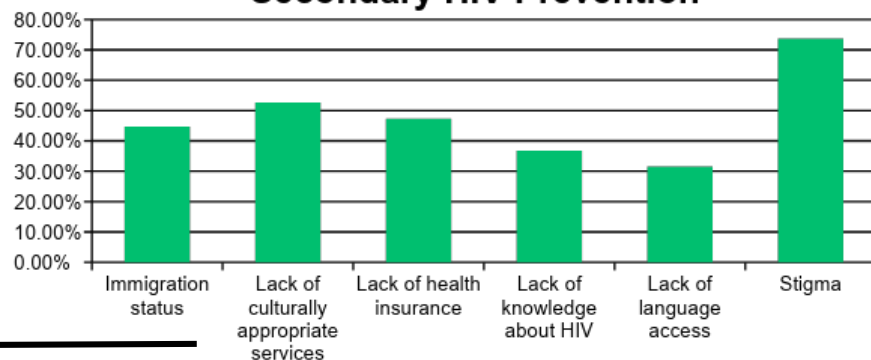


# BARRIERS

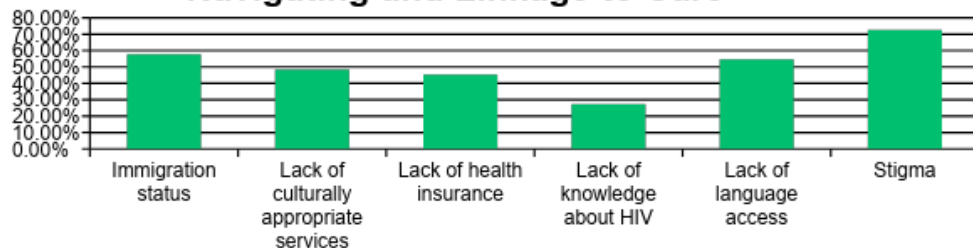
## Primary HIV Prevention



## Secondary HIV Prevention



## Navigating and Linkage to Care



# INTERVENTIONS OR STRATEGIES THAT HAVE WORKED

- 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 OR STRATEGIES THAT HAVE NOT WORKED

- 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

# COMMUNITY FORUMS

## Format:

- Lowell and Boston, Massachusetts
- 'In Our House': An African Story Video and large group discussion
- Small group discussions
- African dance and drumming celebration

## Participant Demographics:

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



# THEMES

## 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



# TULUMBE!

## PROJECT:

Come together, engage, and develop solutions that will address ending the HIV epidemic among the African immigrant community.

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

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### 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



# PCORI (2017 - 2018)

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# STAKEHOLDER REPORT BACK EVENT

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



## RESEARCH 101 WORKSHOP & FOLLOW-UP MEETINGS

- Held a research 101 workshop for the partnership
- Developed research questions from prioritized topics
- Drafted community survey
- Brainstormed ideas for survey dissemination

# COMMUNITY SURVEY

- Boston African Festival - 2018
- 42 participants

## Examples of prioritized research questions:

- What does disclosure (i.e. revealing HIV status) look like for African immigrants living with HIV?
- How is sexual health defined, understood and experienced within African cultural beliefs and understandings?



# DISSEMINATION

- African immigrant community events
- Provider meetings, trainings and conferences
  - Massachusetts Integrated Prevention and Planning Council (MIPPC)
  - Greater Portland Refugee and Immigrant Healthcare Collaborative
- National HIV-related webinars
- Online via facebook and twitter
- Tulumbe listserv

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# Addressing HIV Stigma Through Photovoice

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# WHY HIV STIGMA?

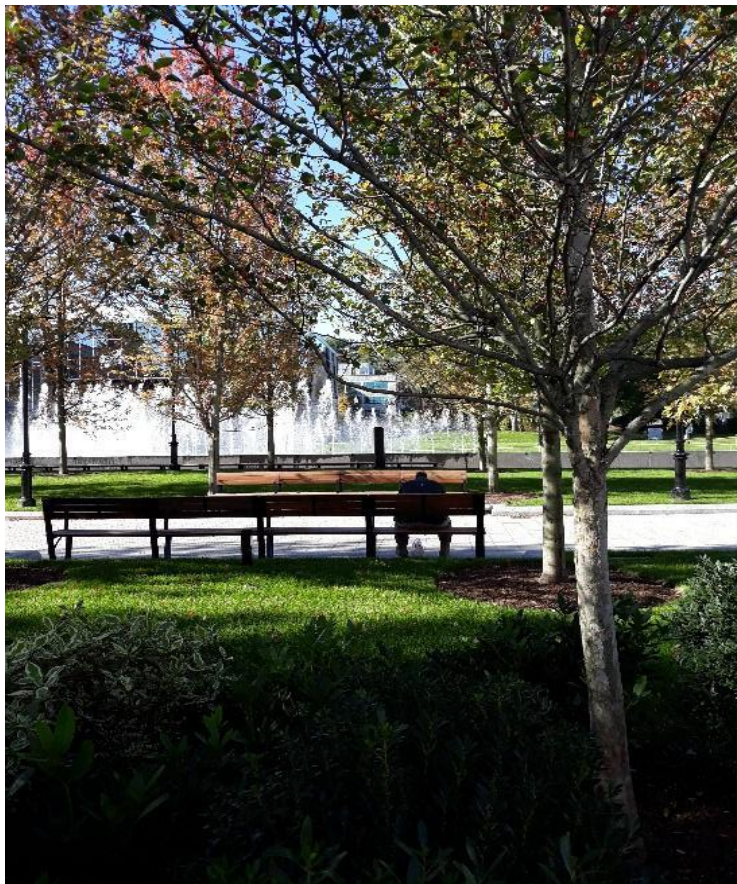
- Stigma is a barrier to talking about sex and other HIV related topics.
- Stigma is a barrier to accessing HIV testing
- Stigma is a barrier to linkage to care
- Stigma is a barrier to seeking HIV treatment

*With your neighbor spend a few minutes discussing what you think the photographer is trying to reflect through this picture.*

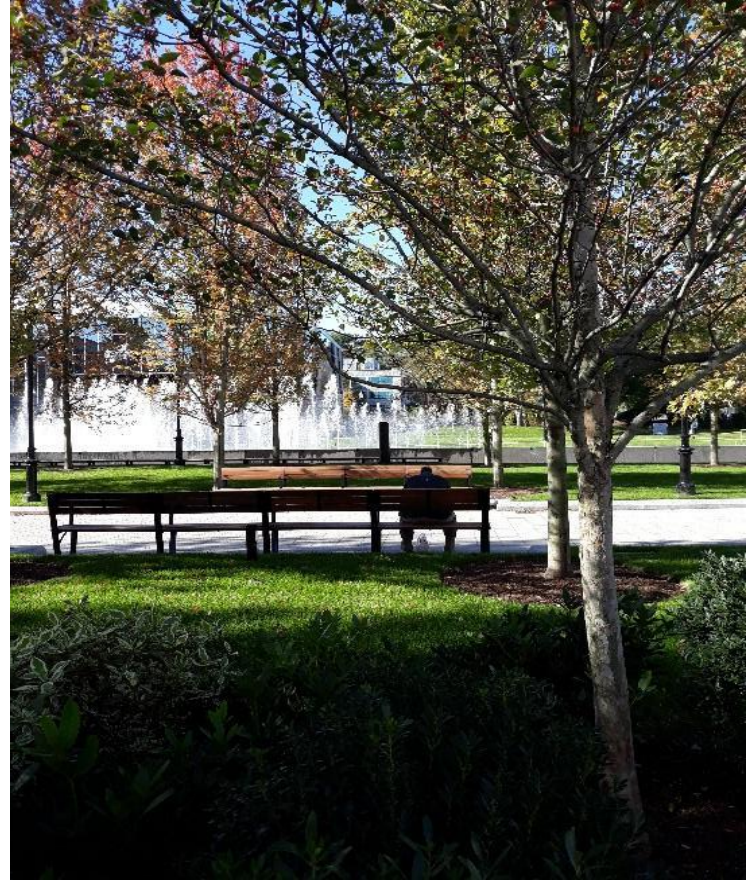
# Photovoice Icebreaker Activity

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**“The highs and lows.  
The pic could pass for  
that alone time to  
process everything  
whether good or bad”**



# WHAT IS PHOTOVOICE?

A group process of community and personal reflection using *photographs and written narratives*. Asks people to represent their lives, point of view and experience using photographs and narratives (Wang & Burris, 1997).

# INTERVENTION PROCESS

- Attend three 2-hour sessions within 6 weeks
- Talk about your experiences and knowledge about HIV-related stigma
- Take photographs that represent HIV stigma for you and your community
- Share your photos with a title or brief explanations with other participants
- The photo project was approved by Partners HealthCare IRB.

Partners HealthCare Institutional Review Board  
APPROVAL Effective Date  
9/14/2018

**We are looking for African immigrants living in Massachusetts to take part in a study on HIV stigma!**

*This is an opportunity to work with other African immigrants to identify solutions and further educate the community.*



You will be asked to do 4 things to be in this study.

- Attend three 2-hour sessions within 6 weeks
- Talk about your experiences and knowledge about HIV-related stigma
- Take photographs that represent HIV stigma for you and your community
- Share you photos with a title or brief explanations with other participants

**You will get \$250 for being a part of the study.**

Call Lorraine Anyango at (617) 840-2611 or [lorismallz@gmail.com](mailto:lorismallz@gmail.com) for more information about how to be a part of this research.

This research is led by the Tulumbe! Partnership, a group of African immigrants living with HIV/AIDS, community members, providers, stakeholders and researchers to reduce the negative impact of HIV among African immigrants through knowledge acquisition, stigma reduction, cultural awareness as well as engagement in care and services.

The study is funded through the AIDS Action Committee Getting to Zero Coalition

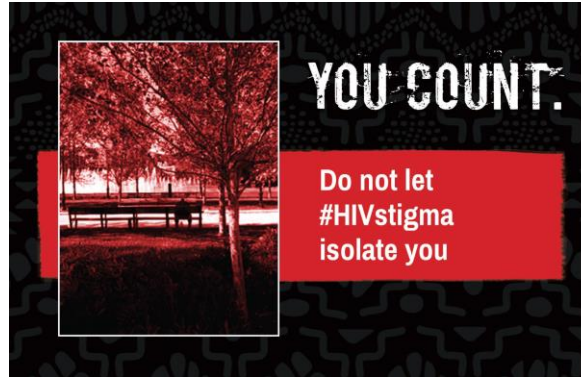


# OUTCOMES

- 35 pictures were taken
- 15 themes were created
- 2 themes and 8 pictures were selected for the development of final products
- Campaign development included (1) *'I Count, You Count, We Count'* (2) action oriented statement, and (3) *#HIVStigma*
- Community feedback through interviews



# PHOTOVOICE CAMPAIGN (examples)



# FEEDBACK FROM COMMUNITY MEMBERS

- Stigma is driven by fear, ignorance, assumption
- Community members appreciated the idea of the project including the use of photos
- Community members were drawn in by the colour but preferred bright pictures to showcase the brightness and diversity of African culture
- Community members thought the colours were stigmatizing
- There was a desire to see more men represented in the pictures
- Disconnect between older Africans and younger Africans, there was a suggestion that future projects target older African men and women

# EVALUATION OF PHOTOVOICE PROJECT

- Community members are open to having a dialogue around the impact of HIV on the African immigrant community
- Project participants highlighted a community need for such spaces and forums
- There was a desire to empower African immigrants to take part in dialogues around issues impacting the community
- The biggest theme was that African immigrants are not equipped with the knowledge of where to access resources and services
- African immigrants do not know where to go to ensure their voices are represented
- Importance of addressing HIV related stigma



# WHAT HAS WORKED FOR TULUMBE

- 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

## WHAT HAVE BEEN THE CHALLENGES FOR TULUMBE!

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

# NEXT STEPS FOR THE TULUMBE! PROJECT

- Grant submissions
  - Barclay-Giel Seed Grant (evaluate photovoice project)
  - PCORI (comparative effectiveness research - African immigrant women)
  - NIH (culturally adapt an intervention for African immigrant women)
- Dissemination
- Publish peer-reviewed articles
- Funding to address other health topics

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**ANY QUESTIONS?**

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# THANK YOU!

For more information about Tulumbe!  
[www.tulumbe.org](http://www.tulumbe.org)

## Contact Information:

Lorraine Anyango, Tulumbe! Project  
Coordinator

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Phone: 617-840-2611

