Community-Based Research:
Is Participation Reality, Rhetoric, or Tokenism?

International Stigma Conference • 2018 November 16

HOWARD UNIVERSITY
1867

If all research involves participation what makes research participatory?

WHAT IS PARTICIPATORY RESEARCH?

ANDREA CORNWALL[1] and RACHEL JEWKES[2]

[1]Department of Anthropology, SOAS, University of London, London WC1H 0XG, England and
[2]Health Promotion Sciences Unit, London School of Hygiene and Tropical Medicine, London, England

"The key element of participatory research lies not in methods but in the attitudes of researchers, which in turn determine how, by and for whom research is conceptualized and conducted."

"The key differences between participatory and other research methodologies lies in the location of power in the various stages of the research process and the perpetual discussion among researchers and community members" *Cornwall & Jewkes, 1995*

Laura Nyblade
RTI International, Washington, DC

Anna Helova
University of Alabama at Birmingham Sparkman Center for Global Health

David Malebranche
Morehouse School of Medicine, GA

Andrew Spieldenner
California State University San Marcos, CA

Kneeshe Parkinson
Positive Women's Network/ Project ARK, MO

Cheriko (Riko) A. Boone
BELIEVE Martin Delaney Cure CAB, Washington, DC

Moderator: **Ezer Kang**

Howard University, Department of Psychology

Discussant Questions

1. Community-research partnerships are often hampered by competing bottom lines. What are they and how have you move towards resolving/ preventing potential conflict?

2. Despite the best of intentions, PLWH are granted token voice on research – how can we be better at inclusivity?

3. What are outcomes of participatory research? Are these outcomes better than ones that are more researcher-driven?

4. How do we best overcome unforeseen, unintended negative consequence of research on communities?

Laura Nyblade

RTI International, Washington, DC

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Building Stigma Free Health Facilities: Participatory Methods are Key

Laura Nyblade, PhD

Senior Technical Advisor, Stigma and Discrimination

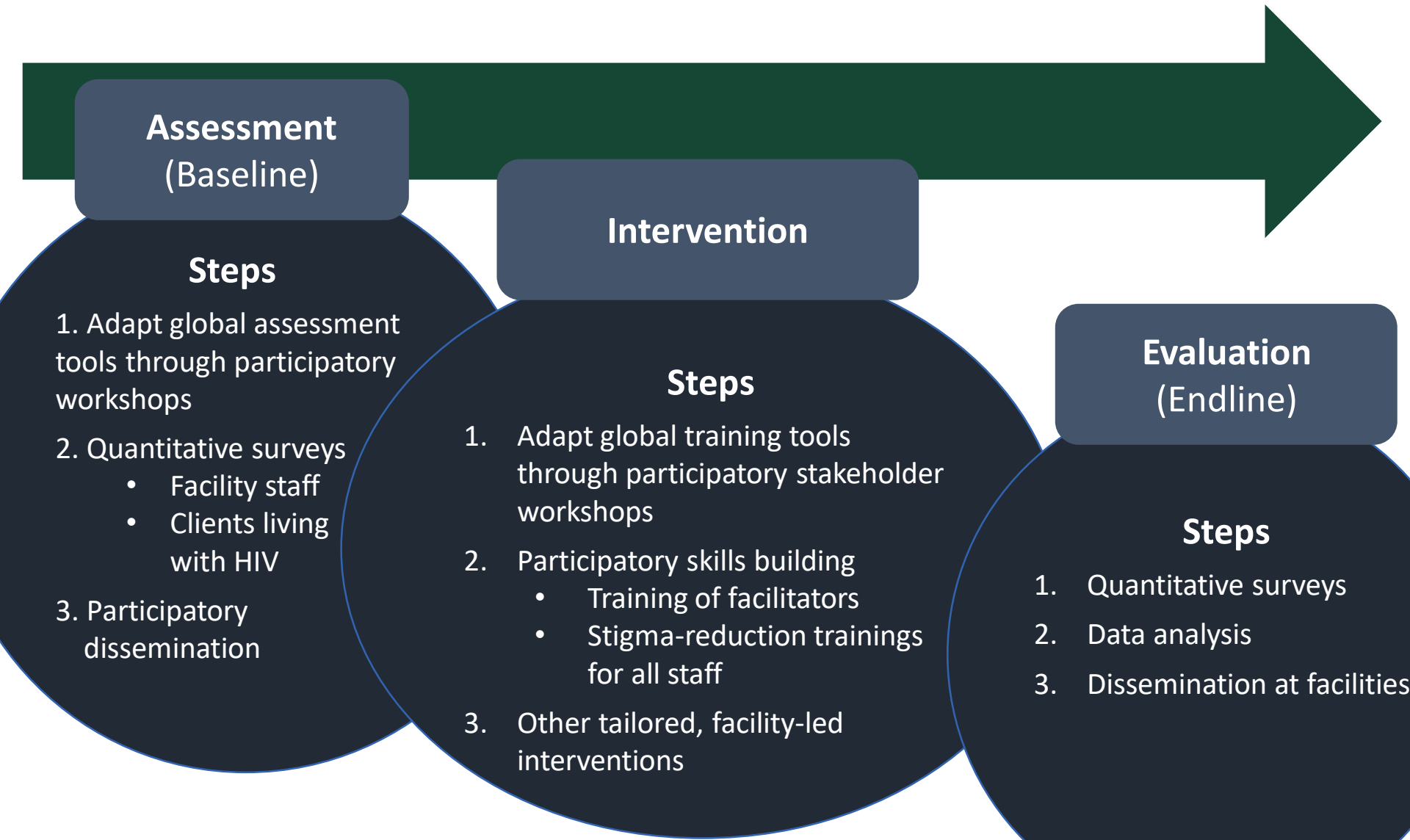RTI, International and the Health Policy Plus Project

Acknowledgments

- **Tanzania**
  - Respondents, facility staff, and management

  - Government of Tanzania
    - National AIDS Control Programme
    - Office of the Morogoro regional medical officer
    - Mvomero and Kilosa districts

  - Local implementing partners
    - Muhimbili University for Health and Allied Sciences (Research)
    - Kimara Peer Educators (Intervention)

  - USAID and PEPFAR

- **Ghana**
  - Respondents, facility staff, and management
  - Ghana AIDS Commission
  - National AIDS Control Programme
  - Educational Assessment Research Center (local implementing partner)
  - USAID and PEPFAR
  - The Global Fund to Fight AIDS, Tuberculosis, and Malaria

The HP+ Total Health Facility Approach to Stigma Reduction: Three Phases

Assessment (Baseline)

Steps

1. Adapt global assessment tools through participatory workshops

2. Quantitative surveys
   - Facility staff
   - Clients living with HIV

3. Participatory dissemination

Intervention

Steps

1. Adapt global training tools through participatory stakeholder workshops

2. Participatory skills building
   - Training of facilitators
   - Stigma-reduction trainings for all staff

3. Other tailored, facility-led interventions

Evaluation (Endline)

Steps

1. Quantitative surveys

2. Data analysis

3. Dissemination at facilities

Participation leads to ownership and lays foundation for success and sustainability

"Training facility staff as facilitators led to much better results… Because they were our own staff, they were able to go and learn and then prepare sustainable trainings for their colleagues … Trainings were easier to understand and better received, because the facilitators know their fellow staff members and understand the facility context and were able to plan the content accordingly"

–Joseoh Ngimba, Medical Officer-In-Charge, Turiani

"This interaction is different from anything else we have experienced so far—we defined the response; we owned it."

—Dr. Akosua Osei Manu, Tema General Hospital

Action to reduce facility stigma is possible!

Global measurement and intervention tools are easily adaptable across diverse contexts

Anna Helova

University of Alabama at Birmingham Sparkman Center for Global Health

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Addressing HIV Stigma Experienced by Pregnant Women in Kenya Using Community-Based Research

Anna Helova, MA, MBA, MPH, DrPH Candidate

Program Director
Sparkman Center for Global Health
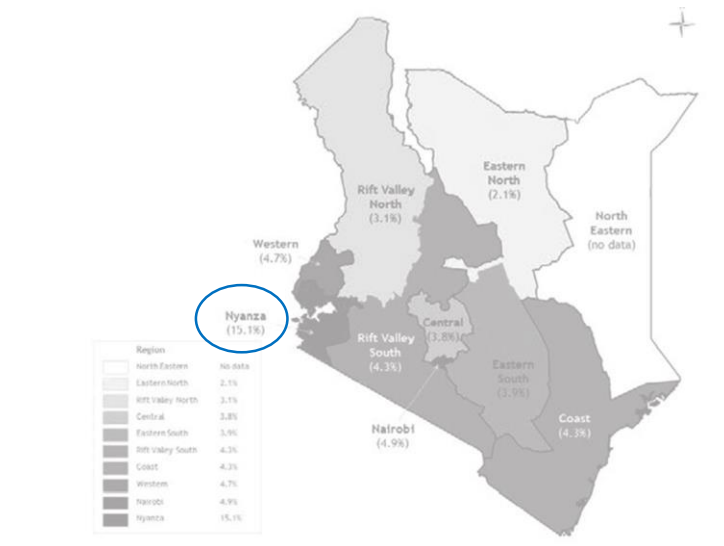*Department of Health Care Organization and Policy*
School of Public Health
University of Alabama at Birmingham, USA

Howard University
November 16, 2018

SCHOOL OF PUBLIC HEALTH
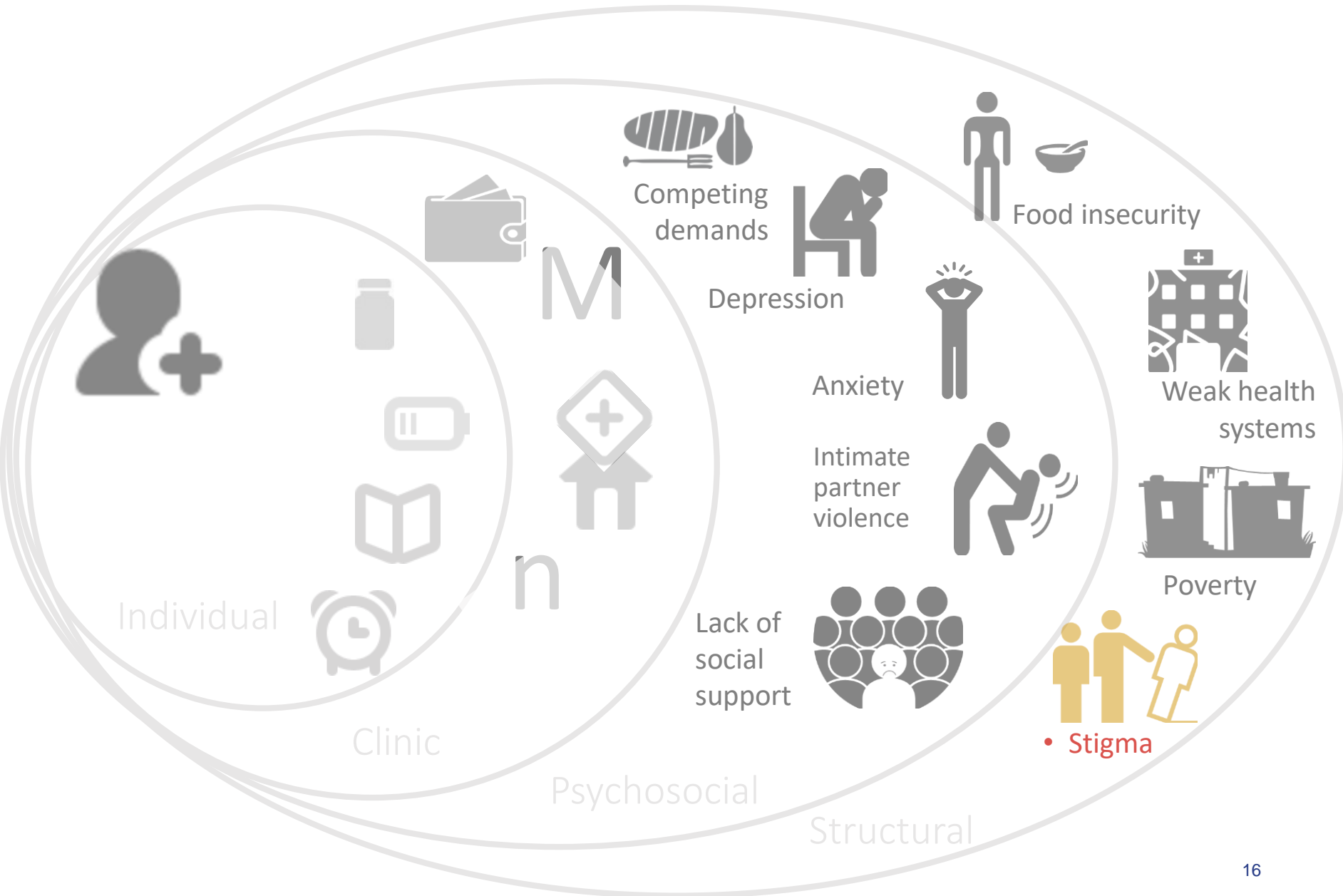The University of Alabama at Birmingham

Kenya and HIV

- HIV prevalence: 6% in Kenya; 15.1% in Nyanza
- 1.5 million people are HIV positive
- HIV prevalence rates higher among women than among men
- MTCT is a continuing health problem (8.3% in 2015)

Women face many barriers to PMTCT

Competing demands

Depression

Food insecurity

Anxiety

Weak health systems

Intimate partner violence

Poverty

Lack of social support

Individual

Clinic

Psychosocial

Structural

- Stigma

RESEARCH PLATFORM

- A Kenya Medical Research Institute (KEMRI)-UCSF Collaboration

- PEPFAR-funded

- Provides HIV-related services, training, and research in the former Nyanza Province, Kenya

- Works closely with the Kenyan Ministries of Health

Examining Pregnancy, HIV-related Stigma, and IPV in Kenya

Qualitative Pilot Study	Observational Study	IPV screening/ referral pilot	Integrating IPV prevention pilot
The effects of HIV on utilization and provision of maternity services in Kisumu 2006	Maternity in Migori and AIDS Stigma (MAMAS Study) 2007	*The Gender-Based Violence (GBV) Study* 2010	The effects of a home-based couples intervention to enhance PMTCT and family health in Kenya (Jamii Bora Study) 2014
UCSF Center for AIDS Research	*U. S. National Institute of Mental Health*	*UCSF Center for AIDS Research*	*U. S. National Institute of Mental Health*

Jamii Bora (Better Family) Study

- GOAL: To develop and pilot **a home-based couples intervention** for safe HIV testing and disclosure for couples, alongside information and counseling for family health during the perinatal period.

Jamii Bora Intervention
- 3 home home-based visits for pregnant women and male partners
- HIV-positive, HIV-negative, and Discordant
- visits by couple counselors: 1 male & 1 female

Community Engagement in the Jamii Bora Study

- Development of the intervention idea together with members of the community, including PLWH

- Involvement of PLWH as research team members

- Community participation in adaptation and refinement of the intervention model

- Community mobilization to communicate with the community prior to home visiting intervention

- Meetings with community advisors throughout the study

- Dissemination of study results back to the community
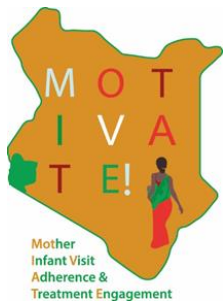
Mother Infant Visit Adherence & Treatment Engagement Study (MOTIVATE!)

This study is a cluster randomized, 2×2 factorial, controlled trial.

Goal: to address potential barriers that may affect uptake and retention in HIV care for Option B+ in Nyanza, Kenya.

Study sites were randomized into one of four groups:
- Community Mentor Mothers (cMM)
- Text messaging
- cMM & text messaging
- Standard of care (control)

		Community mentor mothers (cMM)	
		Yes	No
Text Messaging	Yes	cMM and Text Messaging	Text Messaging only
	No	cMM only	Control

Fig. 1 2 × 2 factorial design. Using a 2 × 2 factorial design, this study will evaluate the effect of community-based mentor mothers (cMMs), text messaging, or both on service utilization and maternal and child health outcome indicators

Community-Based Mentor Mothers

- Mentor mothers are **HIV-infected women** who have been through PMTCT and are tasked with providing peer education and psychosocial support

- They have been shown to increase uptake of services in several settings in sub-Saharan Africa

- In Kenya, mentor mothers have been based out of health facilities rather than in the community.

- We are testing a **community-based mentor mother (cMM)** model, in which cMMs are based in the community and conduct home visits with pregnant and postpartum women.

Community Engagement in the MOTIVATE! Study

- Development of the intervention idea together with members of the community, including PLWH

- Involvement of PLWH as the **community-based mentor mothers** intervention implementers

- Community participation in the **community randomization process**

- Community mobilization to communicate with the community prior to cMM intervention

- Meetings with a Community Advisory Group during the study period

- Dissemination of study results back to the community

Acknowledgments
(Jamii Bora and MOTIVATE Studies)

- University of Alabama at Birmingham:
  - Janet Turan
  - Anna Helova
  - Pamela Musoke
  - Liza Kimbo
  - Ashutosh Tamerhane
  - Meredith Kilgore
- University of Colorado, Denver
  - Lisa Abuogi
  - Karen Hampanda
- Univ. of Witwatersrand:
  - Abigail Hatcher
- University of Pennsylvania
  - Harsha Thirumurthy
- University of Michigan:
  - Lynae Darbes
  - Thomas Braun

- Kenya Medical Research Institute:
  - Zachary Kwena (Site PI)
  - Maricianah Onono
  - Thomas Odeny
  - Elizabeth Bukusi (Site PI)
  - George Owino
  - Tobias Odwar
  - Kevin Owuor
  - Patrick Oyaro
  - Eluid Akama
- Funders
  - U.S. NIH/NIMH
  - U.S. NIH/NICHD
- Collaboration:
  - Kenya Ministry of Health
 - FACES Program

APPENDIX

JAMII BORA PILOT STUDY
Results

- **64%** of women in the intervention arm engaged in Couples HIV Testing and Counseling with their male partner during the study period, compared to **23%** of women in the control arm (Relative Risk=2.78; 95% CI: 1.63-4.75)

- **Any male partner attendance at antenatal care visits** (52% intervention versus 43% control, p=0.42);

- **Giving birth in a health facility** (87% versus 79%, p=0.28);

- **Exclusive breastfeeding** (91% versus 76%, p=0.06);

- **Maternal postpartum check-up** (72% versus 50%, p=0.03).

- **Infant postnatal check-ups** were universal in both study arms (100%)

- **Postpartum family planning use** was very similar in the two groups (79% versus 77%, p=0.77).

  * Turan et al., 2018, *AIDS Patient Care and STDs*.

JAMII BORA R01: STUDY DESIGN

Figure 3. Participant Flow
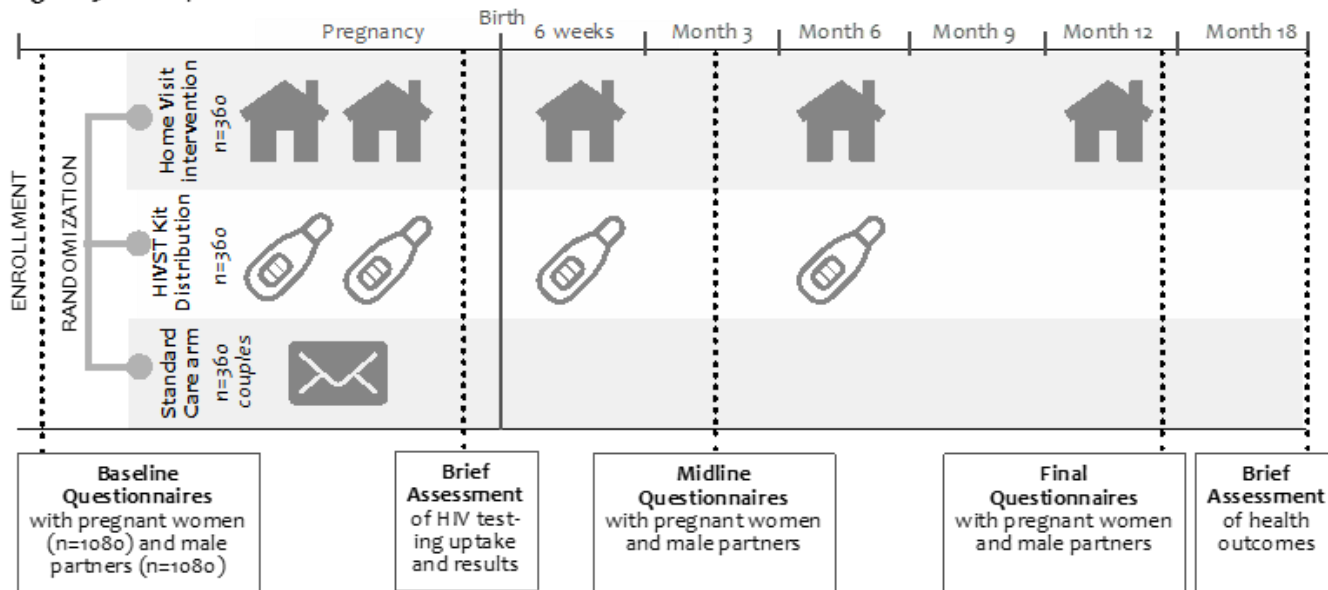
R01MH116736: Testing Strategies For Couple Engagement In PMTCT And Family Health In Kenya

David Malebranche

Morehouse School of Medicine, GA

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Intersecting Stigmas That Impact Healthcare Utilization by Black SGL Men Living with HIV

David Malebranche, MD, MPH

Associate Professor, Department of Medicine

Andrew Spieldenner

California State University San Marcos, CA

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From "Consumer" to Community-Based Researcher: Lessons from the Stigma Index in the United States

Andrew Spieldenner, Ph.D.

Chair, US People living with HIV Caucus

Assistant Professor, Health Communication, California State University – San Marcos

United States People Living with HIV Caucus

- A network of national networks of PLHIV and community leaders

- Emerged 2010 with the dissolution of National Association of People with AIDS

- Host AIDSWatch and other community based PLHIV community work

- The United States People Living with HIV Caucus (the HIV Caucus) has taken on the lead coordination of the Stigma Index as of 2016

Photo credit: *Poz* Magazine (2013)

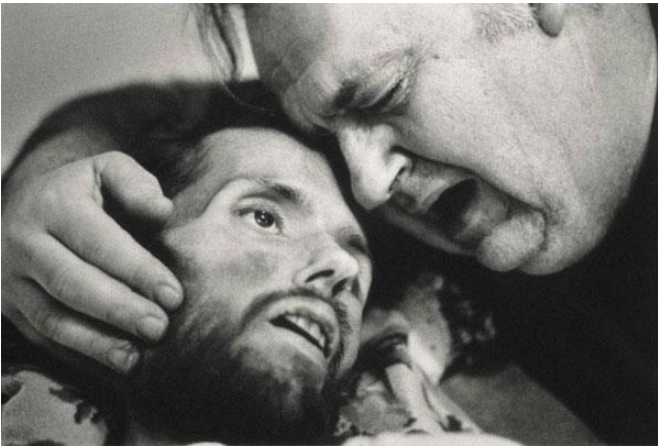# A Changing Epidemic...

Pre-Treatment Era

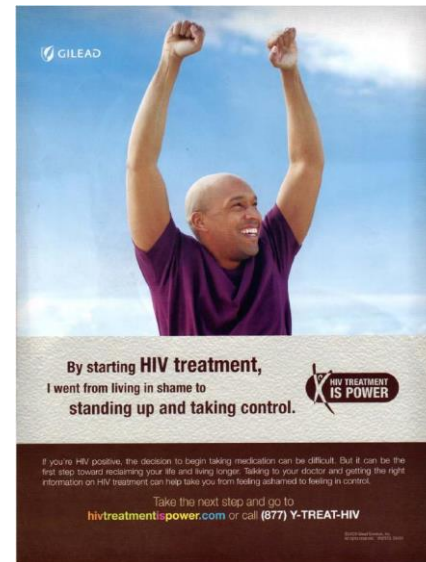Photo Credit: Therese Frare (1990)

Post-Treatment Era

Photo Credit: Gilead

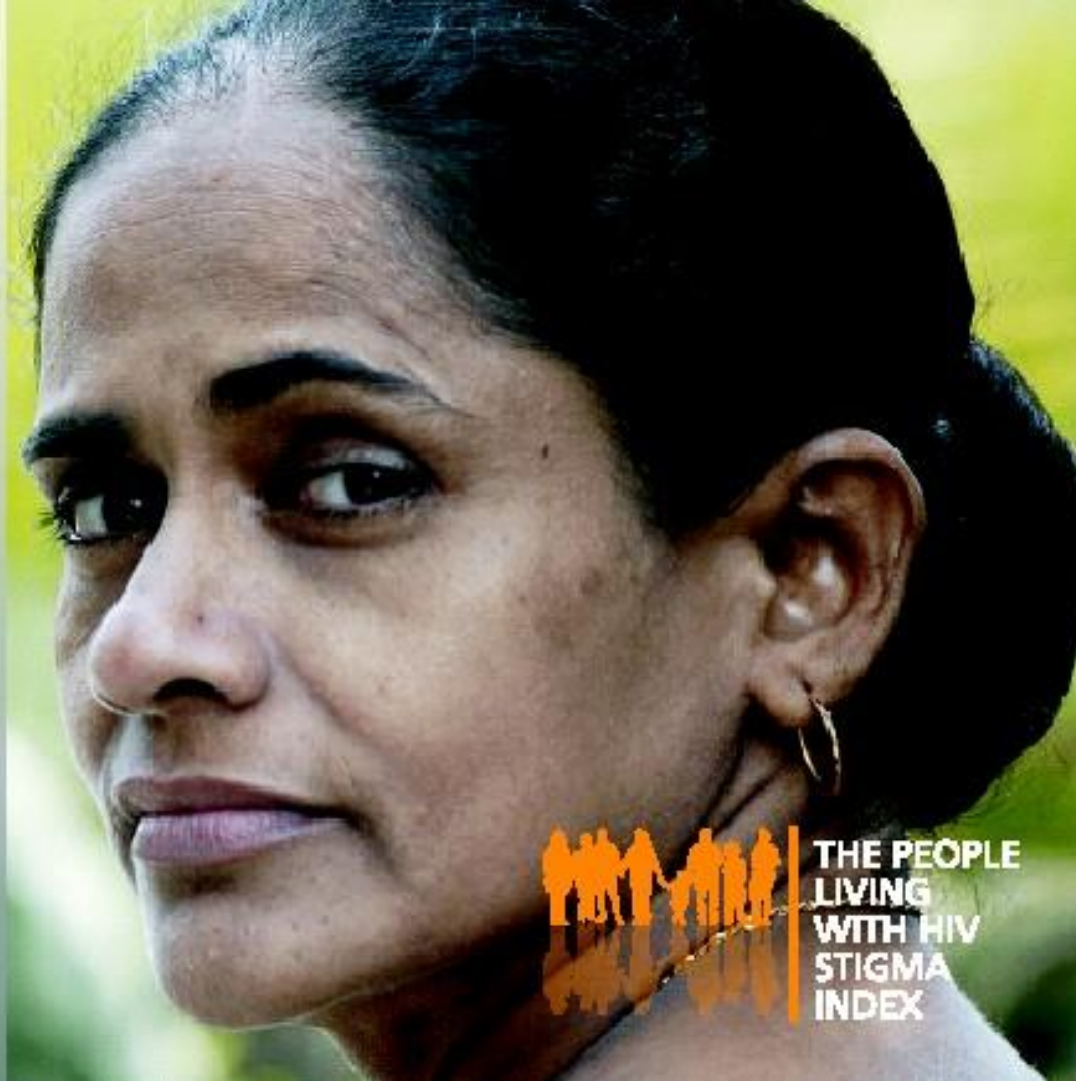# The Stigma Index

- Coordinated by Global Network of People Living with HIV (GNP+) to measure HIV stigma – conducted in 50 countries

- The Stigma Index data is collected and analyzed *by* PLHIV, *with* PLHIV, and *for* PLHIV

- Stigma Index findings drive policy and community organizing efforts

    For more information on global projects using the questionnaire see http://www.stigmaindex.org/

"THE INDEX PROVIDES THE BEST OPPORTUNITY FOR PEOPLE LIVING WITH HIV TO TELL THEIR SECRETS – SO WE NEED TO DEVELOP THE SKILLS TO ASK THEM."

THE PEOPLE LIVING WITH HIV STIGMA INDEX

The Stigma Index Process

▶ Partnership

▶ Capacity-building

▶ Listening to the community

▶ Data analysis and interpretation

▶ Advocacy

United States Implementation

- The Stigma Index has been conducted in three sites:
    - Detroit
    - Louisiana
    - New Jersey
- Over 750 people living with HIV participated
- Anti-stigma work is being conducted in each site
- Data highlight results:
    - Poverty
    - Intersectional stigma
    - Value of resilience

Act Up, 1991. Photograph: Dirck Halstead/Time & Life Pictures/Getty Images

MIPA: Current Challenges

- Current funding environment does not support PLHIV organizing

- Fewer people with HIV receiving disability and more people having to work more hours, multiple or low-wage jobs, to make ends meet.

- Sense of urgency missing, complacency about treatment

- Epidemic larger, more diverse than ever

- Not developing or using PLHIV resources properly
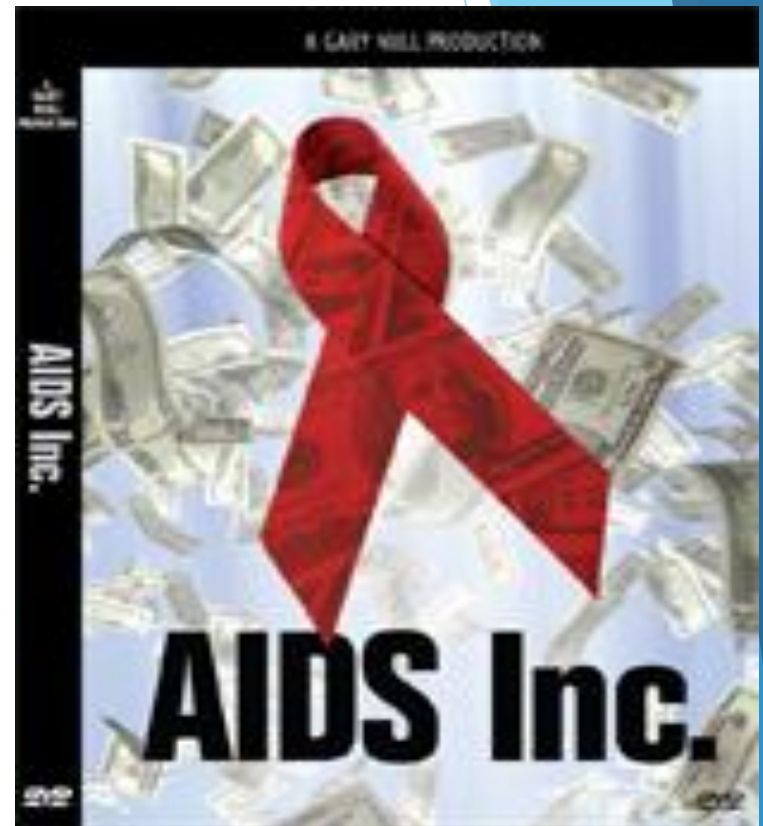
Lessons in Partnership

- In every Stigma Index partnership, there were challenges to being seen as equals in every step - from all sides

- Researchers learned to "trust the process" at each level and keep the PLHIV groups engaged throughout

- PLHIV had to grow into understanding our voice has power, our embodied knowledge has a place

- As Stigma Index implementation phase occurs, these partnerships are more important than ever

- This has resulted in 5 co-authored articles amongst community/researcher teams, several town halls to disseminate

Questions?

Photo credit: Jacob Barrera (2017)

- Contact Info:
- Andrew Spieldenner, Ph.D.
- aspieldenner@csusm.edu
- @aspield on twitter

Kneeshe Parkinson

Positive Women's Network/ Project ARK, MO

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COMMUNITY BRIDGING & MEANINGFUL INVOLVEMENT

KNEESHE PARKINSON –PWN USA-MO , HEALTH NAVIGATOR

DENVER PRINCIPLES ......

- (STATEMENT FROM THE ADVISORY COMMITTEE OF THE PEOPLE WITH AIDS)

WE CONDEMN ATTEMPTS TO LABEL US AS "VICTIMS," A TERM WHICH IMPLIES DEFEAT, AND WE ARE ONLY OCCASIONALLY "PATIENTS," A TERM WHICH IMPLIES PASSIVITY, HELPLESSNESS, AND DEPENDENCE UPON THE CARE OF OTHERS. WE ARE "PEOPLE WITH AIDS."
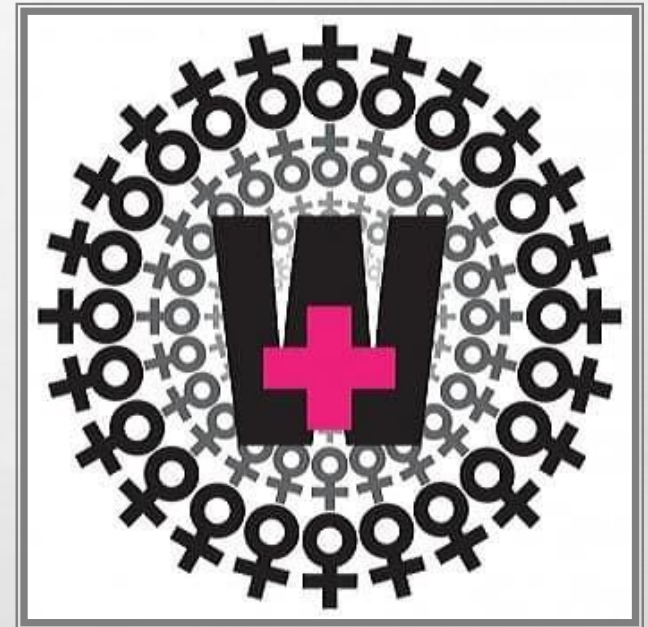
COMMUNITY BRIDGING

LINKAGE TO CARE

- HEALTH COACHES (PEER NAVIGATOR)
- LEADERSHIP
- TOOL KIT
- CULTURE COMPETENCY
- LANGUAGE MATTERS

BUILDING LEADERS OF COLOR

- LENSES
- REDUCING STIGMA
- TREATMENT ADHERENCE
- TIME MANAGEMENT
- EMPOWERMENT

END**AIDS**STIGMA
A BATTLE BEYOND AN ILLNESS

MEANINGFUL INVOLVEMENT

LEADERSHIP

- AIDS WATCH
- BLOC -BUILDING LEADERS OF COLOR
- COMMUNITY ADVISORY BOARD PART C & D
- HIV 50 + CAMPAIGN
- PLANNING COUNCIL
- PWN USA- MOBILIZATION OF FOR WOMEN BY WOMEN

LEADERSHIP

- QUALITY MANAGEMENT TEAMS
- RYAN WHITE NATIONAL CONFERENCE
- TRAINING CONSUMERS ON QUALITY
- U=U CAMPAIGN
- USCA & POSITIVELY LIVING CONFERENCE

Cheriko (Riko) A. Boone

BELIEVE Martin Delaney Cure CAB, Washington, DC

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*BELIEVE*ing in Responsible and Ethical Community Engagement around Emerging Biomedical HIV Research

Riko A. Boone, MSW, MPH

**Co-chair of Community Engagement,
BELIEVE Collaboratory for HIV Cure Research
The George Washington University**

International Conference on Stigma
Howard University
November 16, 2018

THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

BELIEVE
IN THE CURE
MARTIN DELANEY COLLABORATORY

Martin Delaney Collaboratories for HIV Cure Research

I4C: Combined Immunologic Approaches to Cure HIV-1
Dan Barouch, John Mellors, Nelson Michael
(Beth Israel Deaconess, Boston)

defeatHIV: Cell and Gene Therapy for HIV Cure
Keith Jerome & Hans-Peter Kiem
(FHCRC, Seattle)

BEAT-HIV: Delaney Collaboratory to Cure HIV-1 Infection by Combination Immunotherapy
Luis Montaner & James Riley
(Wistar Institute, Philadelphia)

BELIEVE: Bench to Bed Enhanced Lymphoctye Infusions to Engineer Viral Eradication
Douglas Nixon
(Cornell, NYC)

DARE: Delaney AIDS Research Enterprise to Cure HIV
Steven Deeks & Louis Picker
(UCSF, San Francisco)

CARE: Collaboratory of AIDS Researchers for Eradication
David Margolis
(UNC, Chapel Hill)

We BELIEVE in Responsible Community Engagement: Overview of the Structure and Outcomes in the BELIEVE Collaboratory for HIV Cure Research

Cheriko A. Boone, MSW, MPH[1,2]; A. Toni Young[1,3]; Jon Fenech[1]; Richard Strange[1]; Ron Swanda[1]; Thomas J. Villa[1]; Eleanor Sarkodie, MPH[1]; Terry Howard[1]; Evelyn Rodriguez-Estrada, MD[1]; Andre Ceranto[1]; Daniel Barros, MPH[1]; Amanda D. Castel, MD, MPH*[4]; Robert Furler, PhD*[5]; R. Brad Jones, PhD*[5]; Douglas Nixon, MD, PhD*[5] Manya Magnus, PhD, MPH*[4]

[1]Community Advisory Board, BELIEVE Collaboratory for HIV Cure Research; [2]The George Washington University, Department of P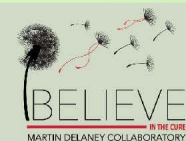sychology; [3]Executive Director, Community Education Group; [4]The George Washington University, Milken Institute School of Public Health; [5]Weill Cornell Medicine
[*Shared senior authors]

THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

Background

The *Bench to Bed Enhanced Lymphocyte Infusions to Engineer Viral Eradication* (BELIEVE) Collaboratory site is:
- One of six Martin Delaney Collaboratory: Towards an HIV-1 Cure sites
- Funded by the U.S. National Institute of Allergy and Infectious Diseases at the National Institutes of Health
- Designed to facilitate public- and private-sector collaborative cure research
- Supports emerging curative strategies across key areas of basic and clinical research
- Includes twenty-two collaborating institutions from Brazil, Canada, Mexico, and the U.S.

Methods

Robust community engagement has been integral to the implementation of BELIEVE. In the first two years of the BELIEVE collaboratory, the Community Advisory Board (CAB) has focused on the following community engagement efforts:
- Recruited CAB members at the four core sites
- Developed an infrastructure to incorporate international partners
- Organized a meeting to build capacity in community engagement, increase awareness, and develop scientific literacy among community stakeholders around HIV cure research
- Integrated input from ongoing community stakeholder reviews of cure research protocols
- Launched a global survey assessing knowledge, attitudes, and perceptions among seropositive and seronegative people about cure research
- Collaborated with other NIH-funded MDC sites to address ethical and regulatory considerations in the development of cellular and genetic therapies toward a functional or sterilizing cure; and to discuss scientific research advancements that may impact either HIV cure development or diffusion.
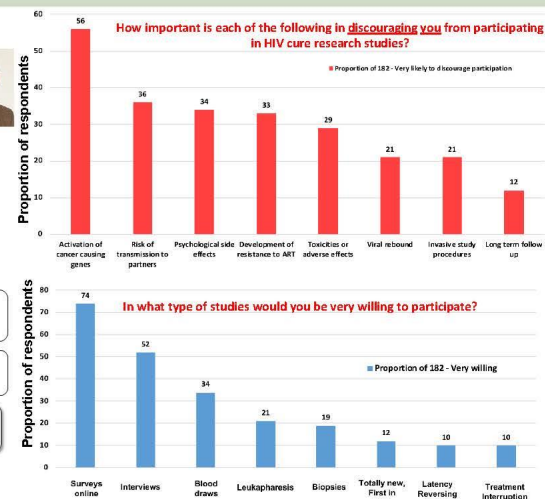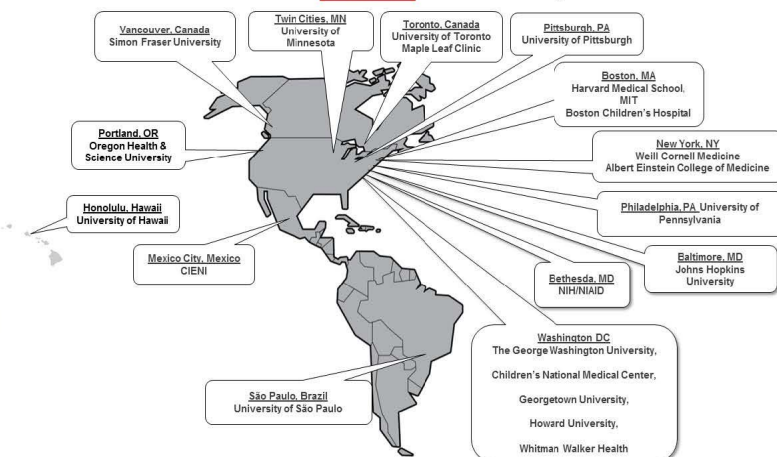
Guiding Principles

The BELIEVE Community Advisory Board applies the following guiding principles of good participatory practice (GPP) described by the Joint United Nations Programme on HIV/AIDS (UNAIDS):

Good Participatory Practices: RESPECT, MUTUAL UNDERSTANDING, INTEGRITY, AUTONOMY, TRANSPARENCY, ACCOUNTABILITY

BELIEVE Community Advisory Board Members

International BELIEVE Collaboratory Sites

Vancouver, Canada — Simon Fraser University
Twin Cities, MN — University of Minnesota
Toronto, Canada — University of Toronto Maple Leaf Clinic
Pittsburgh, PA — University of Pittsburgh
Boston, MA — Harvard Medical School, MIT, Boston Children's Hospital
Portland, OR — Oregon Health & Science University
New York, NY — Weill Cornell Medicine Albert Einstein College of Medicine
Honolulu, Hawaii — University of Hawaii
Philadelphia, PA — University of Pennsylvania
Mexico City, Mexico — CIENI
Baltimore, MD — Johns Hopkins University
Bethesda, MD — NIH/NIAID
Washington DC — The George Washington University, Children's National Medical Center, Georgetown University, Howard University, Whitman Walker Health
São Paulo, Brazil — University of São Paulo

Results

Characteristics of Survey Participants (N=182): Preliminary Findings

Characteristic	%
Male	54
Gay or bisexual	56
Age (median, IQR)	37, 28-49
Lives in East Coast, US	41
Living with HIV (40% > 20 years)	27
Family or friends living with HIV	35
At risk for HIV	14
Black/African American	25
< College degree	20

How important is each of the following in discouraging you from participating in HIV cure research studies?

Proportion of 182 - Very likely to discourage participation: Activation of cancer causing genes 56; Risk of transmission to partners 36; Psychological side effects 34; Development of resistance to ART 33; Toxicities or adverse effects 29; Viral rebound 21; Invasive study procedures 21; Long term follow up 12

In what type of studies would you be very willing to participate?

Proportion of 182 - Very willing: Surveys online 74; Interviews 52; Blood draws 34; Leukapheresis 21; Biopsies 19; Totally new, First in man 12; Latency Reversing Agents 10; Treatment interruption 10

How important is each of the following in motivating you to take part in HIV cure research studies?

Proportion of 182 - Very likely to motivate participation: Contributing to scientific knowledge 72; Caring about future generations 69; Feeling good about contributing to HIV research 62; Care about community 58; Learning about new treatments 39; Hoping my health will improve 26; Payment 16; Offered a meal at study visits 9

Conclusions and Next Steps

Conclusions:
- Community engagement is an essential component of ethical HIV cure research, and is possible to execute across international sites
- There is a need for ongoing assessment of the knowledge, attitudes, and perceptions among seropositive and seronegative people about cure research, particularly regarding studies that involve analytical treatment interruptions (ATIs)
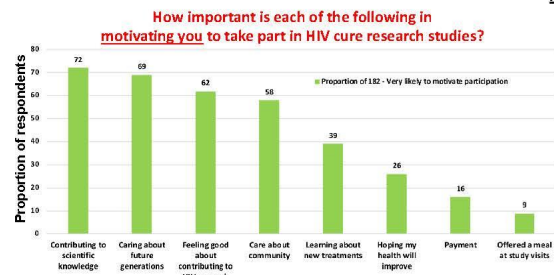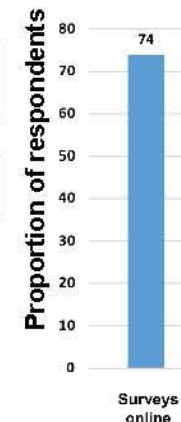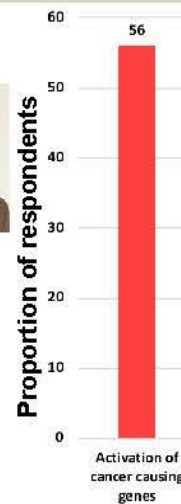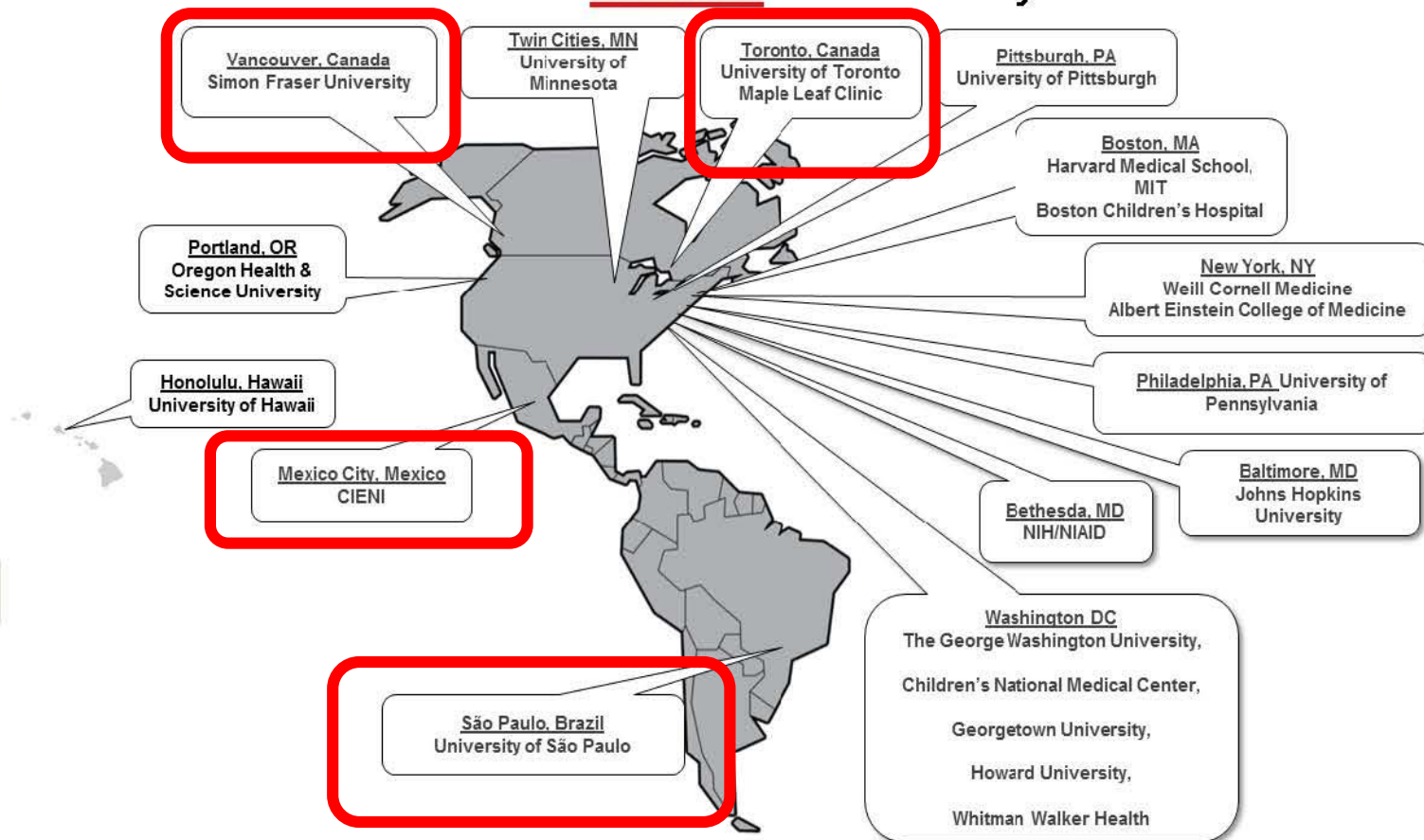
Next Steps:
- Create dynamic, culturally and linguistically appropriate platforms to educate local community stakeholders on the progress of HIV cure research
- Connect community engagement activities around HIV cure research to broader policy implications regarding prevention, treatment, and social-structural barriers to diffusion of HIV research
- Develop strategies to avert possible unintended negative social, structural, and behavioral consequences of HIV cure research
- Integrate community engagement activities across BELIEVE sites through the harnessing of technology and streamlined communication
- Maximize productivity and efficiency of community engagement activities through collaborative international and inter-organizational partnerships
- Increase the effectiveness of BELIEVE community engagement activities by:
  - Conducting comprehensive assessment across sites
  - Implementing leadership development and training opportunities for all incoming and continuing CAB members
  - Seeking capacity building assistance focused on effective review of scientific research protocols, as well as increasing knowledge and skills in evidence-based practices and community-based participatory research

The George Washington University, Milken Institute School of Public Health, Weill Cornell Medicine
[*Shared senior authors]

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Twin Cities, MN
University of Minnesota

Toronto, Canada
University of Toronto
Maple Leaf Clinic

Pittsburgh, PA
University of Pittsburgh

Boston, MA
Harvard Medical School,
MIT
Boston Children's Hospital

Portland, OR
Oregon Health &
Science University

New York, NY
Weill Cornell Medicine
Albert Einstein College of Medicine

Honolulu, Hawaii
University of Hawaii

Philadelphia, PA University of
Pennsylvania

Mexico City, Mexico
CIENI

Baltimore, MD
Johns Hopkins
University

Bethesda, MD
NIH/NIAID

São Paulo, Brazil
University of São Paulo

Washington DC
The George Washington University,
Children's National Medical Center,
Georgetown University,
Howard University,
Whitman Walker Health

Results

**Characteristics of Survey Participants
(N=182): Preliminary Findings**

How important is each of the following in
motivating you to take part in HIV cure research studies?

(Left margin, partial text)

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...BELIEVE. In the first
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(Right side charts)

Proportion of respondents — 56 — Activation of cancer causing genes

Proportion of respondents — 74 — Surveys online

Conclus...

Conclusions:
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- There is
  perceptio...
  particular...
  (ATIs)

Next Steps:
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  local co...

Continuum of HIV
Prevention → Treatment → Cure

Prevention	Antiretroviral Treatment		Reducing HIV Reservoir
Before HIV Infection	**Acute** HIV Infection	**Chronic** HIV Infection	**Viral Load** Suppressed

TIMOTHY RAY BROWN

- The first (and still only) person to be cured of HIV

- On February 7, 2007 , he was transplanted with HIV-resistant donor cells to treat his leukemia

- 68 days later, no more replicating HIV in his body

- still cured 11 years later

"CLASSIC" CURE

- HIV is **completely removed** from every cell in the body

- Person is HIV-free (virus free)

WHAT DOES A CLASSIC HIV CURE LOOK LIKE?

- HIV completely eliminated from the body
- No risk of transmitting HIV to others
- No more HIV treatment needed ever
- No risk of opportunistic infections
- No viral progression or immune damage

"FUNCTIONAL" CURE

- HIV is **NOT completely gone** from the body

- All other qualities are hopefully met

## WHAT DOES A FUNCTIONAL HIV CURE LOOK LIKE?

- HIV **not completely** eliminated from body
- No risk of transmitting HIV to others
- No more HIV treatment needed ever
- No risk of opportunistic infections
- No viral progression or immune damage
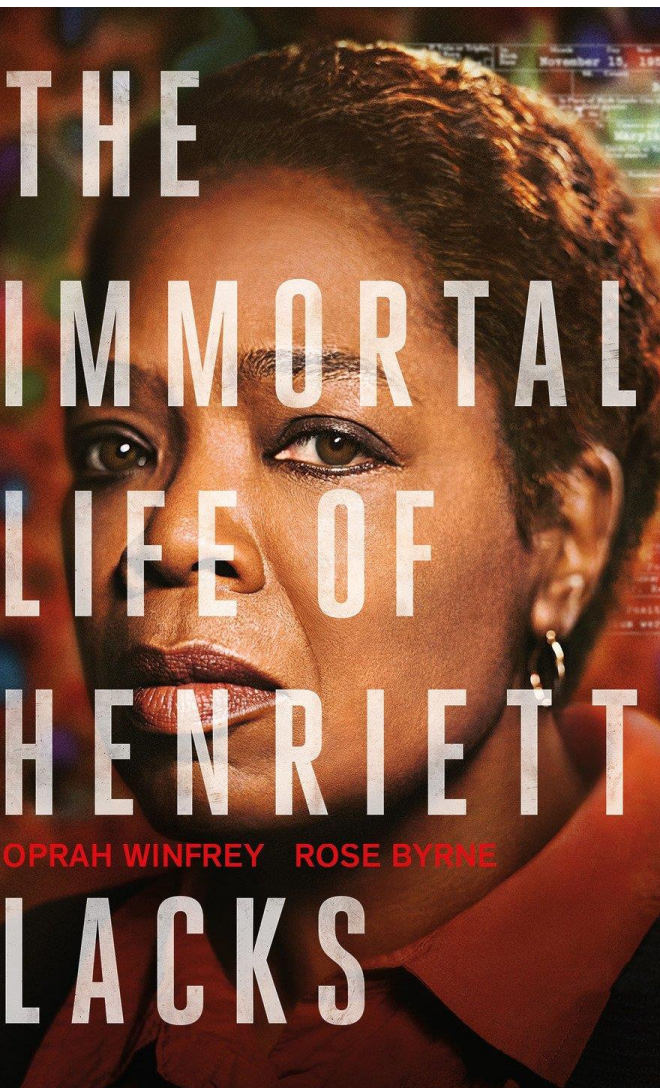
Take Home Messages re: **HIV Cure Research**

- Therapies aimed at reducing viral reservoirs or inducing remission are showing promise – however a cure for HIV remains a long-term goal

- Basic science research is needed to improve methods of targeting and measuring persistent sources of virus

- HIV reservoirs are **dynamic** – proliferation of some infected cells balanced by death of other infected cells
  - ➤ Understanding these dynamics may lead to new or improved strategies to reduce HIV reservoirs

Credit: R. Brad Jones, BELIEVE Co-Director

In what type of studies would you be very willing to participate?
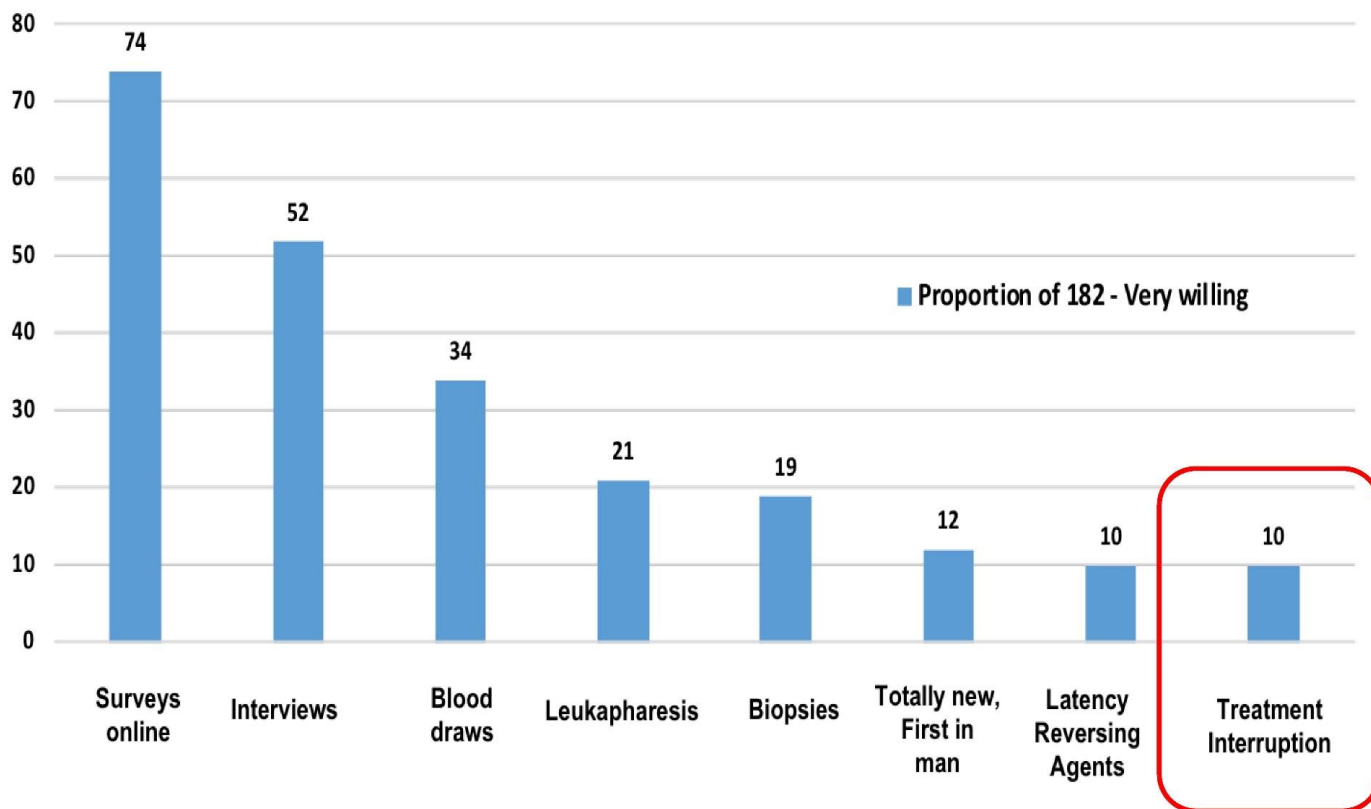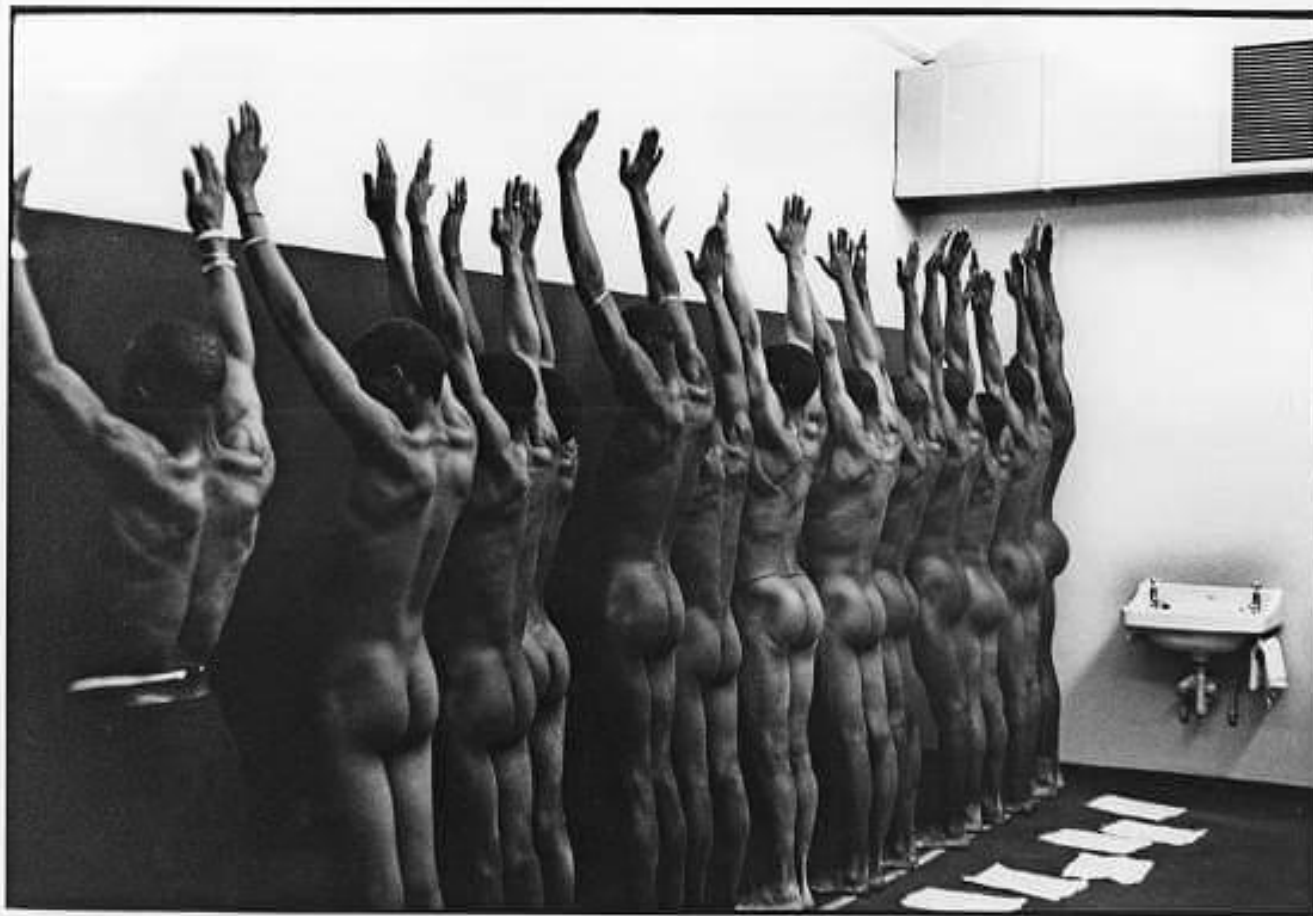
During group medical examination the nude men are herded through a string of doctors' offices. From House of Bondage, 1967.
Credit: The Ernest Cole Family Trust [https://www.thetimes.co.uk/article/ernest-cole-apartheid-from-the-inside-ngljkz9pj3r]

THE IMMORTAL LIFE OF HENRIETT LACKS

OPRAH WINFREY   ROSE BYRNE

This is Henrietta Lacks. Before her death in 1951, her doctor took and saved several tissue samples from her cervix without her permission or knowledge.

From these cells came the world's first "immortal cell line". Her cells have been used to develop everything from cloning to the polio vaccine. They have been used to develop cancer drugs, drugs to treat HIV, herpes, Parkinson's disease, and hundreds of others.

Scientists have grown more than 20 **tons** of her cells, and they're involved in more than **11,00 patents**.

Transgender women taking PrEP have lower levels of PrEP drugs, especially in rectal tissues, than cisgender men

Difference "equivalent to four days of PrEP per week rather than seven"

Good participatory practice

Guidelines for biomedical
HIV prevention trials
2011

Louie A. Ortiz-Fonseca

Apr 27, 2017 at 1:10 PM · 🌐

daily reminder: HIV is STILL and has always been a social justice issue.

"To **act** is to be **committed**, and to be committed is to be in **danger.**"

- James Baldwin

THANK YOU!

For more info:

@RikoAmour
@TheNixonLab
@defeatHIV
@TheBodyDotCom
@TheBodyPROHIV

@awesomeJonesLab
@NixonLab

In closing…

1. Community-research partnerships are often hampered by competing bottom lines. What are they and how have you move towards resolving/ preventing potential conflict?

2. Despite the best of intentions, PLWH are granted token voice on research – how can we be better at inclusivity?

3. What are outcomes of participatory research? Are these outcomes better than ones that are more researcher-driven?

4. How do we best overcome unforeseen, unintended negative consequence of research on communities?