LESSONS LEARNED FROM A COMMUNITY-LEVEL HIV STIGMA AND HOMOPHOBIA PREVENTION INTERVENTION:

IMPLICATIONS FOR SOCIAL INTERVENTIONS TO REDUCE COMMUNITY-LEVEL LAYERED OR INTERSECTIONAL STIGMA

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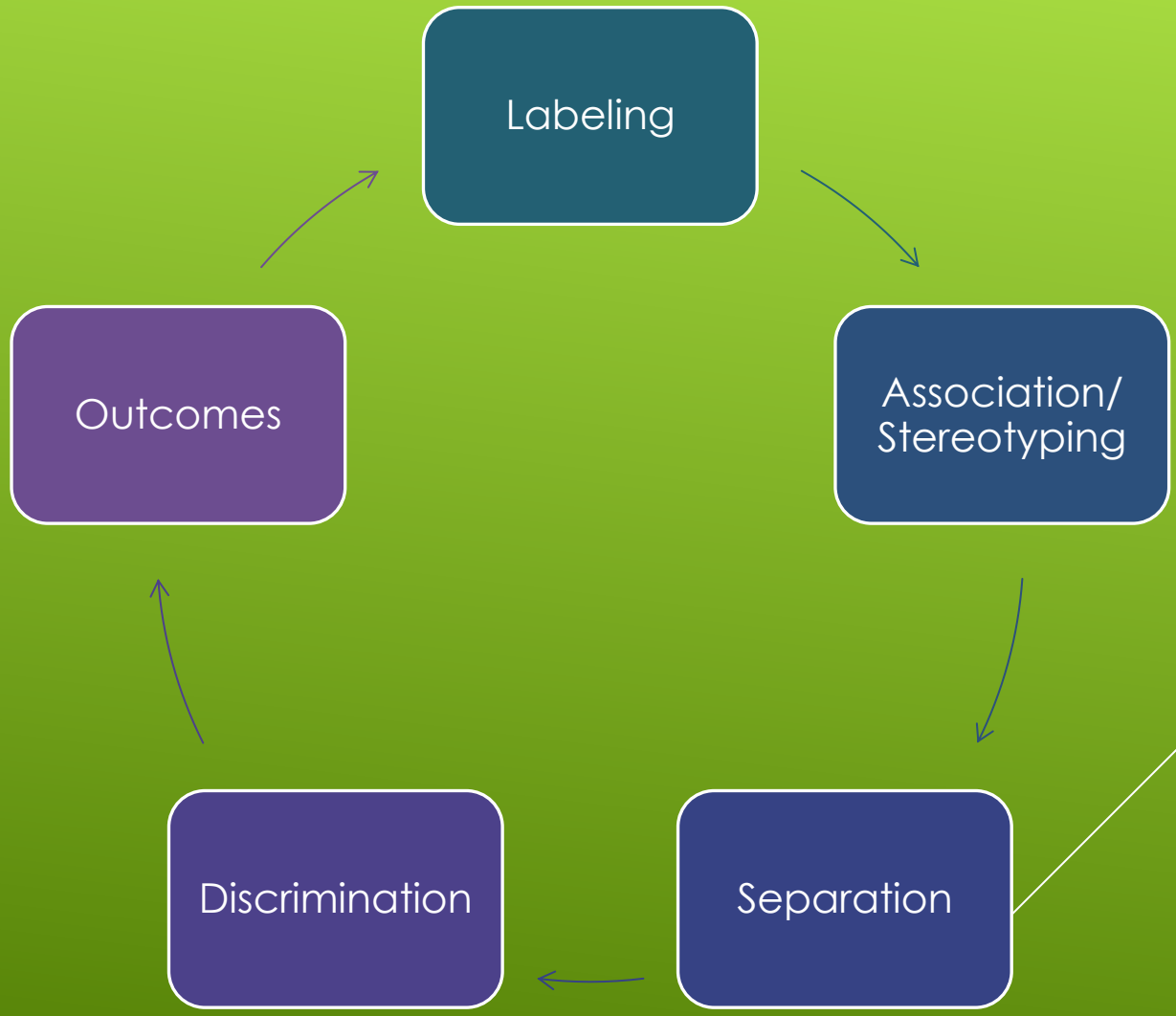
PRESENTATION OUTLINE

- The Problem of HIV Stigma
- Experiences implementing a community-level intervention to reduce layered stigma?
- Considering the overlap of HIV stigma and mental health stigma
- Future potential programs and approaches

WHAT IS STIGMA?

STIGMA IS A DYNAMIC SOCIAL PROCESS THAT INVOLVES LABELING, STEREOTYPING, SEPARATION, DISCRIMINATION, AND STATUS LOSS

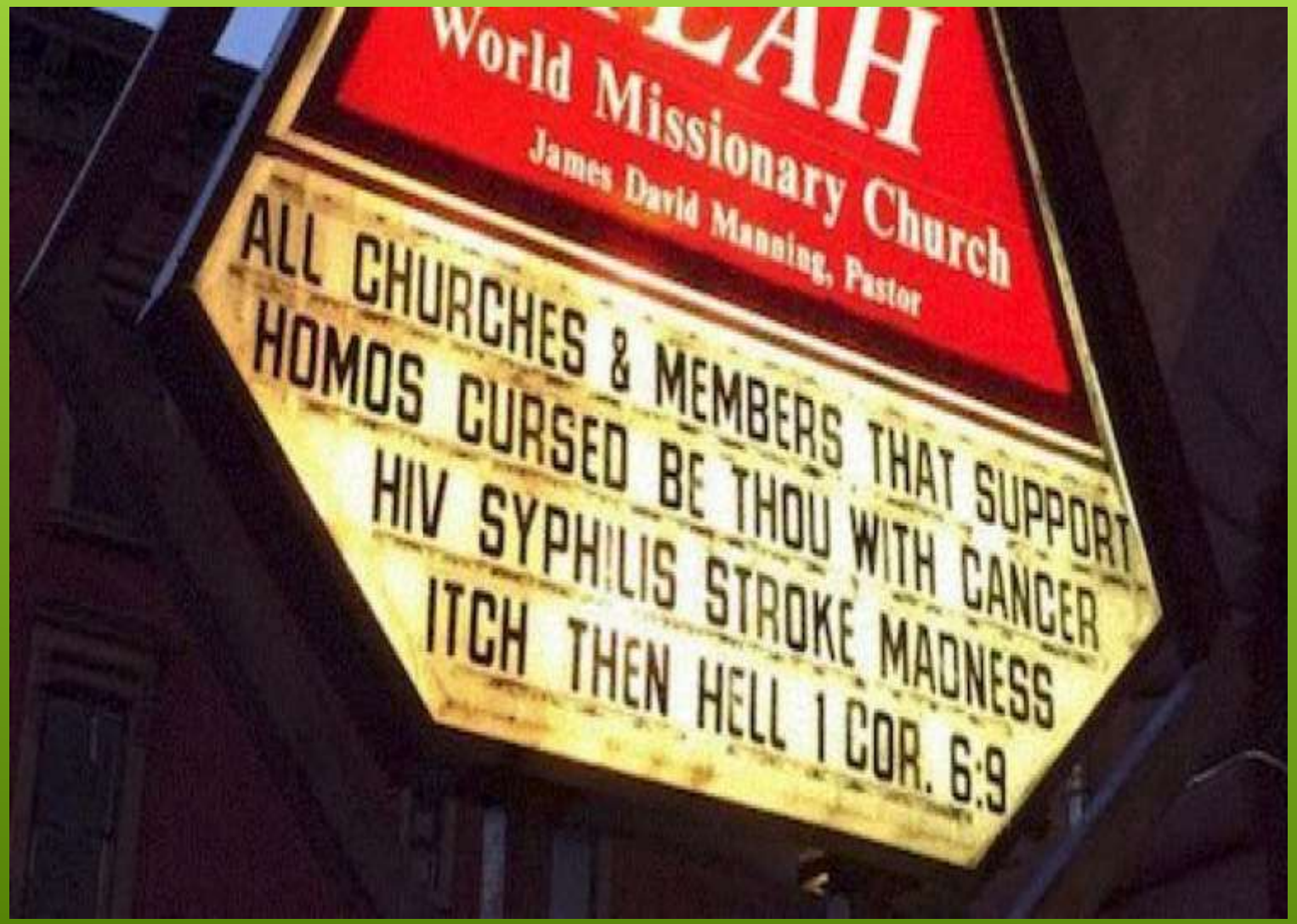


WHAT IS HIV STIGMA?

HIV Stigma is prejudice and discrimination directed towards people believed to have HIV or AIDS, as well as the individuals, groups, and communities with which they associate *or are associated* (Herek & Glunt, 1988; Herek et al., 1998; Herek, Widaman, & Capitanio, 2005).

HIV stigma is often directed - through association - towards gay and bisexual men, even if not HIV-positive.
(Devine, Plant, & Harrison, 1999).

HIV STIGMA: THEN & NOW



NEW YORK POST

FINAL

Triggered 'gay cancer' epidemic in U.S.

THE MAN WHO GAVE US AIDS

STORY ON PAGE THREE

His love's safe after ordeal on icy peak

ENACTED, ANTICIPATED AND INTERNALIZED HIV STIGMA

- **Enacted** stigma includes current and past experiences of discrimination and devaluation that can have direct and negative effects on the targets.
- **Anticipated** stigma involves the anticipation of discriminatory experiences or devaluation by others based on the real or perceived HIV status of the targets.
- **Internalized** or self-stigma is defined as the internalization by the targets of the negative stereotypes, attitudes, beliefs, and perceptions of members of a socially devalued group

WHY IS PUBLIC HEALTH INCREASINGLY CONCERNED ABOUT HIV STIGMA?

HIV stigma is a key barrier to HIV treatment and prevention

Anticipated HIV stigma reduces:

- **HIV testing**
  (Golub & Gamarel, 2013; Mannheimer et al., 2014)
- **Biomedical HIV prevention technologies: PrEP/PEP**
  (Biello et al., 2016; Farhat, Greene, Paige, Koblin, & Frye, 2016; Golub, Gamarel, Rendina, Surace, & Lelutiu-Weinberger, 2013; Haire, 2015)
- **Disclosure of HIV**
  (Ojikutu et al 2016)

Enacted HIV stigma reduces:

- **Anti-retroviral treatment adherence** (ART)
  (Boarts, Bogart, Tabak, Armelie, & Delahanty, 2008; Eaton et al., 2015)
- **Self-care behaviors**

Internalized HIV stigma reduces:

- **ART adherence** (Turan et al 2016; Katz et al 2013)

ANTICIPATED HIV STIGMA AND HIV TESTING

“ The anxiety.

The whole stigma of HIV is just like the black plague, people will get it.

It’s scary and it’s a lot of work.

I think of same sex relationships. And that’s kind of stigmatizing. ”

What do you think of when I say HIV testing?

ANTICIPATED HIV STIGMA AND HIV TESTING

"Fear … I think of hospitals … I think of the AIDS walk … I think of people I know who have it … The fear of being positive … Blood…Needles…Anticipation .. Life changing… Sickness, depression, condoms, wrap it up, and depression."

What do you think of when I say HIV testing?

ANTICIPATED HIV STIGMA AND BIOMEDICAL HIV PREVENTION

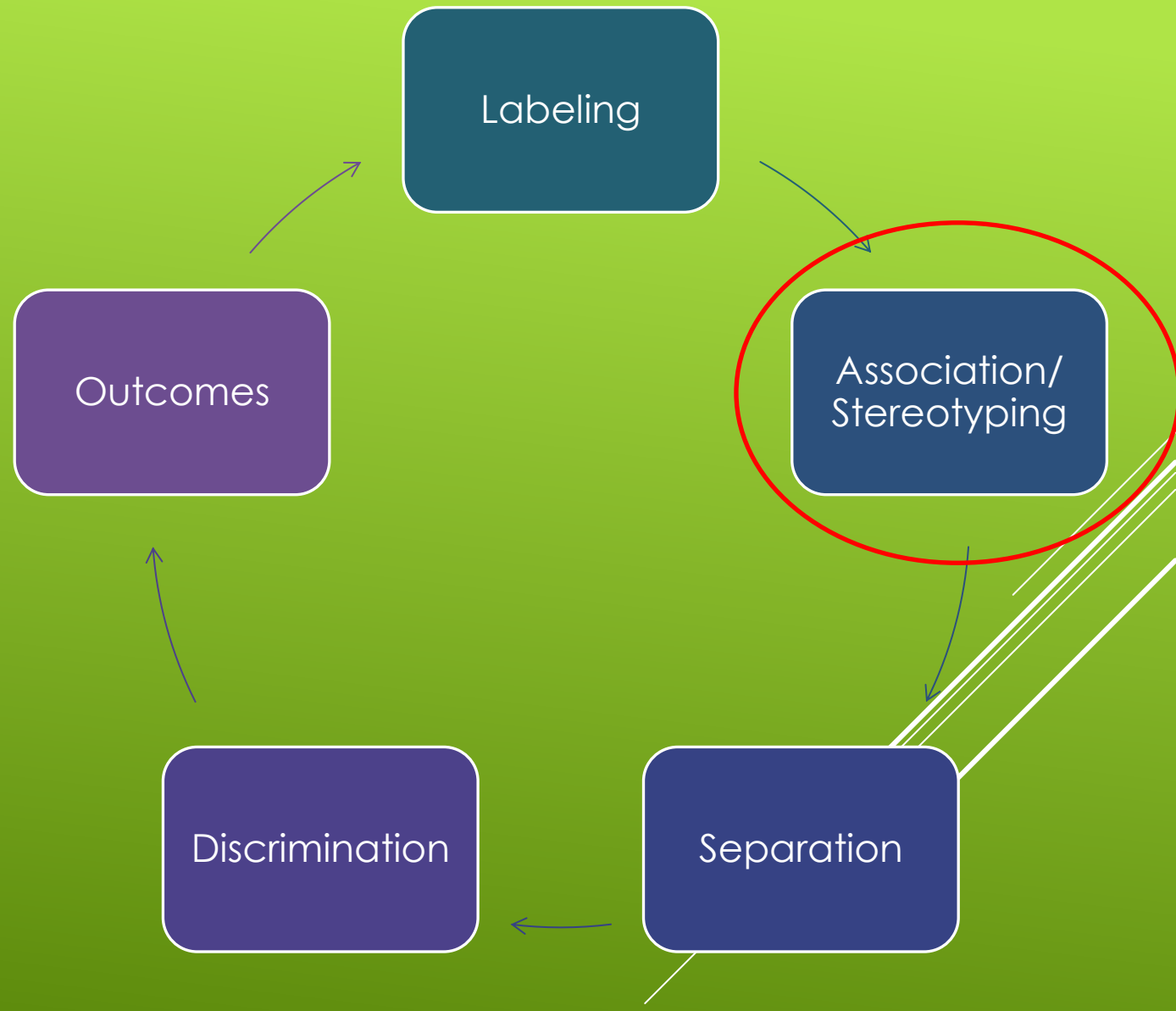
- Anticipated stigma has emerged as a major barrier to uptake and adherence of chemoprophylaxis (PEP/PrEP).

- In international efficacy trials, fears about what partners, family members or community members would believe included that the participant:
  - was HIV infected (and not taking medication to *prevent* HIV);
  - was engaged in male-male sexual activity;
  - had multiple sex partners, or was engaged in high risk sex, sex outside the primary relationship and/or drug use (Haire, 2015)

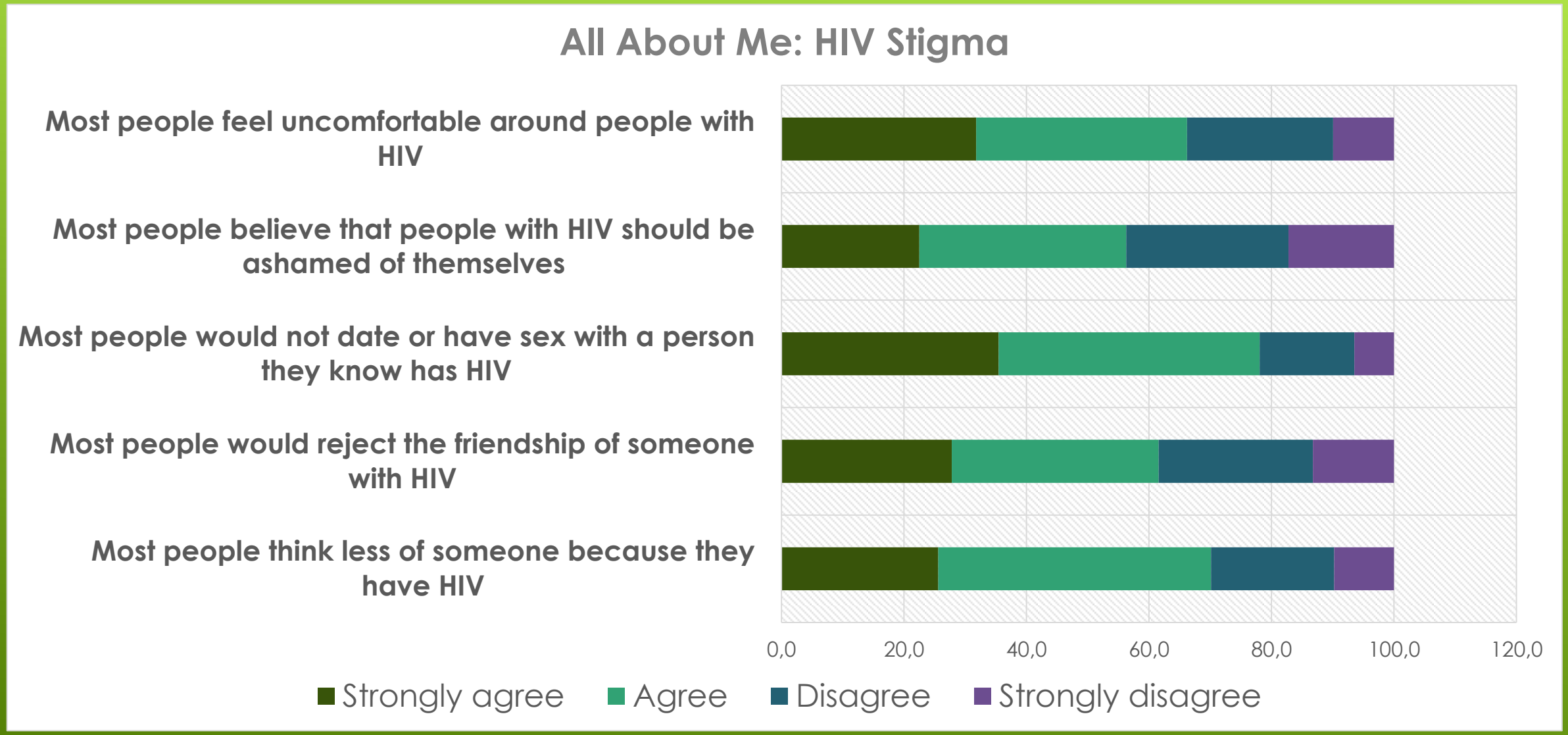
HIV STIGMA PROCESS

WE FEAR BEING LABELED BECAUSE OF WHAT WE BELIEVE "MOST PEOPLE" THINK ABOUT PLWHA & THOSE AT RISK

Community stigma includes the shared behaviors, attitudes, social norms and normative beliefs within a community that form the bases for anticipated stigma and have a reciprocal relationship with structural stigma.

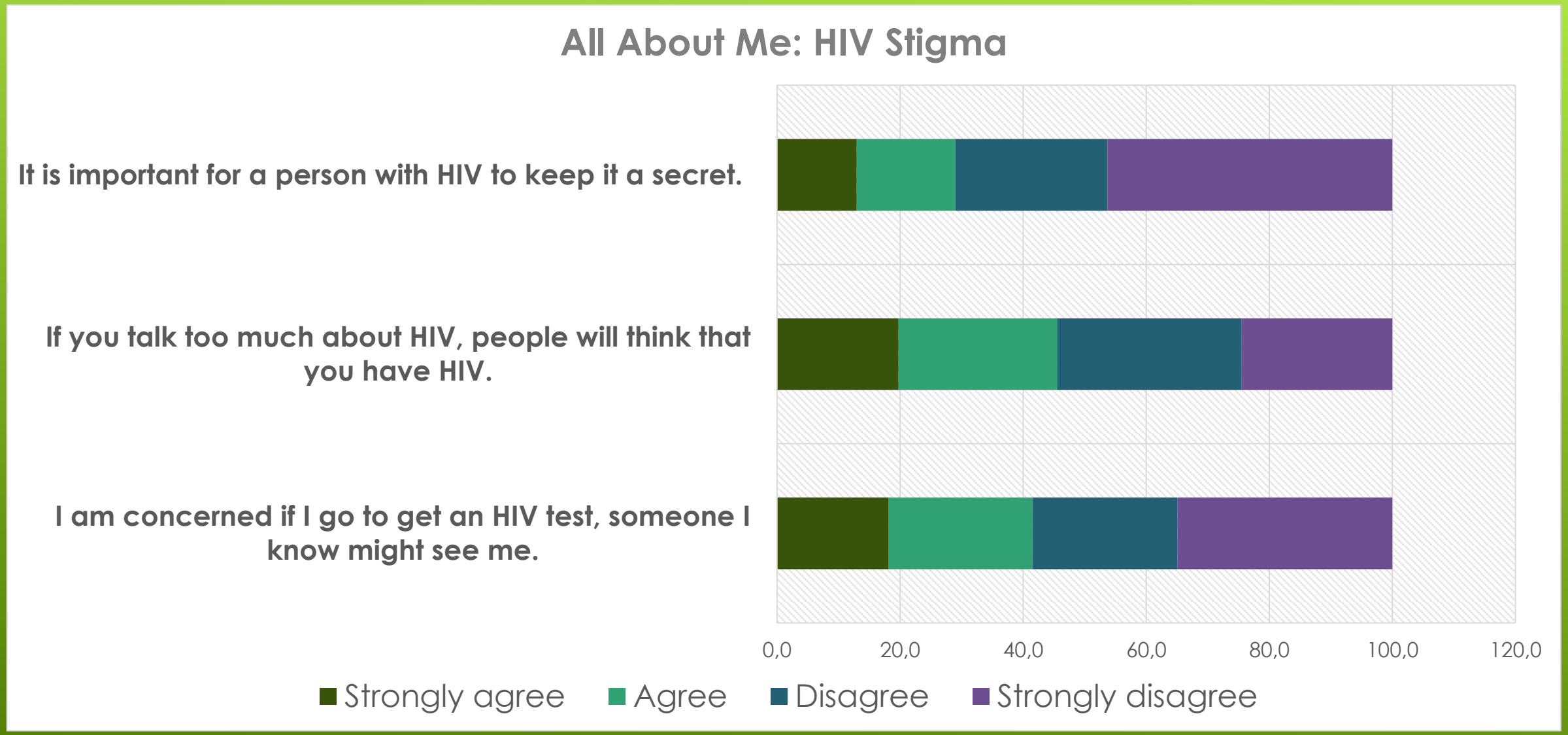


HIV STIGMA AMONG HIV-NEGATIVE, AFRICAN-AMERICAN MSM



- All About Me. PI: Beryl Koblin

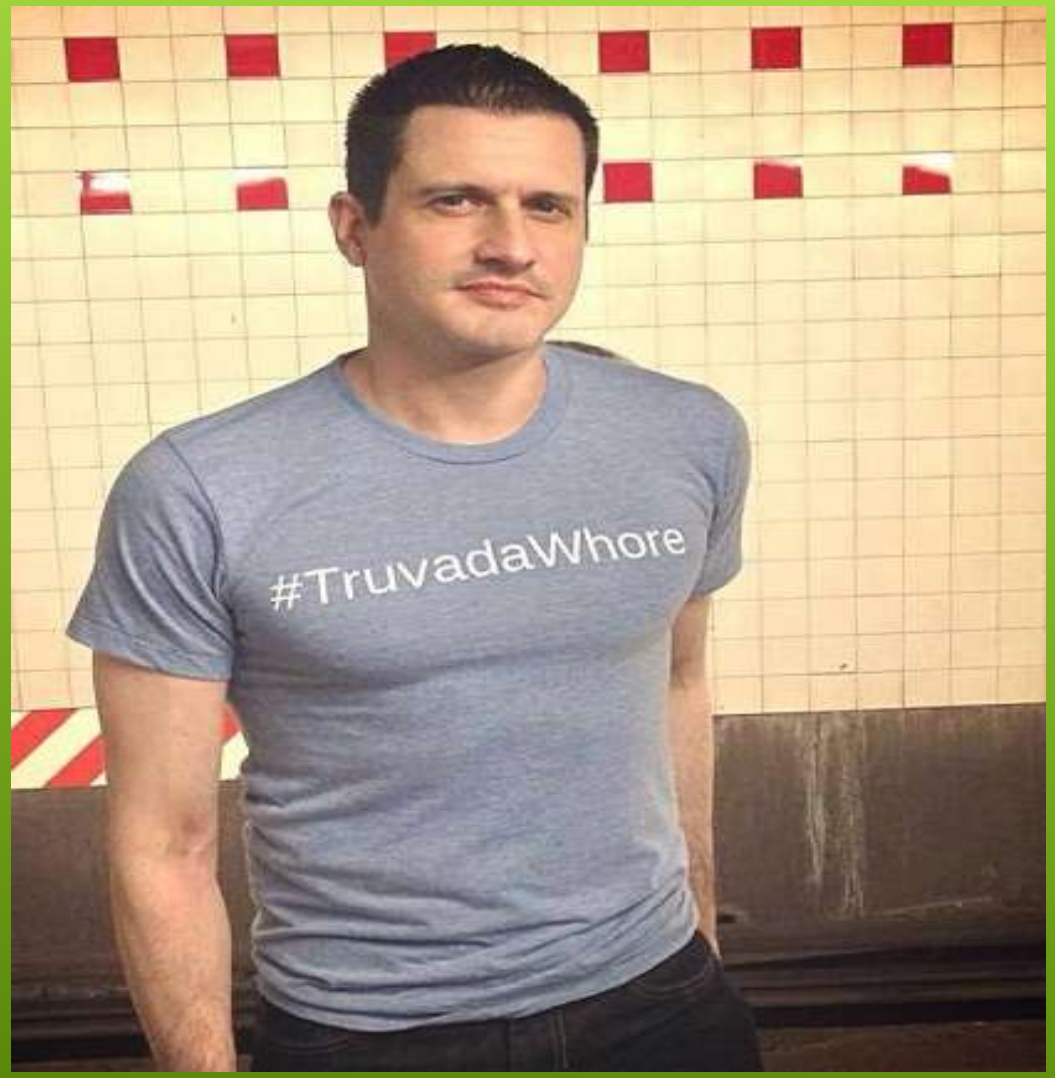
HIV STIGMA AMONG HIV-NEGATIVE, AFRICAN-AMERICAN MSM



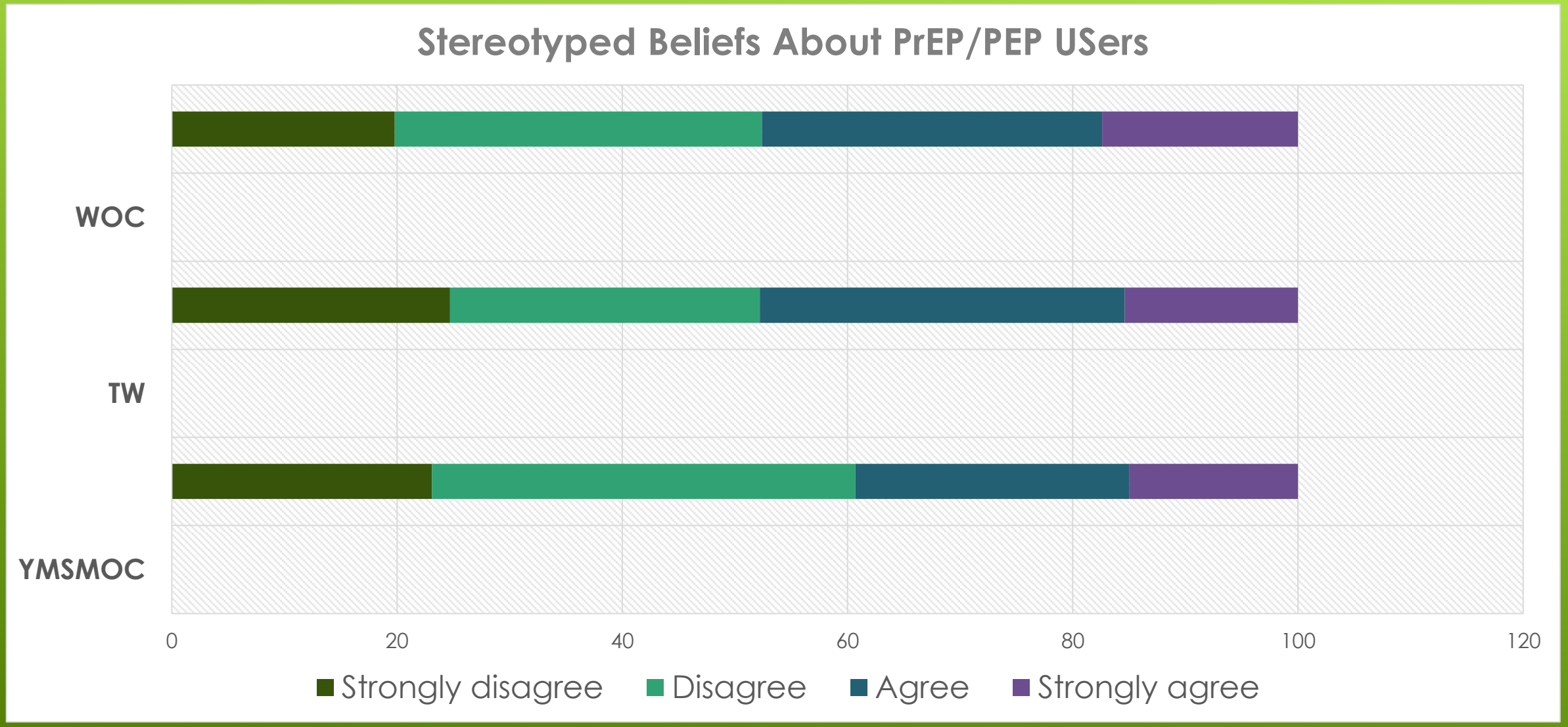
▸ All About Me. PI: Beryl Koblin

STIGMA & BIOMEDICAL HIV PREVENTION (PEP/PREP)

- Stigma associated with the use of PEP and PrEP is emerging.
- “Truvada whore” phenomenon with the gay community in the USA

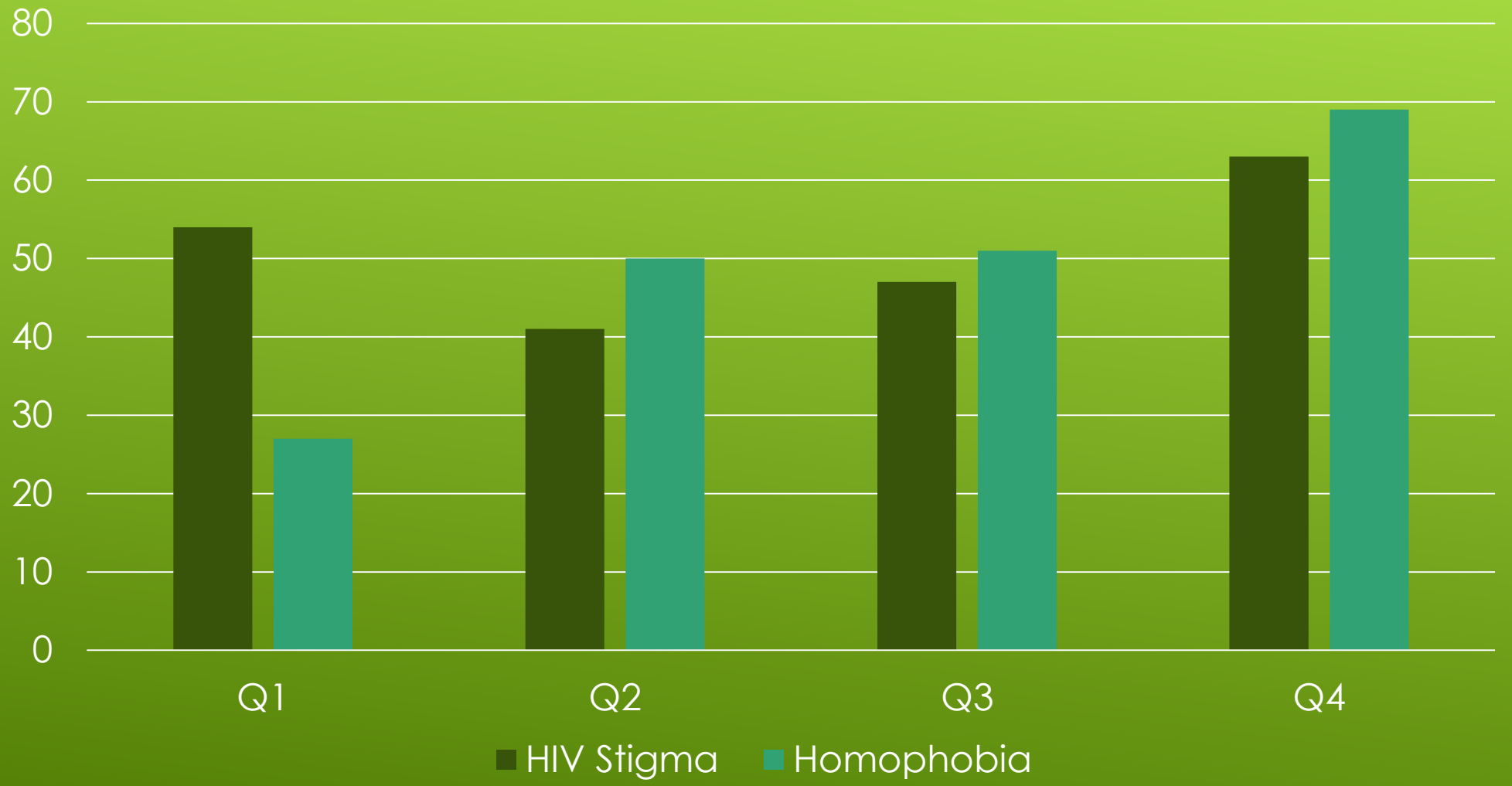


PEP/PrEP STIGMA AMONG AT-RISK POPULATIONS



REACH; PI: Beryl Koblin

Proportions of Community Residents Endorsing PEP/PREP Stereotyped Beliefs by HIV Stigma & Homophobia Quartiles (CHHANGE; N=583)



Among 583 residents in Central Brooklyn, NYC, we found that **53%** endorsed negative stereotyped beliefs. (Farhat et al 2016)

p < .01

HIV STIGMA AND HOMOPHOBIA

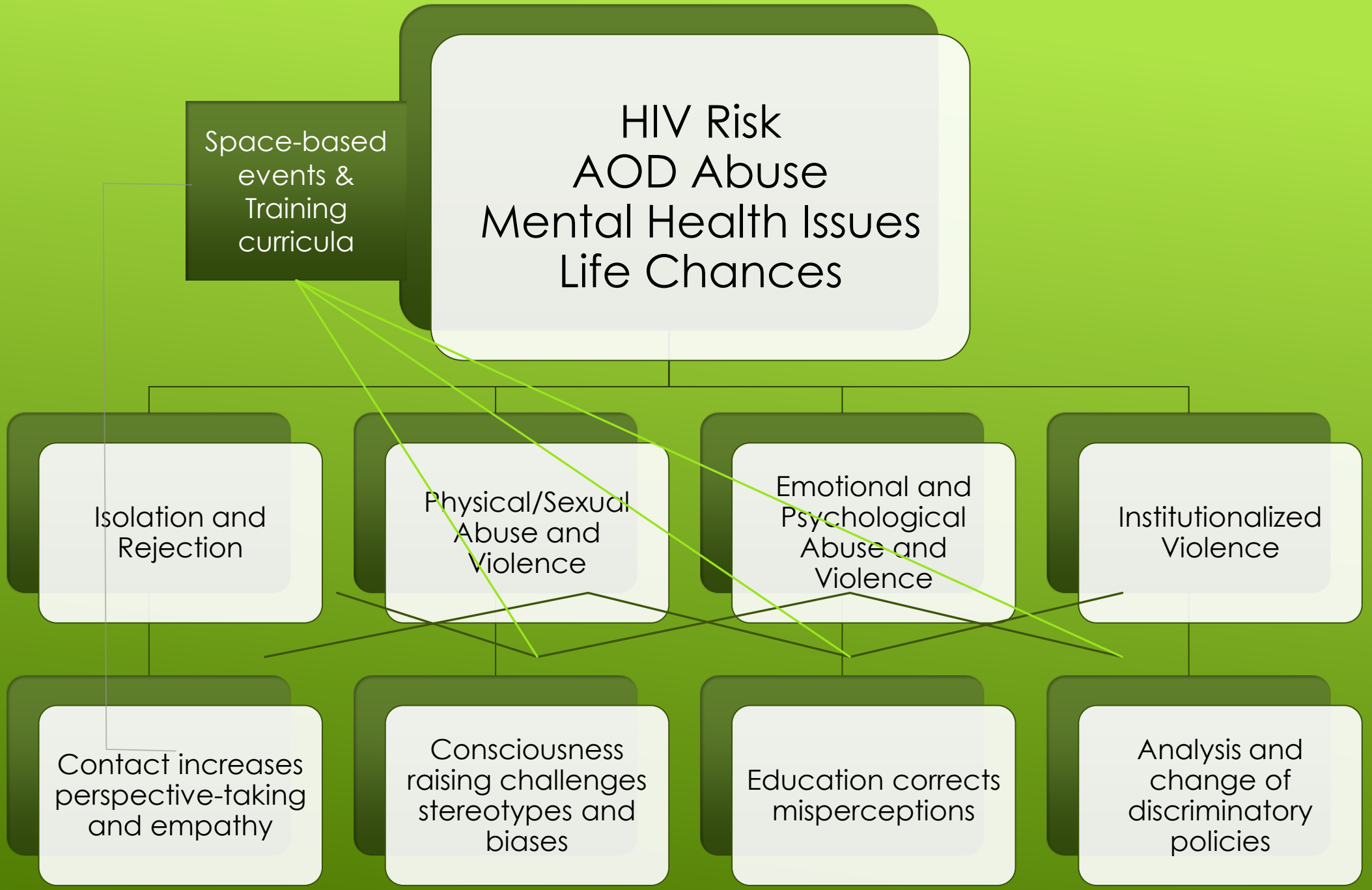
- HIV stigma is still prevalent and strong in 2015-16-17.
  - Anticipated stigma among focal populations, based on:
    - Beliefs around what "most people" would think/believe
    - Steeped in reality about what "most people" do believe (community-level stigma)
    - Stigma within referent or stigmatized (LGB) communities as well
- Major barrier for biomedical HIV prevention among HIV- populations

HIV STIGMA AND HOMOPHOBIA

- HIV stigma interacts with with another critical form of stigma/prejudice: homophobia
- Homophobia (structural, enacted and anticipated) independently predicts negative mental health and sexual risk outcomes. (Hatzenbeuhler et al 2011)
  - Homophobia reduces access to:
    - HIV prevention (ecological analyses)
    - Biomedical prevention (international sample)
    - PrEP among Black MSM (qualitative research)
- Dual stigma or "Double Whammy"
- ***"Young gay black men already are low on the totem pole; then if you are HIV you are even lower."***

PROJECT CHHANGE: STUDY DESIGN

- NIMH-funded R21: test a community-level anti-stigma & homophobia intervention
- Partnership: New York Blood Center (NYBC), Gay Men of African Descent (GMAD) & Brooklyn Men Konnect (BMK) of Bridging Access to Care.
- Three phases:
  1. Steering Committee
  2. Formative research/intervention re-design
  3. Intervention implementation & evaluation
- Multicomponent Intervention:
  - Anti-stigma workshops/trainings
  - Space-based, pop-up, arts-oriented events
  - Bus shelter media campaign
- Quasi-experimental evaluation design


Space-based events & Training curricula
HIV Risk
AOD Abuse
Mental Health Issues
Life Chances
Isolation and Rejection
Physical/Sexual Abuse and Violence
Emotional and Psychological Abuse and Violence
Institutionalized Violence
Contact increases perspective-taking and empathy
Consciousness raising challenges stereotypes and biases
Education corrects misperceptions
Analysis and change of discriminatory policies

CHHANGE INTERVENTION APPROACH

SPACE: Based out of BMK in IV neighborhood

Integrated focus on "gay space"

- Space decreases stigma and homophobia by:
  - Increasing visibility and contact
  - Offering safe space for LGBTQ and PLWHA, social support, etc.
  - Providing accurate information & education to the community
  - Increasing access to HIV prevention and testing services
- Material support @BMK storefront (coupons, food, etc.)
  - Shoe coupons, food, HIV testing, referrals and resources

CHHANGE INTERVENTION APPROACH

- **Adapted multiple *existing* intervention components based on formative research**
  - GMAD's curriculum (& bus ad)
  - CAMBA's "shoe drop" campaign

Funded by NYC DOHMH Early 2000s

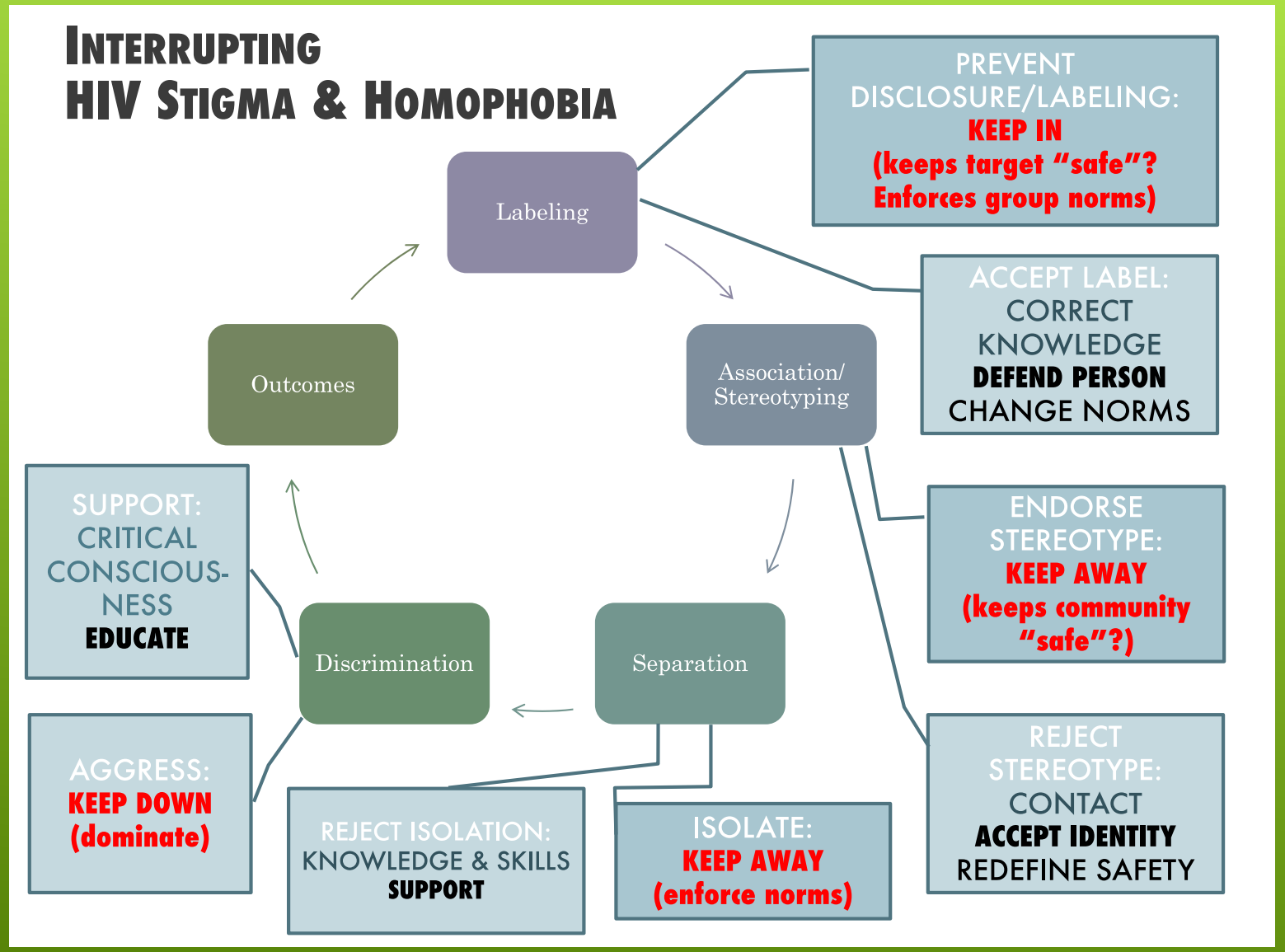
- **Pop-up & Space-based events**
  - 5 events with arts-based elements; organized around holidays or memorial days:
  - World AIDS Day (12/01/2014), Black History Month (01/31/2015), Valentine's Day (02/14/2015), and Mother's Day where the bus shelter ad was unveiled (05/09/2015) and a culminating event (05/30/2015).

CHHANGE SPACE-BASED EVENTS

CHHANGE POP-UP EVENTS

CHHANGE INTERVENTION APPROACH

- **Workshops & Trainings**
  - Delivered to over 900 people
  - 5 minutes to 2-day trainings
  - Structured, manualized
  - 2-3 people delivering
  - CBOs, barber shops & beauty salons



CHHANGE WORKSHOP MECHANISMS

KNOWLEDGE

- HIV 101
- Sexuality 101
- Stigma definition
- Homophobia
- Prevalence (HIV, PLWHA, LGBTQQ) in community, friends, family
- Manifestations
- Consequences
- ID similarities between forms of oppression (racism & homophobia)
- ID how policies and practices reflect values and prejudice

FEELINGS

- Recall response to prior experiences of stigma/discrimination
- Identify affective responses
- Perspective-taking/Imagine feelings of friends and family
- Enhance empathy
- ID fear: contagion, repercussions, negative impact on self/family/ community, etc.

SKILLS

- Assess risk in situations; ID unfounded fear
- Self-monitor affective responses
- Evaluate self, family, work and community
- ID spaces & ways to respond
- Assess feasibility of responding
- Challenge HIV stigma and homophobia (change policies, interrupt hate speech, etc.)

Theoretical Targets:

Cognitions; Affective states/responses; Critical Consciousness; Empathy/Perspective-taking; Self-efficacy; Mastery; Social Support

HIV STIGMA & HOMOPHOBIA

CHHANGE BUS SHELTER AD

News Weather Traffic Numbers & Links Sports Features News Te

NEWS

Bus shelter ads target homophobia, HIV stigma

May 11, 2015 10:22 AM

3 Comments A+ A-

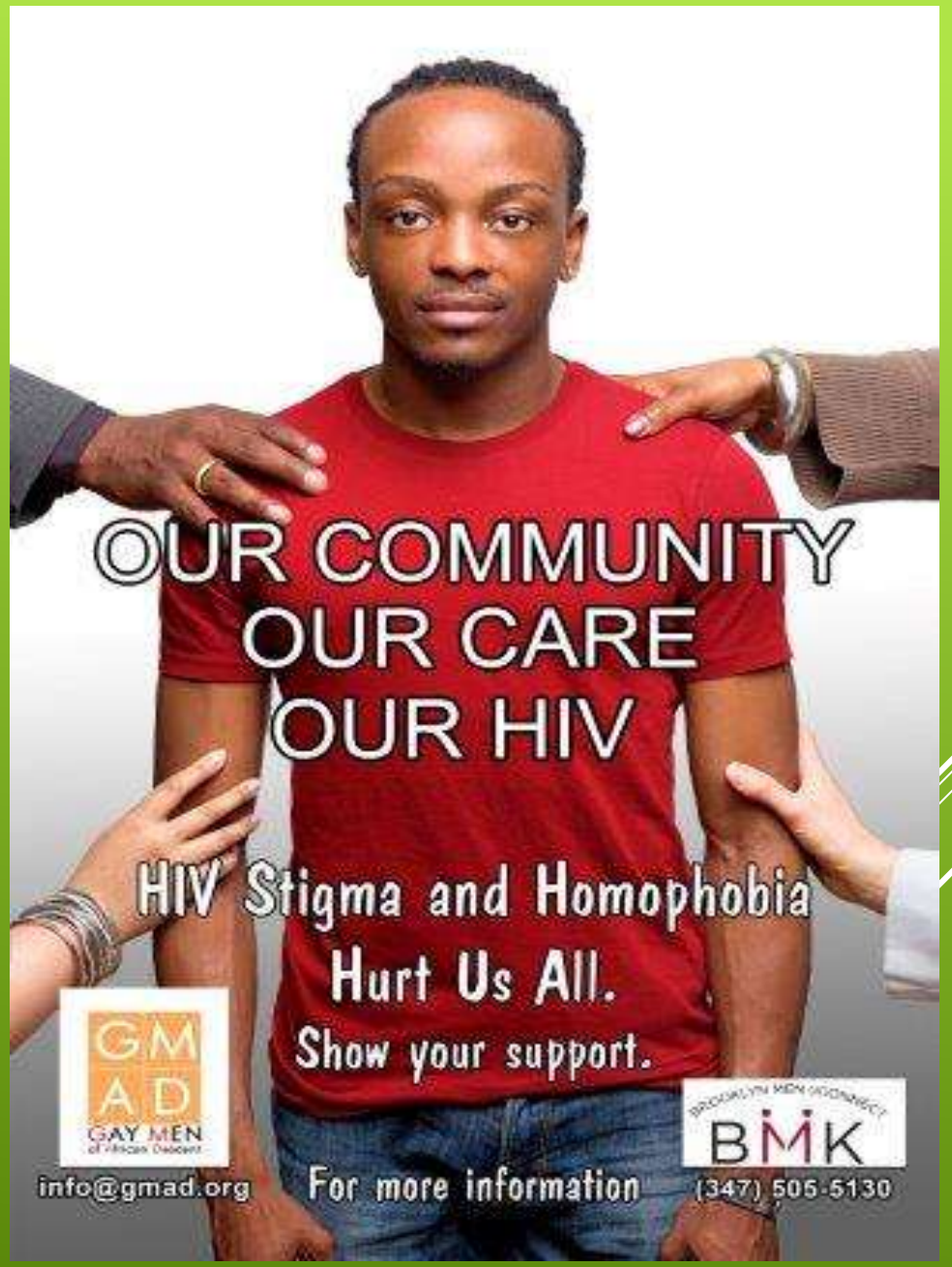
The campaign features the slogan, "Our Community. Our Care. Our HIV." (May 11, 2015 11:49 AM)

A new ad campaign is trying to educate the public about homophobia and the stigma of HIV.

The ads have popped up on bus shelters in Crown Heights with the slogan, "Our Community. Our Care. Our HIV."

The goal is to have community members unite to reduce discrimination against people living with HIV or AIDS, as well as those who are lesbian, gay, bisexual or transgender.

The campaign...



CHHANGE CONTEXT: 2014 - 2015

Black Lives Matter

LESSONS LEARNED ATTEMPTING TO REDUCE LAYERED, COMMUNITY-LEVEL STIGMA

- Addressing layered forms of stigma or discrimination (Reidpath and Chan 2005) presented numerous challenges, including:
  - messaging around two distinct conditions
  - not reinforcing associative stigma by conflating HIV and sexual behavior or identity
  - Significant resources and time needed
- Stigmatized conditions are not necessarily additive, but can have shared, interactive and independent effects (Chan et al 2007).
  - Significantly more receptivity to anti-HIV stigma intervention components than anti-homophobia components

LESSONS LEARNED ATTEMPTING TO REDUCE LAYERED, COMMUNITY-LEVEL STIGMA

- Improvements suggested by implementation team:
  - Train informal community leaders (barbers, salon owners, bodega owners, etc.)
  - Offer more follow-through with CBOs on policy and practice changes
  - Involve religious organizations
  - Integrate technology
- Strengths included efficiency and potential for impact at scale.
- Street-based work perceived to be particularly effective

WHAT DO WE KNOW ABOUT HIV STIGMA AND MENTAL HEALTH STIGMA?

LITERATURE SEARCH

Medline search using the terms "mental health" OR "mental illness" AND "stigma"

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Medline search using the terms "mental health" OR "mental illness" AND "stigma" yields over 3700 articles

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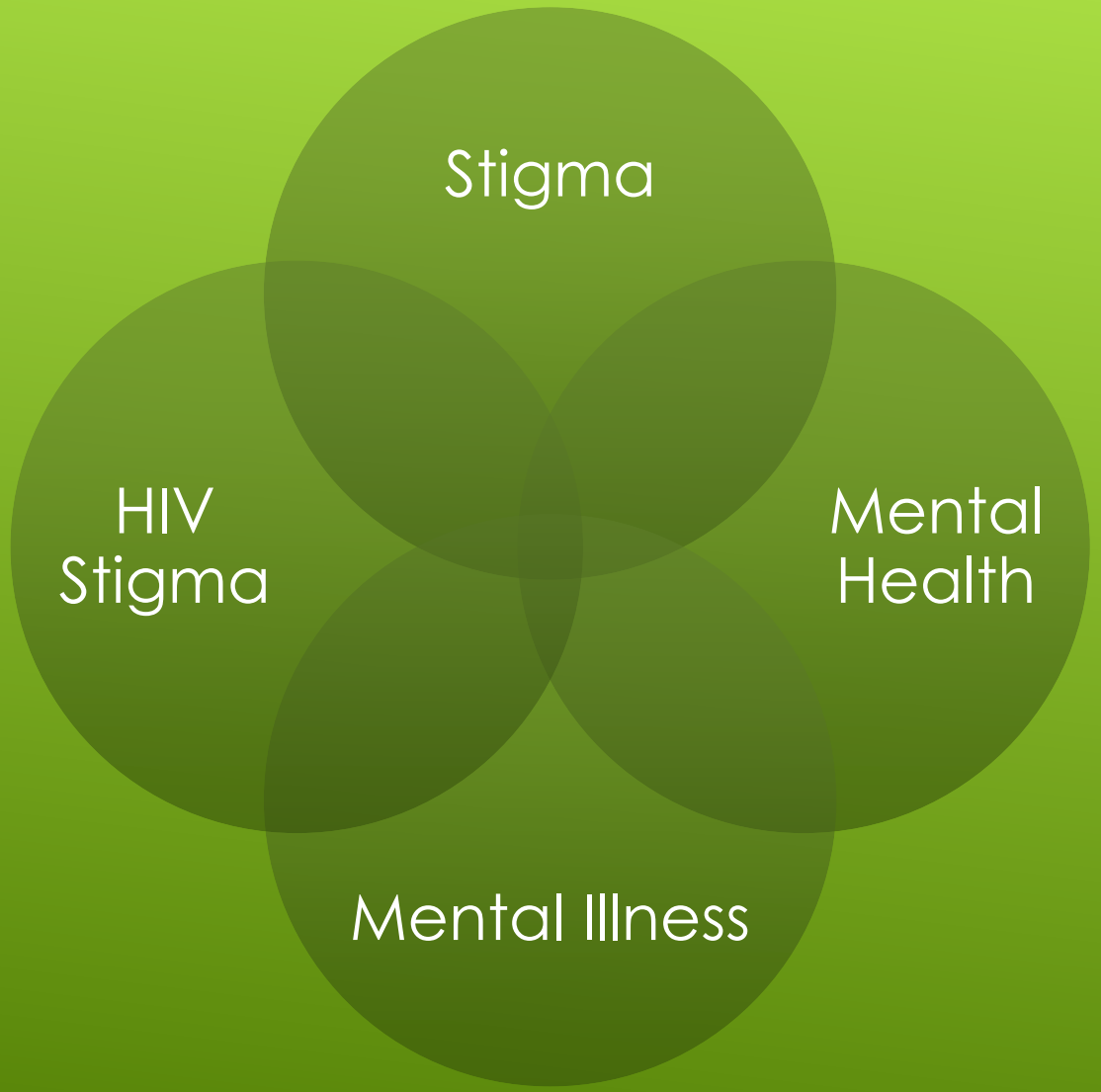

LITERATURE SEARCH

Add "HIV stigma" and that number is reduced to just 63.

The majority of these articles are focused on the effects of HIV stigma on mental health outcomes.

HIV STIGMA & MENTAL HEALTH DISORDERS/OUTCOMES

- Estimated that half of PLWHA meet criteria for MH disorders in representative US study of PLWHA (Bing et al 2001)
- Perceived or enacted HIV-related stigma associated with:
  - Anxiety, depression and panic symptoms among HIV+ MSM (Hatzenbuehler et al 2011)
  - post-traumatic stress symptoms among children orphaned by AIDS in South Africa

HIV STIGMA & MENTAL HEALTH DISORDERS/OUTCOMES

- Pathways from HIV stigma to adverse mental health outcomes:
  - HIV stigma increases isolation, which increases depression
  - HIV stigma increases rejection, which can trigger depressive episodes
  - Anticipated HIV stigma can increase anxiety symptoms
  - Traumas that result in HIV infection also cause MH disorders and symptoms
- MH stigma associated with reduced access to care

HIV STIGMA & MENTAL HEALTH STIGMA: SIMILARITIES

- Can be a "permanent" status, even if undetectable or have not had an episode in 15 years.
- Can be invisible
- Both conditions have criminalization/structural stigma responses
- Associative stigma pervasive and damaging
- Social rejection, distancing and microaggressions common
- Enacted and experienced stigma leads to internalized and anticipated stigma
- Growing literature that structural stigma associated with negative condition-specific outcomes, anticipated and internalized stigma

FUTURE PROGRAM DIRECTIONS

- How to address mental health & HIV or other forms of stigma in US-based community-level interventions?
  1. Developing and testing flexible, multi-component interventions that can be adapted to include two or more forms of community-level stigma;
  2. Incorporating the use of community "space" (drop-in centers) and engaging in natural social network-based (barber shops & salons) education and consciousness-raising
  3. Designing multi-level mental health stigma prevention interventions focused on three levels:
     - HIV-care providers/prevention professionals
     - HIV-care institutions/organizations
     - HIV-positive individuals

FUTURE PROGRAM DIRECTIONS

- How to address mental health & HIV or other forms of stigma in US-based community-level interventions?
  4. framing the identification of and response to community sources of mental health and HIV stigma as resistance to modern authoritarianism.
     - Consciousness raising around functions of systems of oppression a key component of CHHANGE
     - Connecting HIV stigma and homophobia to racism as another way to keep people down was an effective tool
     - Murders of transgender women during CHHANGE implementation period suggested phrases like “Black Trans Lives Matter”

CHHANGE CONTEXT: 2014 - 2015

HIV stigma and discrimination in the context of the race system, white supremacy and institutional racism

CHHANGE @THE WHITE HOUSE IN 2016!

THANK YOU:

Funders:

- CHHANGE: NIMH
- TRUST: NIDA
- ALL ABOUT ME: NIDA
- REACH: New York State DOH
- New York Blood Center

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