

# Barriers and Facilitators to Engagement in HIV Primary Care in New York City

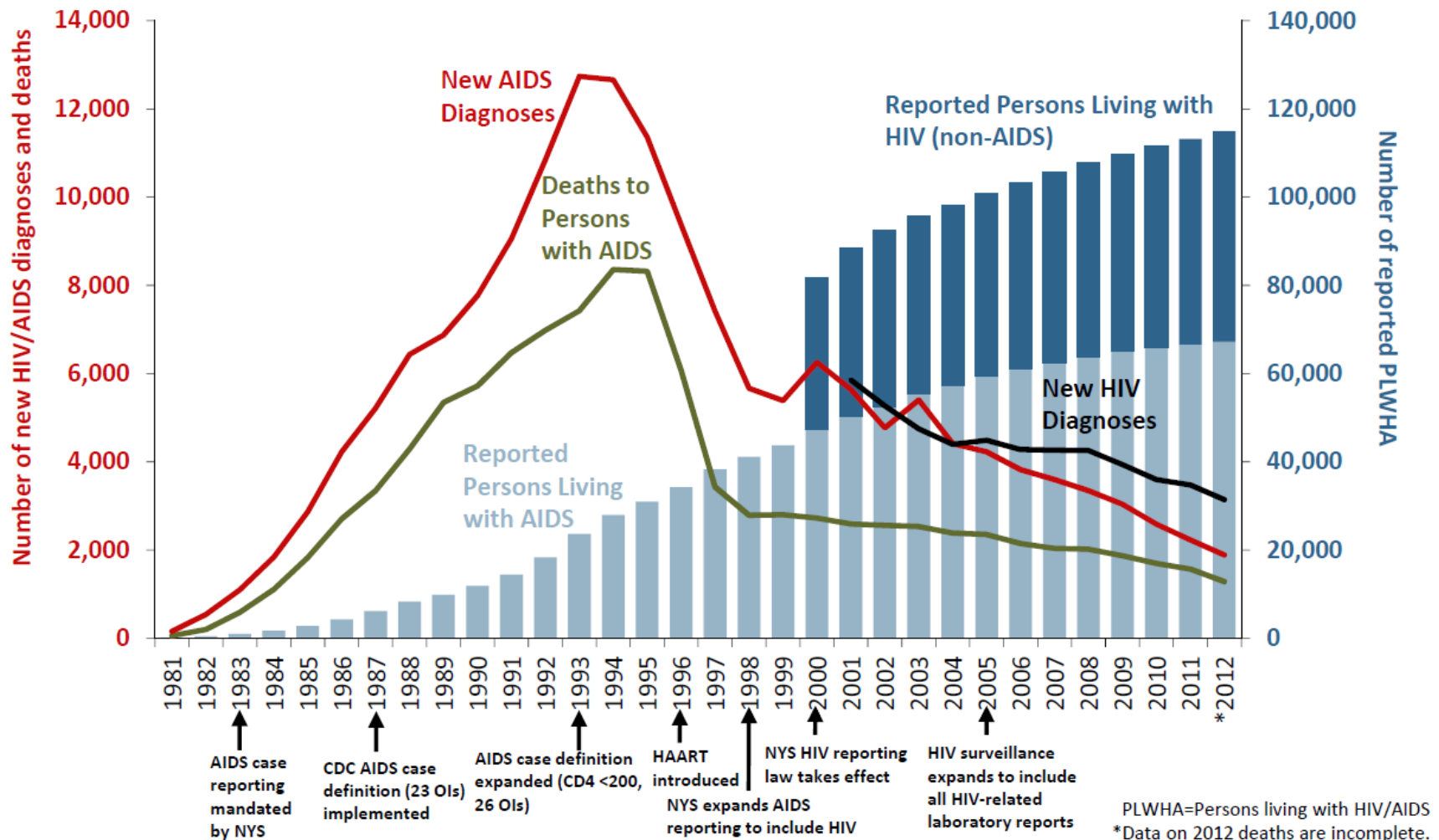
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**HIV Center for Clinical and Behavioral Studies/NY State Psychiatric Institute and Columbia University**

**Acknowledgements:**      **The National Institute of Allergy and Infectious Diseases**  
                                      **The National Institute of Mental Health**

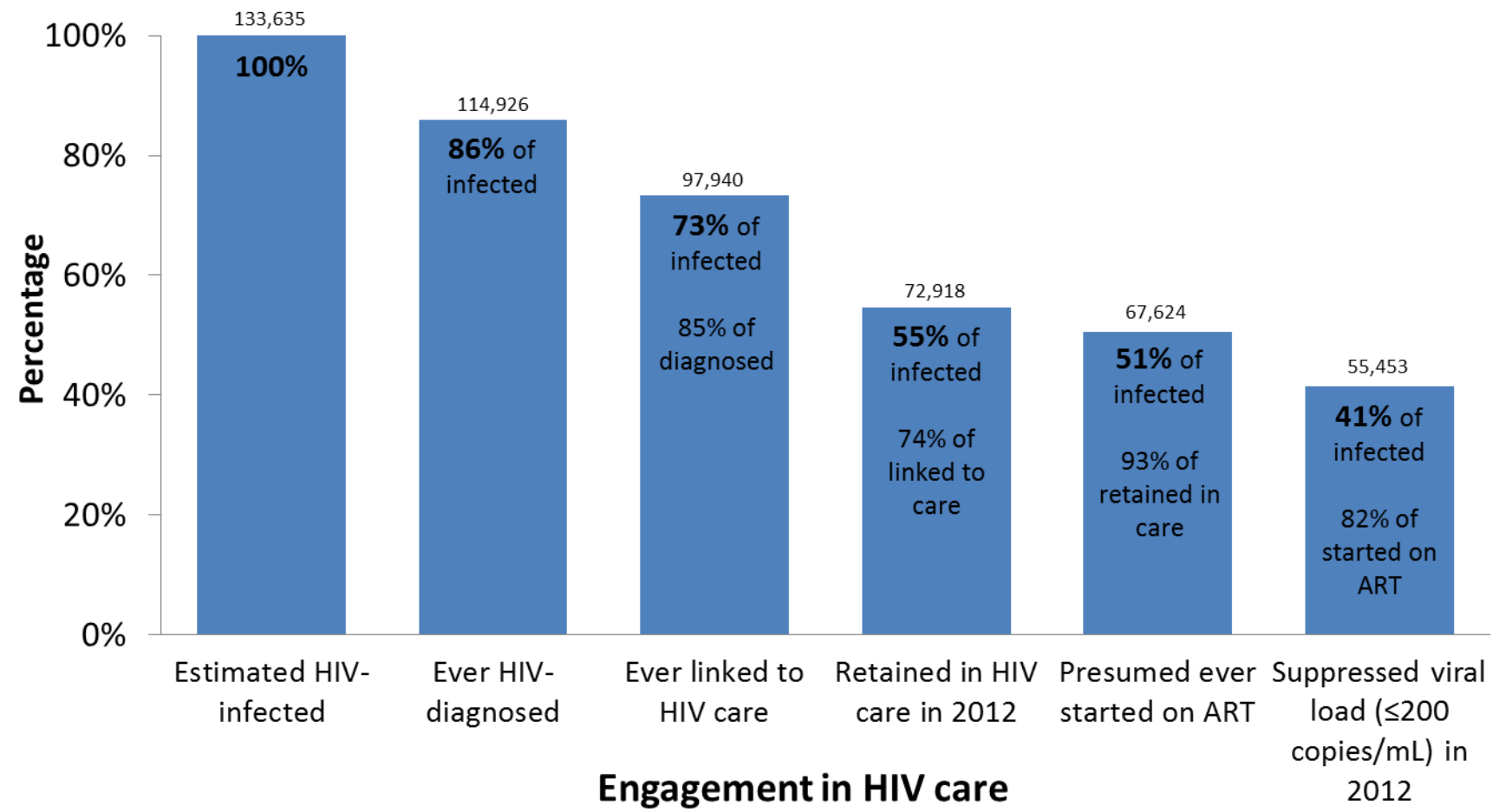
# History of HIV/AIDS in NYC, 1981-2012



# HIV/AIDS in New York City, 2012

- **3,141 new HIV diagnoses**
  - 2,529 HIV without AIDS
  - 612 HIV concurrent with AIDS (19.5%)
- **1,889 new AIDS diagnoses**
  - Includes 612 concurrent HIV/AIDS diagnoses
- **114,926 persons living with HIV/AIDS**
  - 1.4% of the population of NYC
- **1,578 deaths among persons with HIV/AIDS**
  - 14.9 deaths per 1,000 persons

# Number and proportion of persons diagnosed with HIV in New York City engaged in selected stages of the continuum of care at the end of 2012

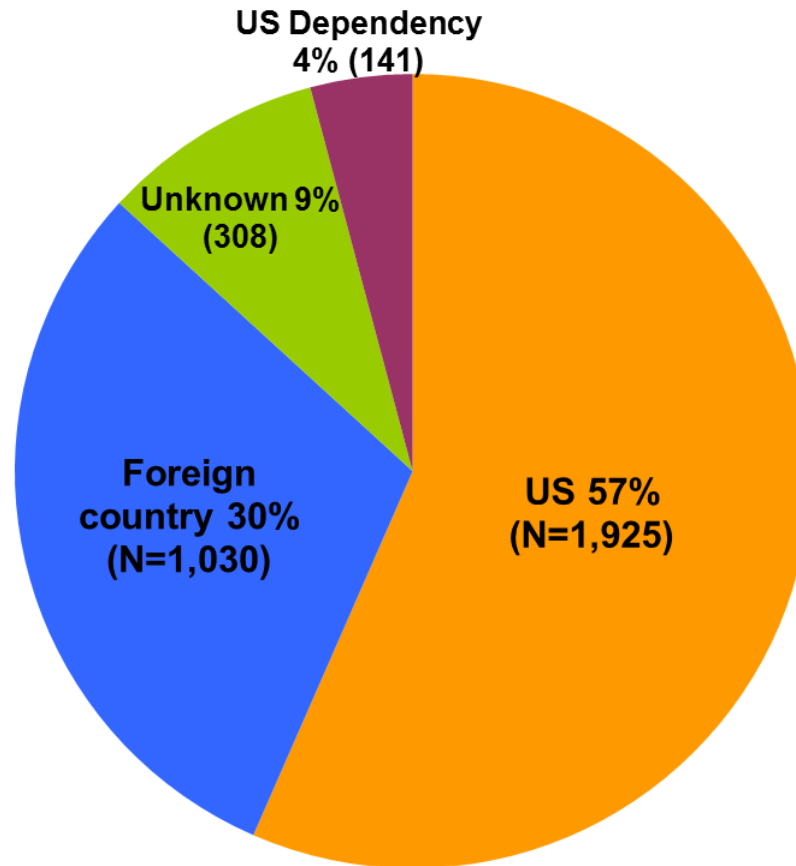


**Of all persons estimated to be infected with HIV in NYC, 41% have a suppressed viral load.**

As reported to the New York City Department of Health and Mental Hygiene by June 30, 2013.  
For definitions of the stages of the continuum of care, see Appendix.

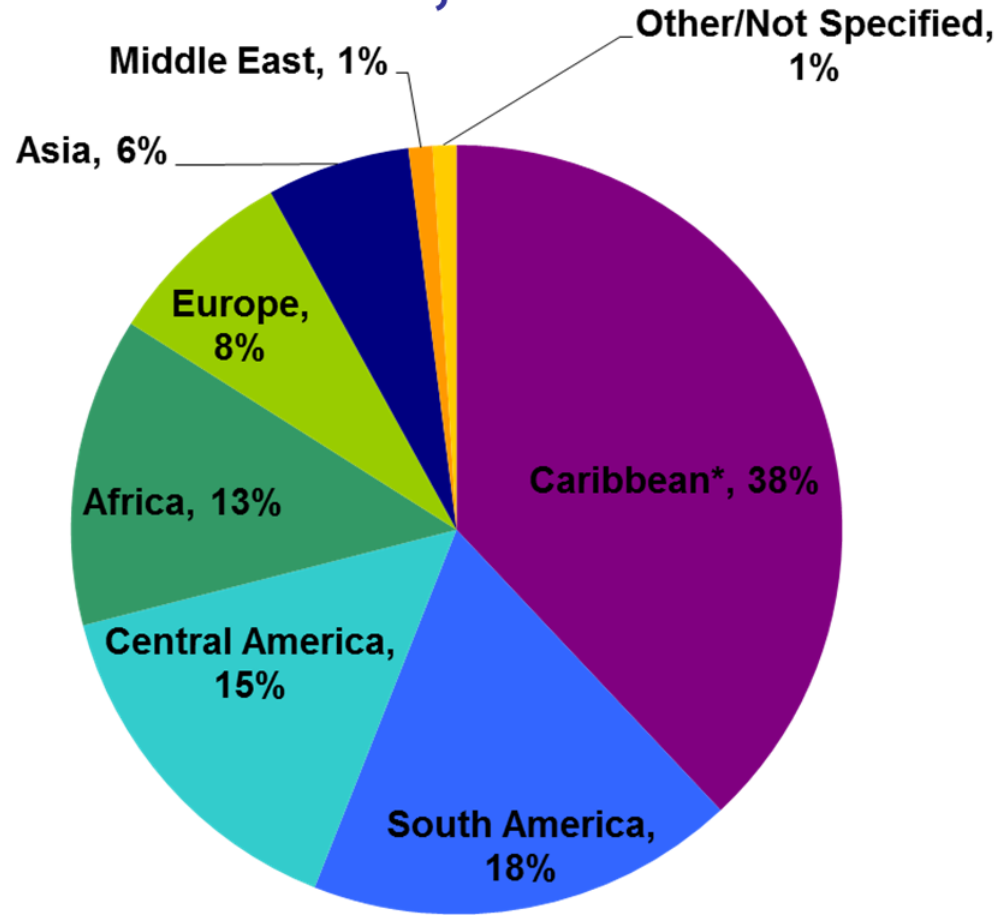
# **THE FOREIGN BORN POPULATION IN NYC AND HIV DIAGNOSES**

# New HIV Diagnoses by Area of Birth in NYC, 2011



**In 2011, 3,404 New Yorkers were newly diagnosed with HIV. Of these, 1,030 persons (30%) were born in a foreign country.**

# Percentage of New HIV Diagnoses among Foreign-born Individuals by Region of Birth in NYC, 2011

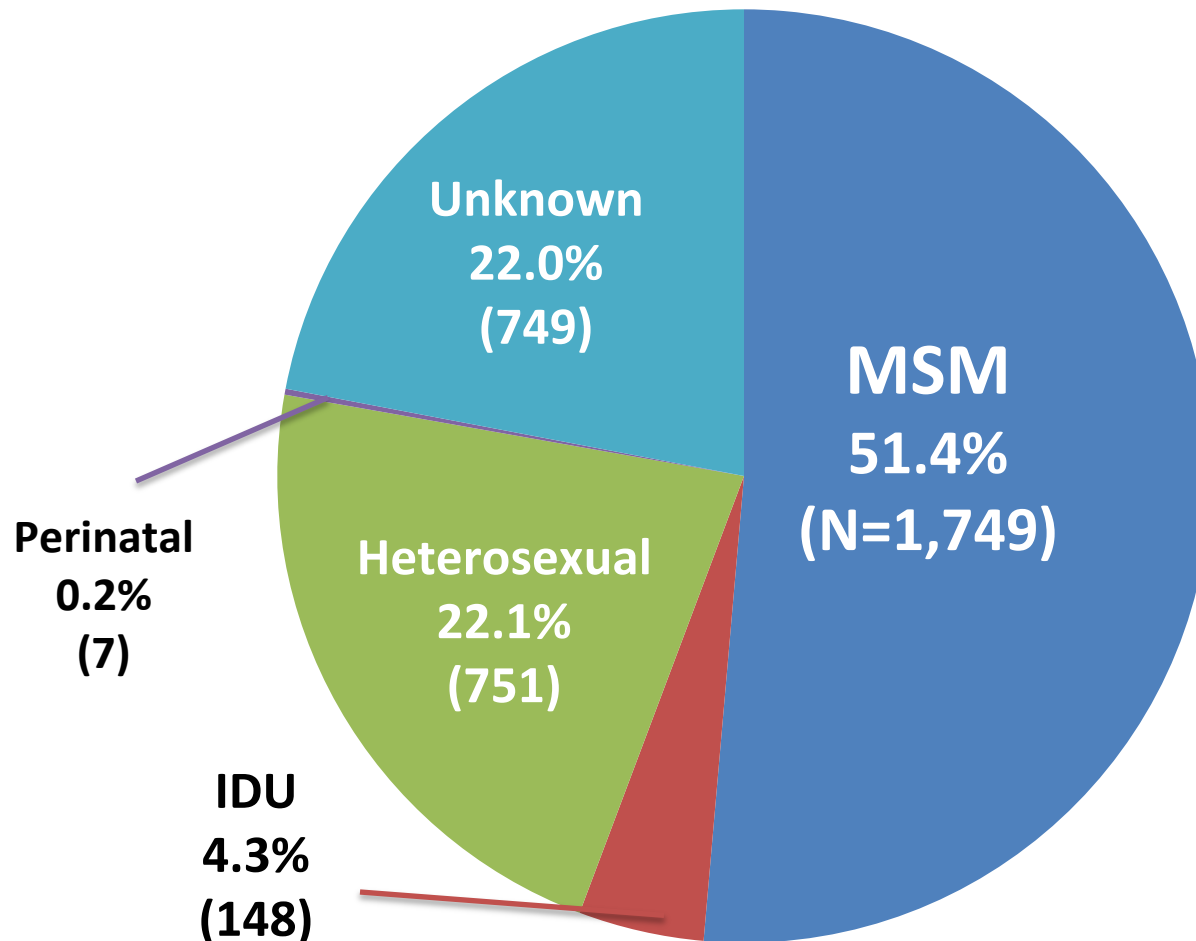


**The Caribbean, South America and Central America accounted for 71% of new HIV diagnoses among foreign-born New Yorkers.**

# **HIV AMONG MSM IN NYC**



# Percentage of New HIV Diagnoses by Transmission Risk in NYC, 2011



As reported to the New York City Department of Health and Mental Hygiene by September 30, 2012

# **HIV AMONG TRANSGENDER NEW YORKERS**

# **New HIV Diagnoses among Transgender Persons in NYC, 2007–2011**

## **Basic Statistics**

- **191 new HIV diagnoses in 2007–2011**
  - 189 transgender women (MTF; 99%)
  - 2 transgender men (FTM; 1%)
- **Includes 27 diagnoses of HIV concurrent with AIDS\* (14%)**
- **Transgender persons comprised 1% of all new HIV diagnoses in NYC in 2007–2011**

\* AIDS diagnosis within 31 day of HIV diagnosis; suggests late diagnosis of HIV.  
As reported to the New York City Department of Health and Mental Hygiene by September 30, 2012.

# **New HIV Diagnoses among Transgender Persons in NYC, 2011**

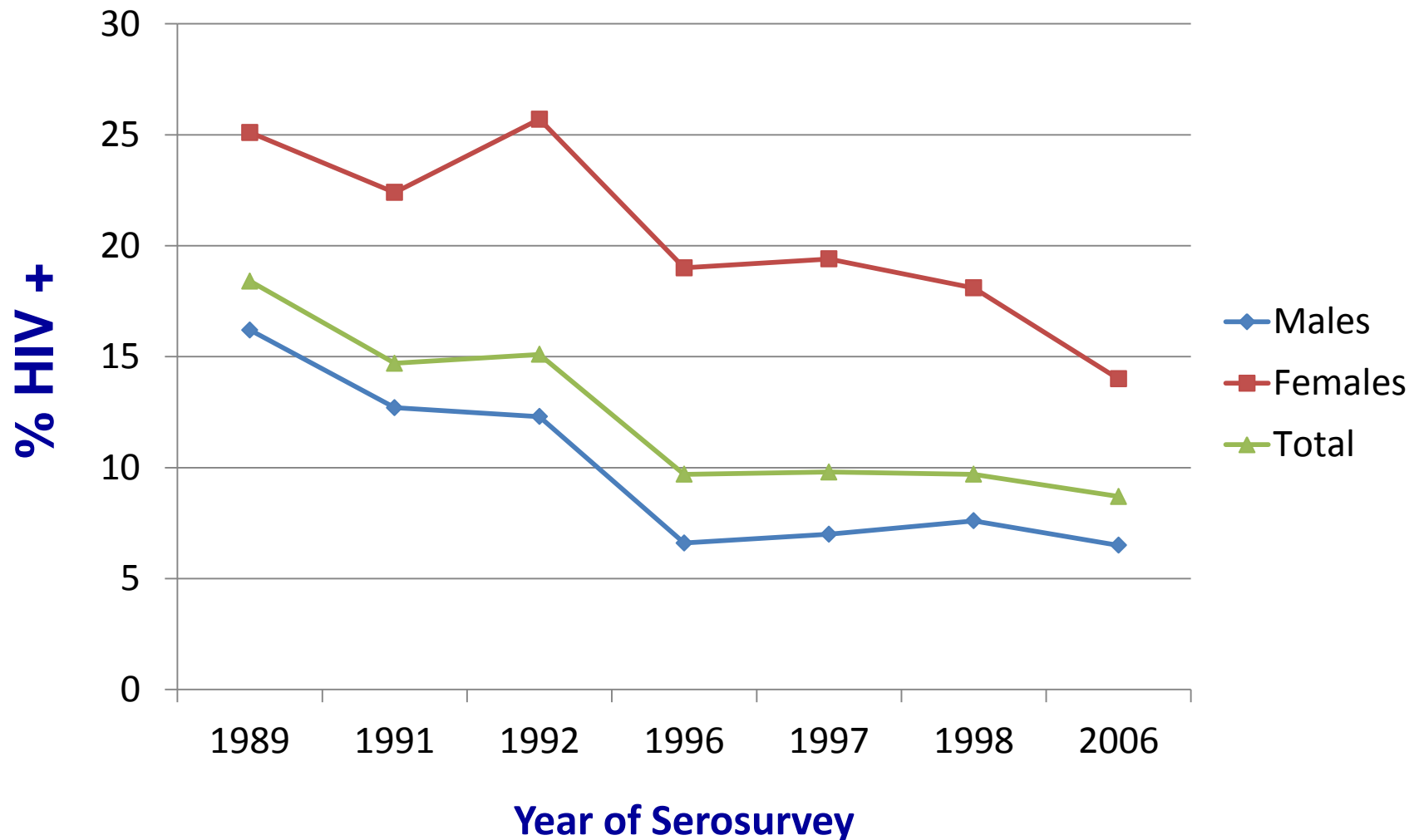
## **Basic Statistics**

- **31 new HIV diagnoses in 2011**
  - 31 transgender women (MTF; 100%)
  - 0 transgender men (FTM; 0%)
- **Includes 5 diagnoses of HIV concurrent with AIDS\* (16%)**
- **Transgender persons comprised 1% of all new HIV diagnoses in NYC in 2011**

# **HIV AMONG JAIL DETAINEES IN NYC**

# Blinded HIV Serosurveys

## *NYC Jails, 1989–2006*



# Barriers and Facilitators of Engagement in HIV Primary Care in New York City

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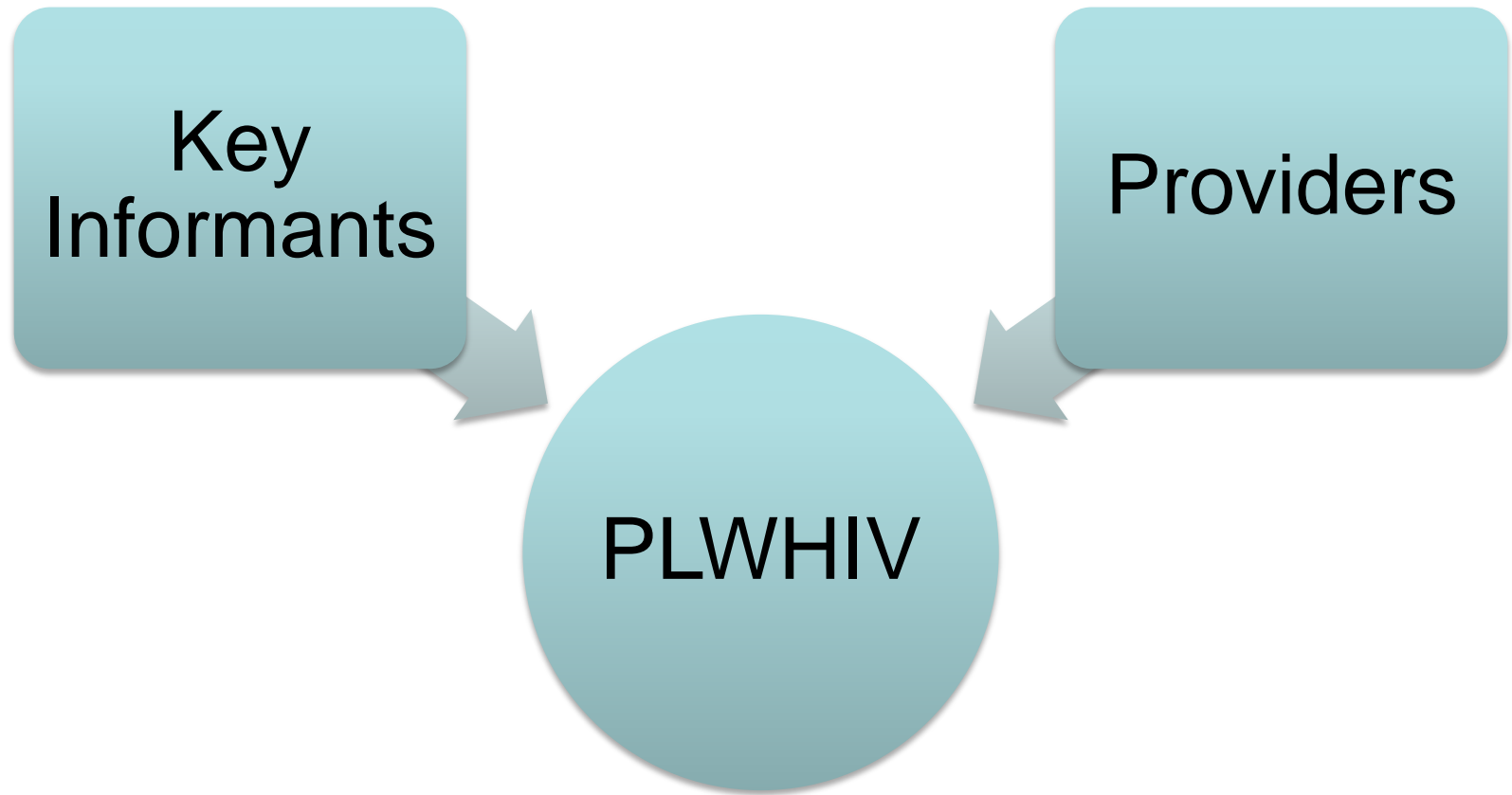
# Goal

To understand engagement in HIV medical care in four groups of people living with HIV (PLWHIV):

- African immigrants
- Previously incarcerated
- Transgender women (male-to-female transgender persons)
- Young men who have sex with men (YMSM)



# Study Design



# Recruitment

## All four populations

- Aged 18+
- HIV+ diagnosed more than 3 months before
- Had linked to care at least once

**Previously incarcerated:** released within previous year

**African immigrant:** born in Africa

**YMSM:** aged 18-29, identified as a gay man or MSM

**Transgender women:** self identified

# Methods

- One-hour in-person interviews were digitally-recorded and transcribed.
- Teams of analysts at Einstein and the Columbia separately coded a subset of their own interviews to generate initial codebooks.
- Codebooks were shared and mapped.
- Interviews are now being coded.
- ***Findings in this presentation are preliminary.***

# Barriers to Engagement

## All Four Populations

- Linkage fails to engage
  - > health is not a priority
  - > disrespected, judged
  - > fear of disclosure
  - > doctor didn't take the time to explain
- Unstable housing

# African Immigrants

## Background

- aged 27-61 (mean=45 years)
- 65% women
- from 9 African countries

## Continuum of care

- Over three-quarters engaged in care soon after diagnosis.
- Once engaged, all stayed engaged consistently from the beginning.

# African Immigrants

## Facilitators of Engagement

- **“It’s like a gift for my life”**

*I know I have HIV and I need the doctor...to be alive...and they give me all this for free....I have to thank America for that (crying).” F111*

- **Trusted provider**

*“...my doctor...he takes care of me. He also give me his cell phone number just in case.” F114*

- **Parent status**

*“I never forget my appointment...I want to stay alive, live with my child and grandchild.” F113*

# African Immigrants

## Barriers to Engagement

- **Undocumented**
- **HIV stigma**
  - > Dependence on local immigrant community
  - > Fear of community ostracism
- **Life stressors:** hunger, rape, domestic violence, loss, and resulting depression

# Previously Incarcerated

## Background

- aged 25-60 (mean=49 years)
- 65% men
- 58% Black and 37% Hispanic

## Continuum of care

- Only 1 in 4 engaged in care within 1 year.
- Only half stayed in care consistently.
- More than half had psychiatric diagnoses.
- All had a history of substance abuse.
- Different barriers while incarcerated, at discharge, and in the community



# Previously Incarcerated

## Barriers to Engagement while Incarcerated

- **Lack of trust in medical care**

*“Don't trust doctors in prison. They are not well qualified, do not care about the patient...I just didn't trust his judgment because we were a bunch of criminals and they treat us like shit.” M 105*

- **Afraid to disclose HIV status**

- > **Lack confidentiality**

*“[The doctors] got really close to the correction officers.” M 105*

- > **Fear ostracism**

*“You don't want nobody to know your status in there.... You don't want them going around saying, 'Don't eat with her. Don't sit with her. Don't talk with her because she got the monster’” F 132*

# Previously Incarcerated

## Barriers at Discharge

### Discharge problems

- > Reinstating Medicaid

*“They gave me a Medicaid card so I thought my Medicaid was activated so I went to [CLINIC] where they suggested I go. They turned me away because I didn't have Medicaid. That experience alone just shut me down. I’m sitting out here living with AIDS and you’re going to turn me down?”*  
M127

- > Conditions of probation

# Previously Incarcerated

## Barriers in the Community

- **Homelessness**
- **Substance use**

*“(Being in prison) is the time to rest, work out, eat well – it’s like recuperation time when you are getting ready to leave...and then you get out and start getting high, smoking crack cocaine.” M 136*

- **Psychiatric disorder**
- **Life stressors**

*..you know deep down in your mind you’re supposed to... but you get the fuck-its. You get a lot of that. “ F141*

# Previously Incarcerated Facilitators of Engagement

- **Comprehensive discharge plan**

*“They have counselors come in and talk with you and they set you up for when you’re coming out, tell you what to do and where to go.”  
M107*

- **Navigator**

- **Housing**

- **Community provider**

*“She wasn’t judgmental, so I felt comfortable with confiding in her what I was doing.” F104*

# Transgender Women

## BACKGROUND

- Age
  - Mean: 31.9; Median: 30.0
- Race/Ethnicity
  - 70% Black; 40% Hispanic
- Education
  - 45% less than high school diploma
  - 40% high school diploma
  - 15% had more than a high school diploma
- Care Engagement
  - Approximately 1/3 described significant lapses in care

# Transgender Women

## Barriers to Engagement

- **Social and environmental factors are drivers of inconsistent engagement in care**
  - Stigma, homelessness, sex work, substance use, family instability, etc.
  - Competing priorities

*“Being homeless and having HIV is probably the worst because, you know, you’re already like focusing on one thing, and then you have another thing that’s going on with you...There’s no stability, so you know, you can’t worry -- there’s just so much going on...It’s like you’re more worried about what you’re going to eat than your health.” (TGWP-12)*

# Transgender Women

## Barriers to Engagement

- **Stigma and lack of social support may significantly hinder engagement in care**
  - Lack of social support and little expectation of having it  
*“People use the word friends too loosely. I have one friend...That’s it...Other people, they will use what they know against you to hurt you in the worst way they can.” (TGWP-13)*
  - Trans stigma compounded by HIV+ status
    - Difficult to *care* about *care*  
*“I mean, being transgender, it’s bad enough when you try to hide from the world who you are...Then, on top of that, you try to hide HIV status...And when you get through the end of the day, you don’t give a damn about medical care no more. You just don’t care. You get to that point, because life is just constantly beating you down.” (TGWP-07)*

# Transgender Women: Facilitators of Engagement

## **Provider knowledge and understanding of social/environmental factors**

*“You don't want [a doctor to] just to come in, take your blood pressure, take your pants down, lift up, cough. No, you don't want no doctor. You need a doctor [to whom you can say] – ‘Well, Doc, I'm homeless, so I wasn't eating right, so if I take my medicine, will it affect me, my stomach?’” (TGWP-20)*

## **Provider knowledge and understanding of trans issues**

*“[My HIV care provider] has a real good doctor. I guess maybe the training that they do, even with the interns, [I've] never had a problem...They call me by the name that I want to be called and I've been doing well....A lot of people are not trained to do that. Many people just -- they call you ‘he’ by mistake and make you feel uncomfortable; it makes you feel not to want to come back to that place.” (TGWP-02)*



# Young Men Who Have Sex with Men

## BACKGROUND

- Age
  - Mean: 25.1; Median: 25.0
- Race/Ethnicity
  - 60% Black; 35% Hispanic
- Education
  - 74% had at least some college education
- Care Engagement
  - Approximately 1/2 described lapses in care

# Young Men Who Have Sex with Men: Barriers to Engagement

- **Social and environmental factors** as drivers of inconsistent engagement in care
  - Substance use, homelessness, sex work, family instability, stigma
  - Competing priorities

*“I mean, when I first initially came [to NYC, I slept in] Central Park or on the train...I was friends with this guy who would always get me into clubs, so then I started escorting...But then I started, like, using drugs, and...me being in care didn’t work really, because I was getting high, and I was like, **I’m not gonna take [HIV meds] and get high.** You know, that defeats the purpose of me trying to take care of myself, you know, especially because I wasn’t ready to stop using drugs.” (YMSM-06)*

# Young Men Who Have Sex with Men: Barriers to Engagement

- **Delays in linking to care** after testing HIV-positive  
*“So I was kind of confused [after testing HIV-positive], and I was like, what the hell? ...It took me about four or five years after [testing] to start getting care. I don’t know.” (YMSM-17)*
- Providers who seem **unwilling to listen, collaborate, and learn may serve as barriers** to maintaining HIV care  
*“But [my provider] was just really, really adamant about like, ‘Oh, start medications as soon as possible.’ And I’m like, ‘Yeah, OK, I hear what you’re saying...however, if I’m not ready to start medication, I’m not going to start.’ I’d much rather wait until I’m ready and be adherent, as opposed to start and stop and just do more damage to myself...She’s like, ‘Well, research says.’ I’m like, ‘I know what the research says. I look at it every day.’” (YMSM-12)*

# Young Men Who Have Sex with Men: Facilitators of Engagement

- Providers who are willing to collaborate with patients and allow the patient to be an **active participant in their own healthcare**

*“I would love for my doctor to have the wherewithal and the mental capacity to have an open courteous malleable mind when talking to patients...You should be empathetic. [But] don’t be sympathetic and going down ‘Oh yeah, pity. I don’t pity, girl. I need you to reason and be real with me.’ (YMSM-18)*

# Young Men Who Have Sex with Men: Facilitators of Engagement

- **Provider flexibility**

*“[I want] flexibility. I want to be able to go to a doctor’s appointment Saturday after class...And during that appointment, can I see my case worker and see my nurse practitioner or doctor, whoever it is that I need to see? **One stop shop.** Can I go online from my computer, or even my phone, and refill my prescriptions or schedule a doctor’s appointment? Can you pick me up in a cab and take me to my appointment? Right? That would be great....If I make a phone call and say, ‘Look, I’m running 20 minutes late,’ don’t tell me I have to push my appointment out another month. Just be flexible with me, please.” (YMSM-12)*

# YMSM and TGW: Institutional Support as a Facilitator of Engagement

- Institutional support as a facilitator of social support
  - > Both TGW and YMSM have faced great social isolation and stigma, possibly reinforcing a **sense of self-reliance**
  - > Groups and programs can increase feelings of social support
- Institutional support as a facilitator of engagement and retention in care
  - > **Housing assistance**
  - > **Transportation**
  - > **Mental health and substance use services**

# When basic life needs are in place, healthcare can become a priority

*What's made it easy is me being stable, having a place to stay [through HASA]. I feel like with me being -- having, you know, my own place and being able to live the way I want to live, I could focus on me and my health. You know, I'm not worried about what I'm going to eat tomorrow, where I'm going to be tomorrow. **So I feel more stable, and I feel like I'm in a place where I could, you know, worry about me,** what's going on with me [in terms of my health]. (TGWP-12)*

# What We Learned

- Conceptualization across cascade steps
  - Often what was a barrier or facilitator of **engagement** also was a barrier or facilitator **throughout the cascade**
- Treatment for chronic health condition vs “treatment as prevention”
  - Little mention of treatment in order to prevent transmission to others
- Ostracism is real; social support from family and friends is vital



# What We Learned

- Medical providers are the lynchpin in the care continuum
- Supportive services and other community providers can make a difference
- Services work, when:
  - Caring, respectful provider and care site
  - Good care coordination
  - Support groups; mental health services
  - Housing

# What We Learned

- Life is hard
  - Significant and multiple stressors
  - Hierarchy of needs -- to eat, feed a habit, have a place to sleep
  - Health can become a priority only when you are not hungry, scared, sleeping in a park, or alone

# Limitations

- Site Selection Bias (recruited through agencies and programs)
- Most people we recruited were currently engaged
- Many diagnosed a long time ago

# Conclusions

- **ACA focus on primary care**
  - Care from a specialist is key to engagement – HIV care providers understand the social context and challenges of these vulnerable groups
  - Ryan White funding for wrap-around services for these vulnerable groups facilitates engagement
- **Intervention development**
  - Jobs for peer educators and navigators would provide benefits to both counselors and those they counsel

# Conclusions

- The need for stable housing cannot be overstated
- Substance use and mental health treatment need to be available and accessible to these vulnerable populations
- We need more research to identify ways of reaching the “hidden” populations not yet tested or linked to care

# Study Team

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