

## The stigma of HIV prevention

**Jeremiah Johnson**, HIV Prevention Research and Policy Coordinator,  
*Treatment Action Group*

**Matthew Rose**, Policy Associate, *National Minority AIDS Council*

**Sarit A. Golub**, Professor, *Hunter College and the Graduate Center of  
City University of New York*

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*Download slides & materials at: [www.preventionjustice.org](http://www.preventionjustice.org)*



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  - This webinar has too many attendees for questions to be submitted over the phone.
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# Today's Agenda

- **Introductions**
  - **Maxx Boykin**, Community Organizer, *AIDS Foundation of Chicago*
- **Sex, drugs, stigma, and HIV prevention**
  - **Jeremiah Johnson**, HIV Prevention Research and Policy Coordinator, *Treatment Action Group*
- **The fact remains that racism and discrimination are impeding that progress in black communities**
  - **Matthew Rose**, Policy Associate, *National Minority AIDS Council*
- **Three thoughts about prevention stigma**
  - **Sarit A. Golub**, Professor, *Hunter College and the Graduate Center of City University of New York*

- **Q&A**

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# Sex, drugs, stigma, and HIV prevention

Jeremiah Johnson, HIV Prevention Research and  
Policy Coordinator, *Treatment Action Group*





# About Treatment Action Group

- Treatment Action Group is an independent research and policy think tank focused on activism to accelerate research, treatment, access, and community information to prevent, treat, and cure HIV and its most common coinfections, hepatitis C virus (HCV) and tuberculosis (TB).
- [www.treatmentactiongroup.org](http://www.treatmentactiongroup.org)

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# What is Stigma?

In our conceptualization, stigma exists when the following interrelated components converge. In the first component, people distinguish and label human differences. In the second, dominant cultural beliefs link labeled persons to undesirable characteristics—to negative stereotypes. In the third, labeled persons are placed in distinct categories so as to accomplish some degree of separation of “us” from “them.” In the fourth, labeled persons experience status loss and discrimination that lead to unequal outcomes. Finally, stigmatization is entirely contingent

## Conceptualizing Stigma

Author(s): Bruce G. Link and Jo C. Phelan

Reviewed work(s):

Source: *Annual Review of Sociology*, Vol. 27 (2001), pp. 363–385

Published by: [Annual Reviews](#)

Stable URL: <http://www.jstor.org/stable/2678626>



# Power

tion that lead to stigmatization. Finally, stigmatization is entirely contingent on access to social, economic, and political power that allows the identification of differentness, the construction of stereotypes, the separation of labeled persons into distinct categories, and the full execution of disapproval, rejection, exclusion, and discrimination.

# Power Holders in HIV prevention

Legislative Governance (Law-Making Bodies)	Executive Governance & Administrative (Implementation) Agencies	Judicial Governance (Interpretation)	Law Enforcement	NGOs	Others
-State Senate, State House of Representatives, U.S. Congress.	-Departments of Health, Housing, Public Assistance, Child & Family Services, etc.  -Governor, Mayor, County Commissioners, City Council Members.	-Local, state & federal courts (trial & appellate).	-State & city police.  -Prosecutors & Public Defenders.  -State & fed attorney general.  -Department of Justice.	-CBOs.  -Small, medium large non-profits/for-profits.  -ASOs.	-Providers.  -Media (traditional and social media).  -Academia; research bodies.  -Funders.  -Business community.  -Celebrities.

*Many thanks to Melanie Medalle from Sisterlove, Inc.*

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# HIV-related stigma

- “HIV/AIDS-related stigma is a complex concept that refers to prejudice, discounting, discrediting and discrimination directed at persons perceived to have AIDS or HIV, as well as their partners, friends, families and communities.”
- Umbrella term that houses several more specific types of stigma
  - More than just the virus (or living with the virus)
  - Unnecessary/unusual use of coercion/power, shame
  - Reinforces stigmatization of marginalized groups (racism, misogyny, transphobia, homophobia)
  - Reinforces stigmatization of certain behaviors

*Ekstrand, Maria. How does stigma affect HIV prevention and treatment?. Center for AIDS Prevention Studies at UCSF. Available at: <http://caps.ucsf.edu/archives/factsheets/stigma>*

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# What is sexual stigma?

- Stigma related to:
  - With whom we have sex
  - How we have sex
  - Quantity of sex
  - Sexual disease prevention methods
- Perceiving things related to sex more negatively in comparison to other routine human activities



# What is sexual stigma?

Imagine that a thousand people—randomly selected from the U.S. population—had unprotected sex yesterday. How many of them will eventually die from contracting HIV from that single sexual encounter?

Now, imagine a different thousand people. These people will drive from Detroit to Chicago tomorrow—about 300 miles. How many will die on the trip as a result of a car crash?

Which of those two numbers is bigger?

From: Earp, Brian. “People Are Terrified of Sex.” The Atlantic. 2015 November 12.



# What is sexual stigma?

According to [statistics](#) from the U.S. Centers for Disease Control and Prevention and the United States National Highway Traffic Safety Administration, you are actually 20 times more likely to die from the car trip than from HIV contracted during an act of unprotected sex.

From: Earp, Brian. "People Are Terrified of Sex." The Atlantic. 2015 November 12.





# What is sexual stigma?

Conley and her colleagues think the answer has to do with stigma: Risky behavior related to sex is judged more harshly than comparable (or even objectively worse) health risks, when you control for the relevant differences between the behaviors.

“It seems that as a culture we have decided that sex is something dangerous and to be feared,” Conley told me in an interview. That’s why, she argues, U.S. parents try to “micromanage” their children’s sexuality, “with the danger of STIs [Sexually Transmitted Infections] being a large part of that.”

From: Earp, Brian. “People Are Terrified of Sex.” The Atlantic.  
2015 November 12.




# Condoms: A Tricky Topic

Wow, I didn't really read the entire article, but just the fact that they titled it this is irresponsible on their part alone.

Like · Reply ·  6 · Mar 1, 2016 12:53pm

Please stop trying to cast your orgasm as a noble pursuit.

If such things only affected you, I'd say go for it. But it doesn't. Your actions not only put your partners at risk, but they become a drain on healthcare, and they reflect on the entire LGBT community.

Like · Reply ·  40 · Mar 1, 2016 2:16pm · Edited

Sorry, but bareback Grindr hook ups is not what it means to be gay. And conflating to two is little different than how our haters see us.

Try getting intimacy by connecting to the person instead of the body.

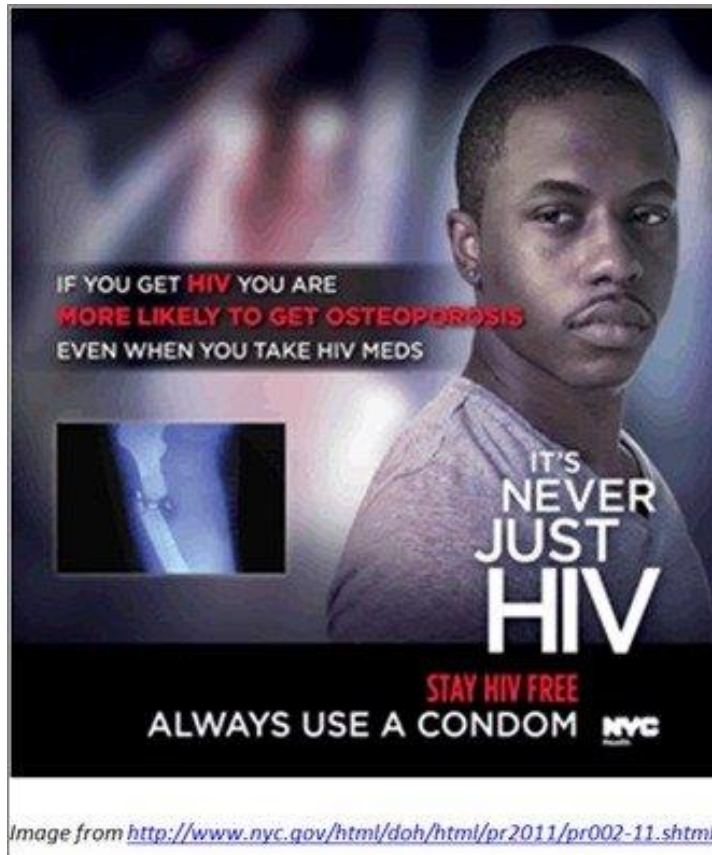
Like · Reply ·  13 · Mar 2, 2016 1:52pm

Comments from: *Johnson, Jeremiah. It's Not Irresponsible to Like Bareback Sex. HuffPo. 2016 February 29.*

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# Stigma as Public Health Practice



# Justified Stigma?

- Growing body of evidence that we are very limited in our ability to increase condom usage or reduce number of sexual partners

*(Sullivan PS, et al. Successes and challenges of HIV prevention in men who have sex with men. Lancet. 2012 Jul 28;380(9839):388-99.)*

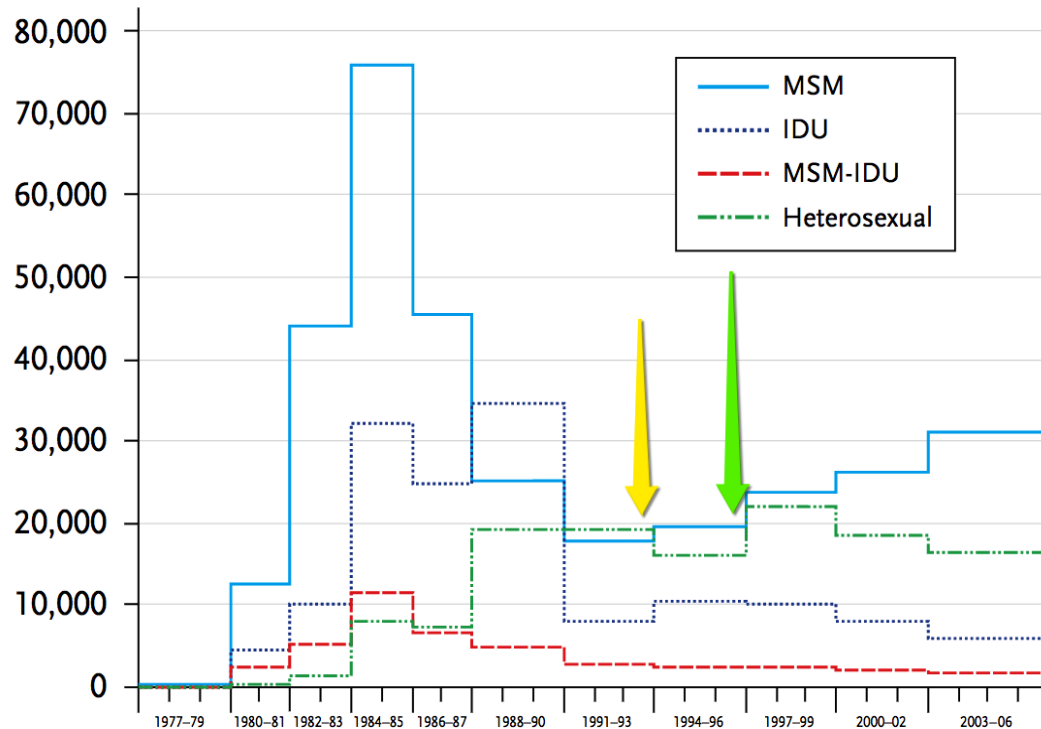
- Fear and shame based approaches very likely do not work- and may be harmful

*(Albarracin D, et al. A test of major assumptions about behaviour change: a comprehensive look at the effects of passive and active HIV-prevention interventions since the beginning of the epidemic. Psychological Bulletin. 2005; 131(6): 856-97.)*





**Figure 2. Estimated Number of New HIV Infections, Extended Back-Calculation Model, 1977–2006, by Transmission Category**



Note: Estimates are for 2-year intervals during 1980–1987, 3-year intervals during 1977–1979 and 1988–2002, and a 4-year interval for 2003–2006.

CDC. Estimates of New HIV Infections in the US. August 2008. Available at:  
<https://www.cdc.gov/nchhstp/newsroom/docs/fact-sheet-on-hiv-estimates.pdf>

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# Drug-related stigma

- Criminalization of a health-related issue
- Viewing drug use or addiction as a moral or personal failing
- Pathologizing drug use
- Patronize and fear people who use drugs
- Isolate people who use drugs





# Stigma as Public Health Practice

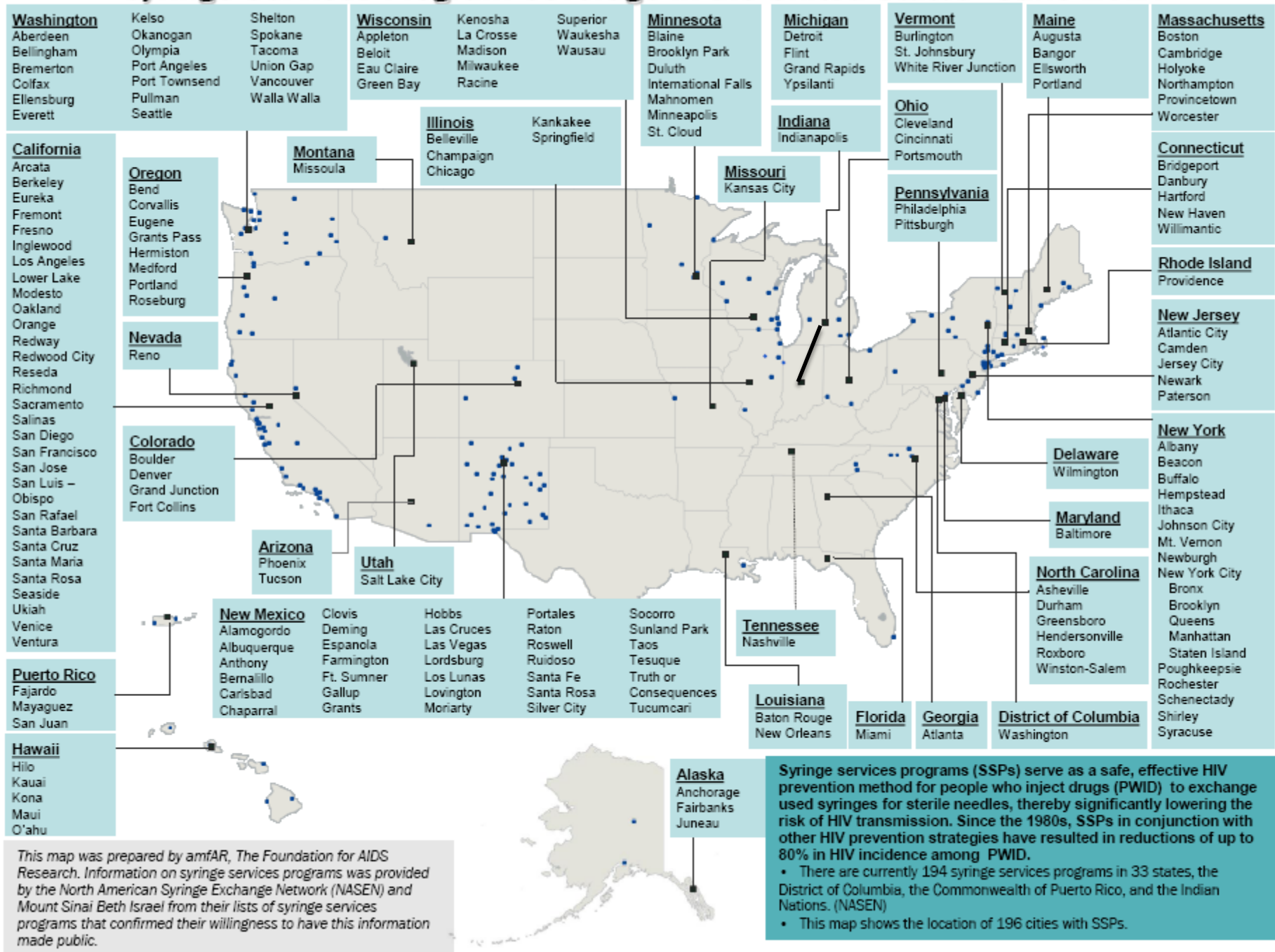


# Justified Stigma?

- Research showing that stigmatizing people who use drugs may do more harm than good  
*(Ahern J, Stuber J, Galea S. Stigma, discrimination and the health of illicit drug users. Drug Alcohol Depend. 2007 May 11;88(2-3):188-96.)*
- May make problems worse by serving as a major deterrent to accessing actual evidence-based methods of HIV-prevention.



# Syringe Services Program Coverage in the United States – June 2014



# Stigma creates barriers in HIV prevention

Legislative Governance (Law-Making Bodies)	Executive Governance & Administrative (Implementation) Agencies	Judicial Governance (Interpretation)	Law Enforcement	NGOs	Others
-State Senate, State House of Representatives, U.S. Congress.	-Departments of Health, Housing, Public Assistance, Child & Family Services, etc.  -Governor, Mayor, County Commissioners, City Council Members.	-Local, state & federal courts (trial & appellate).	-State & city police.  -Prosecutors & Public Defenders.  -State & fed attorney general.  -Department of Justice.	-CBOs.  -Small, medium large non-profits/for-profits.  -ASOs.	-Providers.  -Media (traditional and social media).  -Academia; research bodies.  -Funders.  -Business community.  -Celebrities.

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# Creating Barriers to HIV Prevention Services

- Creation of unusually harsh or shaming policies/laws
- Reductions in availability of evidence-based HIV prevention programs
- Discourage healthcare providers to provide PrEP/PEP, clean syringes
- Internalized stigma/deterrent to accessing services



# How do we combat it?

- Research: We need better research on HIV prevention stigma. We also need to change the way we talk about sex and drug behaviors in research.
- Policy: National indicator/HIV stigma index that includes HIV prevention specific stigma. Addressing the legacy of the Helms amendment. Decriminalizing consensual sexual practices and drug use.
- Education: National campaign to stop shaming people for consensual sexual choices or drug addiction. Wide use of honest, evidence-based, and comprehensive sex ed curriculum.
- Programmatic: Training for HIV prevention providers to fully accept and avoid judging the consensual sexual practices of clients- including condom usage and number of partners. Training to address drug use as a health issue- not as a moral or criminal issue.





# **The fact remains that racism and discrimination are impeding that progress in black communities**

**Matthew Rose**, Policy Associate, *National Minority AIDS Council*



# Racial discrimination increase risk for long-term health problems.

- ongoing disenfranchisement of Black and Latino community have both them in the cross hairs of HIV,
- This syndemic or cross section interwoven oppressions such as poverty and homelessness are rampant, with lower access to education and healthcare the pile of barriers raises.
- The majority of doctors harbor “unconscious racial biases” toward their black patients.



# Stigma and the interplay of racism

- The literature demonstrates that experiences of racism lead to minority stress and poor health outcomes for people of color, often due to felt micro and macro aggressions that then trigger stressful physical responses when individuals are confronted with potentially stigmatizing situations
- Homophobia and HIV-related stigma existed within the larger social context of racism



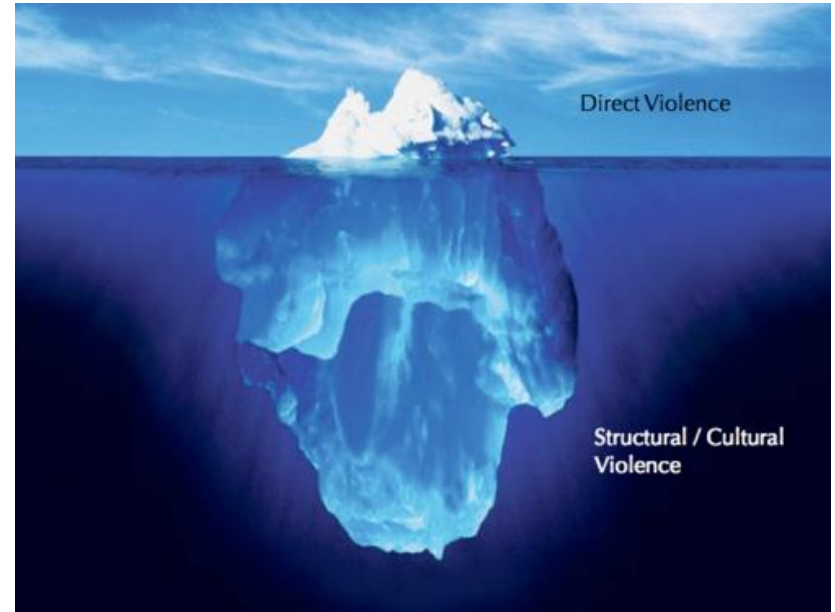
# History of Stigma of HIV and Black bodies

- Stigma is the changing of history to edit out the parts that don't sit well with you
- The creation and imagination of the danger of black sexuality and other people of color
- Societal racism and anticipation of racism from white gay community members led some participants to feel apathy about reducing HIV risk, because they felt devalued in society.



# Stigma kills

- HIV's relationship with death and sickness fueled slights that cause those living with HIV mental distress and fear of rejection.
- Slights and rejection hindered efforts to disclose a positive serostatus to friends, family, and sexual partners, to go for HIV testing, and to seek treatment
- It allows the negative person to deny their own risk of infection
- Structural violence



# Routes to restore, overcome and redress

- Community based modules to help create discussion and increase education
- Open dialogue around sexual history and sexual health
- Inviting medical providers to come experience community events
- Support cultural responsive multivariate issues that can look at the interactions of identities





# Three thoughts about prevention stigma

**Sarit A. Golub**, Professor, *Hunter College and the  
Graduate Center of City University of New York*



# 3 thoughts about Prevention Stigma

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1. Traditional prevention language fosters stigmatization.



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2. Reducing prevention stigma requires re-focusing on sexual health (rather than disease).



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1. Traditional prevention language fosters stigmatization.
2. Reducing prevention stigma requires re-focusing on sexual health (rather than disease).
3. PrEP provides an opportunity to reduce HIV prevention stigma.



**Traditional prevention language  
fosters stigmatization.**





# Focusing on "high-risk"...

Life | Fri Jul 11, 2014 3:34am EDT

Related: HEALTH

## Key high-risk HIV groups threaten AIDS progress, warns the WHO

BY STEPHANIE NEBEHAY AND KATE KELLAND



GENEVA/LONDON - Five key groups, including gay men, prostitutes and prisoners, have stubbornly high rates of HIV that are threatening progress in the global AIDS battle, the World Health Organisation (WHO) said on Friday.

These people are most at risk of becoming infected with the human immunodeficiency virus that causes AIDS, yet are least likely to get HIV prevention, testing and treatment services, the Geneva-based United Nations health agency said.

"Globally we are failing certain populations that have the greatest risk yet we know have universally poorer access to health services. These are men who have sex with men, sex workers, transgender persons, specifically transgender women, persons who inject drugs and persons who are in prisons or other closed settings," Gottfried Himschall, director of the WHO's department, told reporters at a briefing.



Putting growth ahead of gripes

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## Obama shifts AIDS strategy to high-risk groups

HEALTH POLICY Obama turns focus to high-risk groups - but initiative lacks increased funding

Andrew Aghward, Chronicle Washington Bureau Published 4:00 am, Wednesday, July 14, 2010



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On World Chocolate Day.

CDC Recommends Anti-HIV Pill for High-Risk Groups

Denver Nicks @DenverNicks May 14, 2014

The daily medication, sold in generic form as Truvada, could transform AIDS prevention in America. If taken regularly, the drug can reduce risk of infection in high-risk populations by up to 92%, the Centers for Disease Control and Prevention says

The U.S. government has recommended that hundreds of thousands of people at risk for

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Against All Odds: What Are Your Chances of Getting HIV in These Scenarios?

Music Industry Insider David Russell on Living With HIV

Positive on PrEP

What Is Chronic Inflammation and Why Is It Such a Big Deal for People With HIV?

POZ

People With HIV and Other High-Risk Groups Should Test for Syphilis Quarterly

June 13, 2016

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SHARE 3 COMMENTS

People at high risk of syphilis, including men who have sex with men (MSM) and people with HIV, should get tested for the sexually transmitted infection (STI) every three months, USA Today reports. This is according to revised syphilis screening

# Focusing on “high-risk”...

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- No one self-identifies as high-risk, and using this language may make people less likely to seek services.
- Describing groups with higher incidence rates as “higher-risk” is inaccurate.
- Calling all condomless sex “high-risk” pathologizes normal, healthy sexuality.



# Focusing on “high-risk”...

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“...when gay men engage in the act of intercourse without a barrier we label it psychotic barebacking, but when straight people do it we call it sex.”

-- Mark King (2013), *Your mother liked it bareback*



# Focusing on inevitability...



THE DAILY BEAST | POLITICS | ENTERTAINMENT | WORLD | U.S. NEWS | TECH + HEALTH | BEASTSTYLE | VIDEO | GET OUT OF TOWN

EPIDEMIC | 02.23.16 12:00 PM ET

## CDC: Half of Gay Black Men Will Get HIV

For the first time ever, federal officials estimated how likely blacks and Hispanics are likely to be diagnosed with the virus that causes AIDS.

Half of gay and bisexual black men and a quarter of gay and bisexual Hispanic men will be diagnosed with HIV in their lifetime, according to a new study from the Centers for Disease Control and Prevention.

SAMANTHA ALLEN

# THINK AGAIN

[www.gmfa.org.uk/thinkagainHIV](http://www.gmfa.org.uk/thinkagainHIV)

Know the Facts. Use Condoms. Test for HIV.

The image shows a young man with a beard and a red beanie, wearing a patterned sweater, holding a white sign that reads "I'm too young to get HIV". To his right, a hand holds a purple sign with the same text. The background is a blurred indoor setting.

I guess, the stress is really from like the marketing materials that are out there. So in Atlantic terminal right now ...it's a really nice marketing campaign encouraging people in my demographic to become better agents of their health for themselves and for their community. So when I see these marketing messages, I'm thinking 'Wow, like everybody that's black and gay and young is HIV positive. **So it's just a matter of time before I become HIV positive.**' And even if I am not doing, even if, even times when like I'm not sexually active, that marketing message still penetrates my consciousness...in that realm of your life you can't even, **I just feel like you can't escape the anxiety.**

-- *"Michael," a 27 year old Black gay man from Brooklyn*

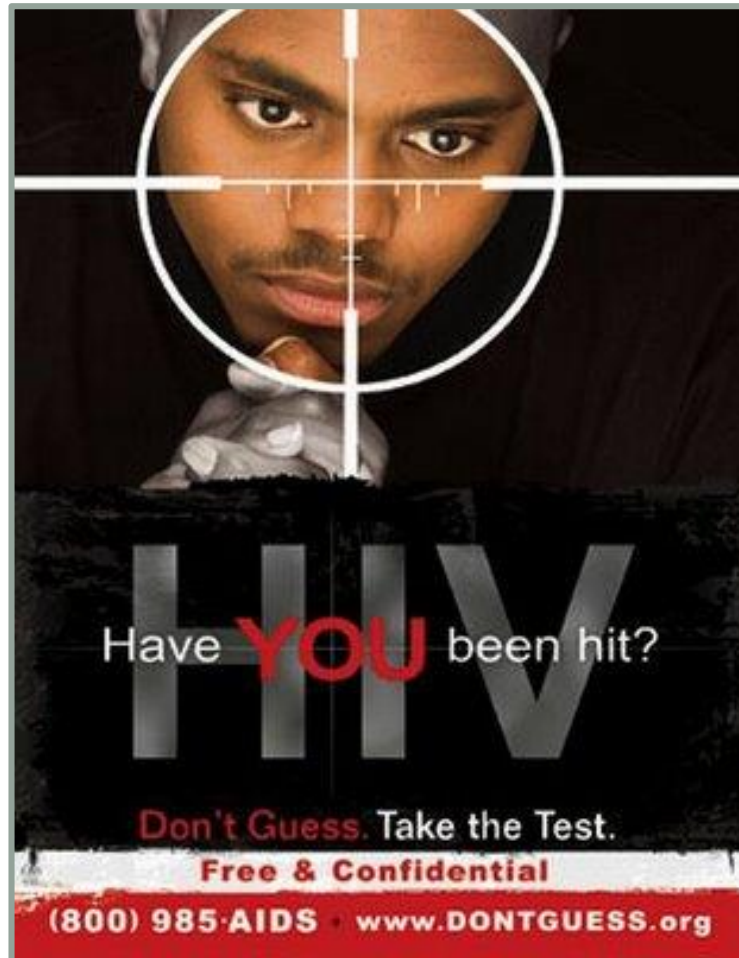


# Focusing on mistrust...



# Focusing on “targeting”...

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**Reducing prevention stigma  
requires focusing on sexual  
health (rather than disease).**



# *What's the difference between **risk assessment** and **sexual history**?*

Choosing PrEP vs. being  
identified as a PrEP “candidate”



Self-Fulfilling Prophecy

PrEP as a vehicle for being the  
sexual person you want to be



# Focusing on “theme” not plot...

---

## *How would you describe your ideal sex life?*

“To be honest, my ideal sex life would be with no condoms, but you can never really say that because people freak out”

## *My ideal sex life would be...*

A monogamous,  
loving partner  
55%

Full of pleasure and  
fulfillment  
48%

Freedom from  
anxiety and guilt  
48%

# Reported benefits of PrEP...

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“I feel good. It's like an extra layer of protection.”

“Feeling more comfortable and free during sex and in life.”

“Less shame about my sexual habits.”

“It's made me more health conscious in general.”

“Opens up doors to date HIV+ w/out same kind of worry ”

***“Let me tell you about why people like you choose to engage in HIV prevention...”***



“Being on PrEP reduced/eliminated anxiety that I had regarding contracting HIV, and made me a lot more knowledgeable about the experiences of people living with HIV (and the risk they pose to HIV- people). I definitely underestimated the effects that this type of anxiety had had on me in my adult life. Remaining on PrEP was a no-brainer when I realized how much better I felt mental health-wise about health, sex and sexuality.

-- “Ruben,” a 25 year old Latino man who has been on PrEP for 12 months

PrEP

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ONCE A DAY.  
Protect against HIV.

[PrEP4love.com](http://PrEP4love.com)

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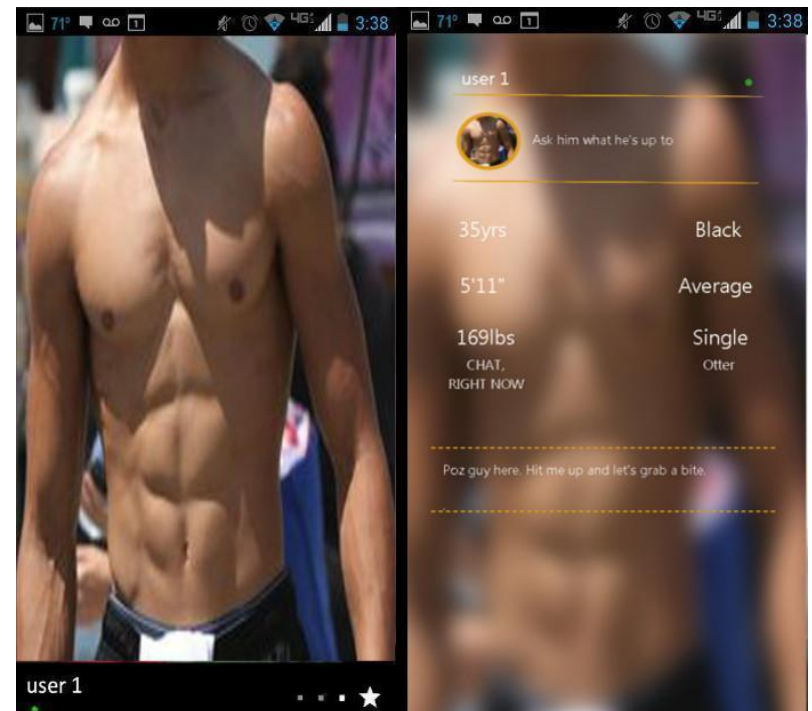
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**PrEP provides an opportunity to  
reduce prevention stigma**



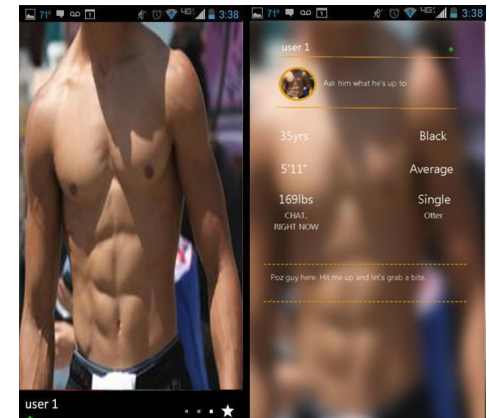
# Experimental Study of Implicit Stigma

- Created simulated Grindr profiles
- Profiles included one of four “stats”
  - HIV-negative (date)
  - Poz, undetectable
  - Like to parTy?
  - On PrEP
- Rated on
  - Attractiveness
  - Desirability
  - Trustworthiness
  - Risk



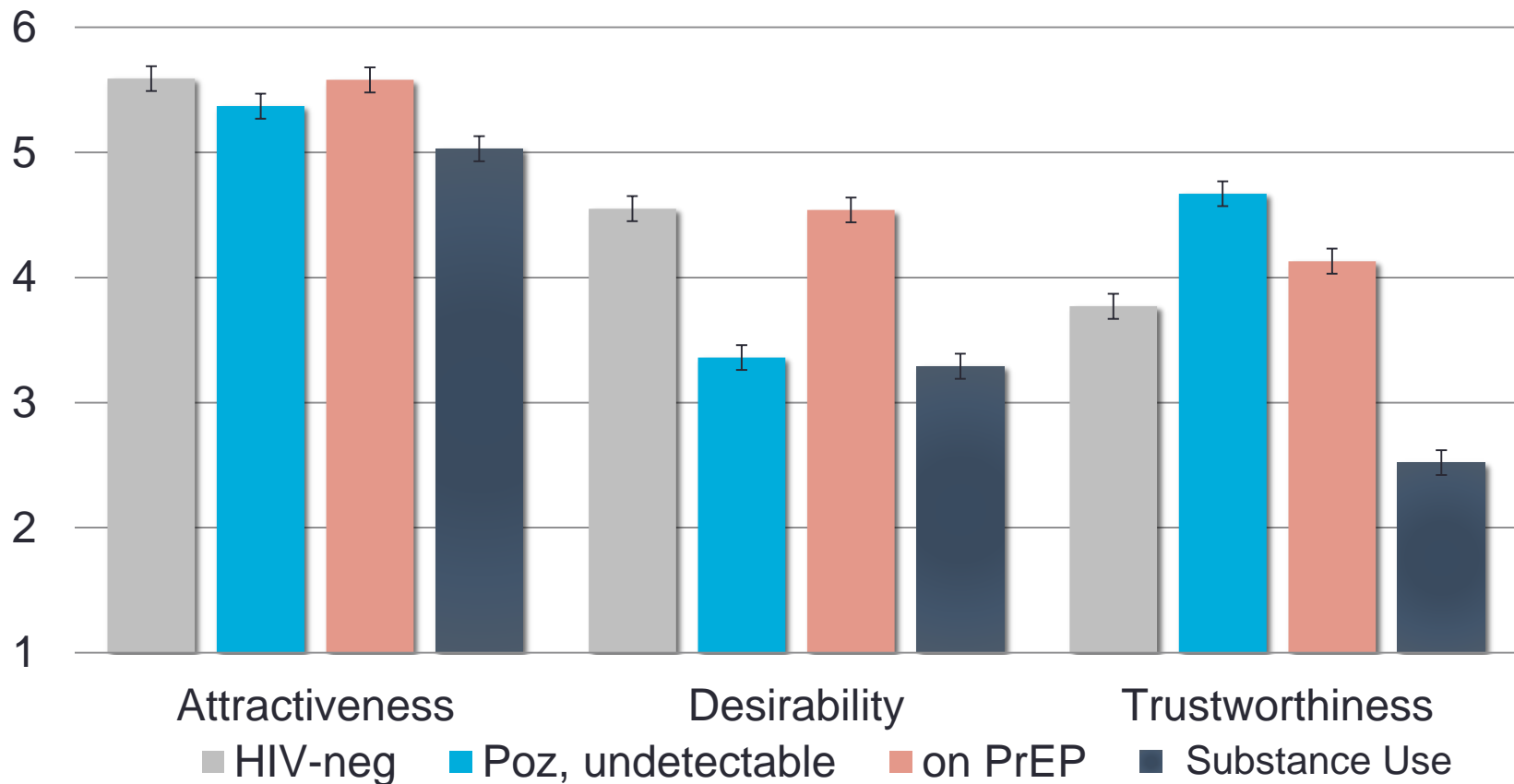
# Experimental Study of Implicit Stigma

- Pre-tested 16 images without any of the “stats”
- Chose #5-8 (mean = 6.5/10)
- Recruited with pop-up ad on Grindr
- All participants saw and rated four profiles
- Different participants saw different profiles matched with different stats
- Photos and stats were provided in a random order



# Experimental Study of Implicit Stigma

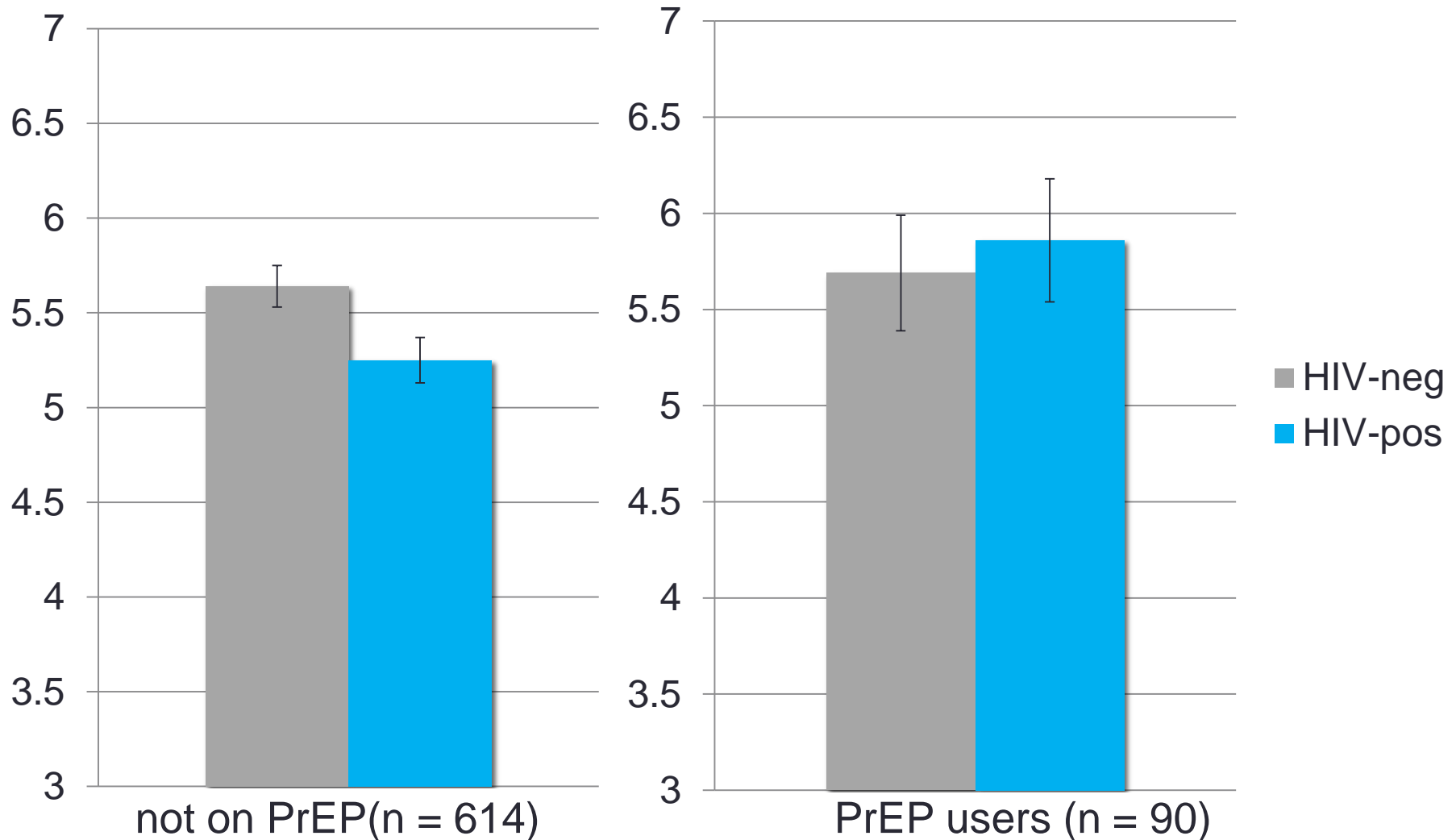
*Overall, HIV+ profiles were rated as less attractive and less desirable...*





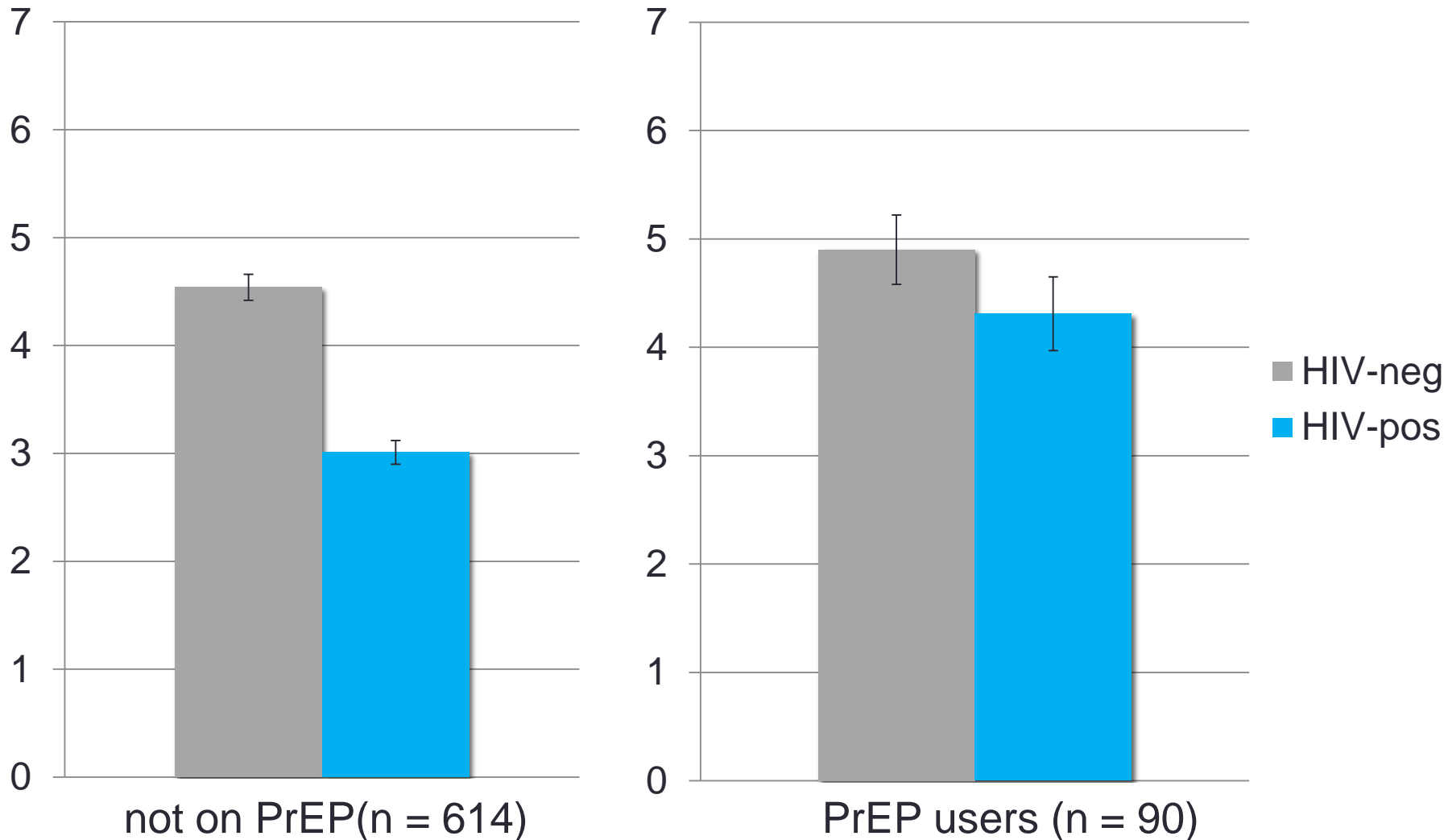
# Attractiveness Ratings

*But for PrEP users, this difference went away completely...*



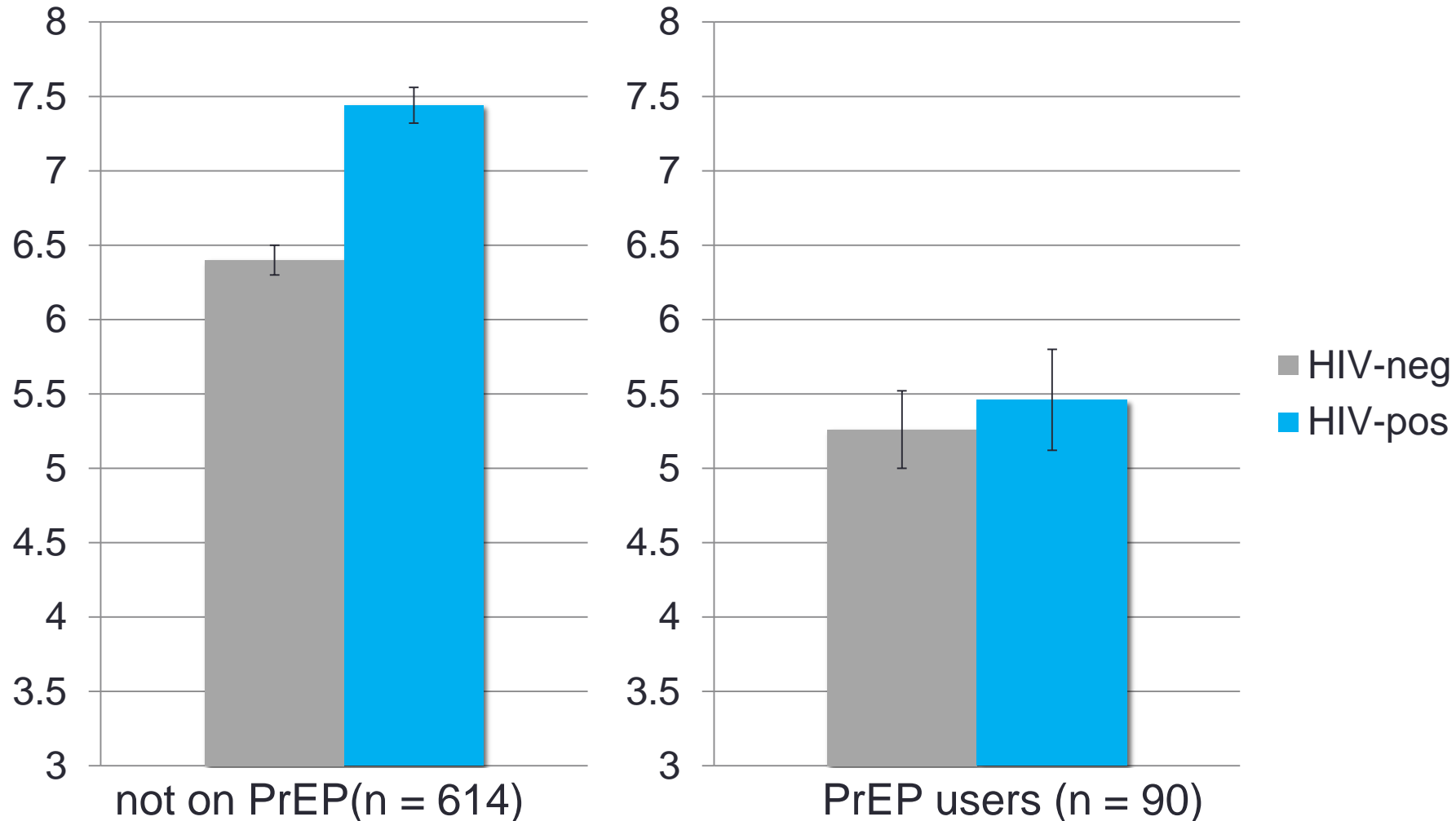
# Desirability Ratings

*But for PrEP users, this difference went away completely...*



# Riskiness Ratings

*PrEP users rated sex as less risky overall  
and their ratings of risk did not differ by HIV-status*



# Stigma-Related Benefits of PrEP

---

“I’m open to dating HIV+ guys, whereas before I wasn’t.”

“”It opens up doors to date HIV+ guys without the same kind of worry.”

“I got over the stigma of sex with HIV+ guys and had a really fun sexual encounter with one.”

# 3 thoughts about Prevention Stigma

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1. Traditional prevention language fosters stigmatization.
2. Reducing prevention stigma requires re-focusing on sexual health (rather than disease).
3. PrEP provides an opportunity to reduce HIV prevention stigma.



“You will be sorry if you do not do what you should do. You can’t carry on like this, it is not right, you will find out soon enough, everything you do matters too much.”

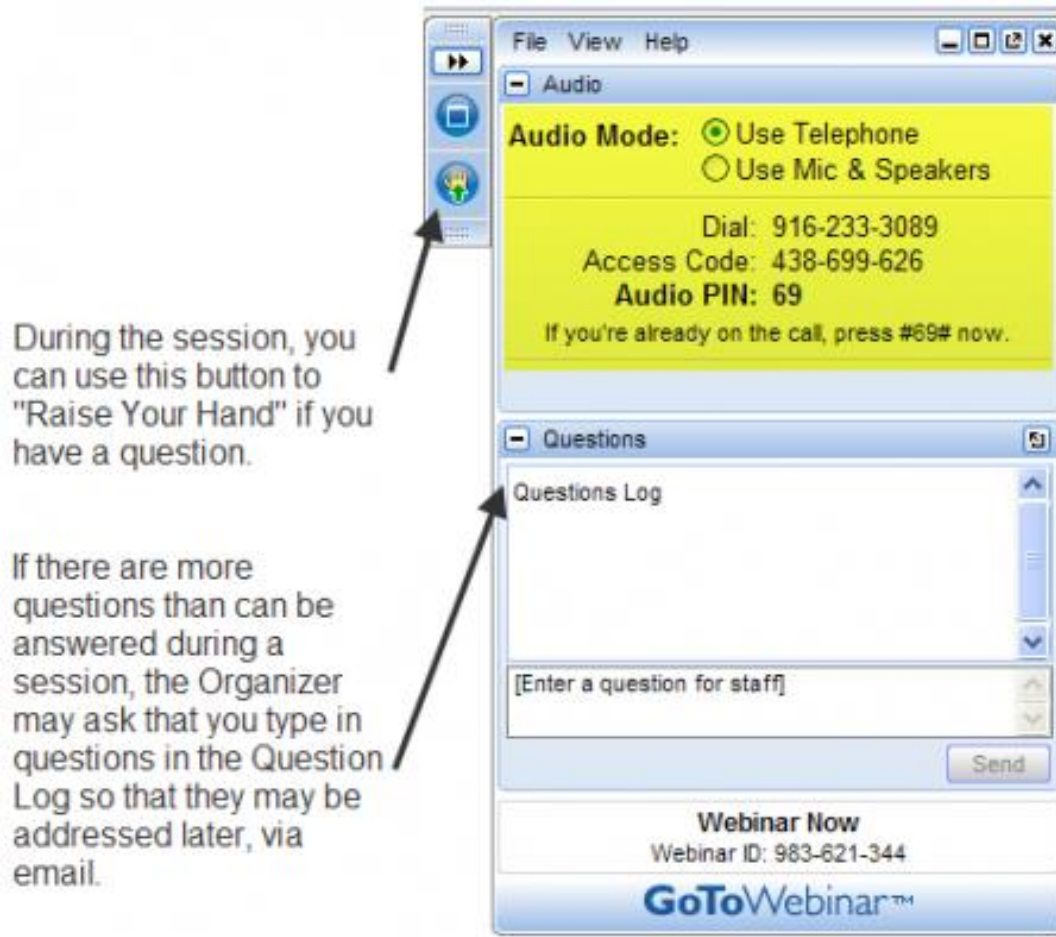
-- Delmore Schwartz  
*In Dreams Begin Responsibilities*





# Questions?

- You may also email your questions to [mboykin@aidschicago.org](mailto:mboykin@aidschicago.org)



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# Stay Informed, Visit & Connect:

- **Treatment Action Group**
  - Jeremiah Johnson, HIV Prevention Research and Policy Coordinator
  - Email: [jeremiah.johnson@treatmentactiongroup.org](mailto:jeremiah.johnson@treatmentactiongroup.org)
  - Web: <http://www.treatmentactiongroup.org/>
  - Twitter: @TAGTeam\_Tweets
- **National Minority AIDS Council**
  - Matthew Rose, Policy Associate
  - Email: [mrose@nmac.org](mailto:mrose@nmac.org)
  - Web: <http://nmac.org/>
  - Twitter: @NMACCommunity
- **Hunter College and the Graduate Center of City University of New York**
  - Sarit A. Golub, Professor
  - Email: [sgolub@hunter.cuny.edu](mailto:sgolub@hunter.cuny.edu)
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