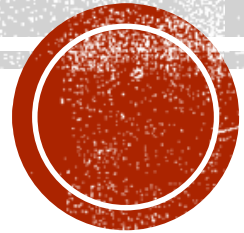
THE LANDSCAPE OF ADOLESCENT HIV INFECTION IN THE U.S., ADDRESSING STIGMA, BIAS AND CULTURAL HUMILITY



Molly McHenry FNP
Adolescent HIV Prevention ECHO
May 7, 2019

OBJECTIVES

- 1) Describe the contributing factors to the disproportionate impact of HIV in the Southeast to LGBTQ populations and unique risks for adolescents.
- 2) Examine the impact of HIV and LGBTQ stigma in my community and the role of my organization in responding to this.
- 3) Assess the impact of my personal values and biases on my ability to provide high quality and appropriate care to reduce HIV and STDs in adolescents who identify as LGBTQ.

TOPICS

- Intersectionality
- Role of stigma
- Implicit bias
- Cultural humility
- Terms
- HIV overview
- Prep overview

Intersectionality:

The interconnected nature of social categorizations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage.

DEGRAFFENREID V. GENERAL MOTORS 1976

- Sex based vs. race based discrimination
- Black men were being hired on the factory floor
- White women were being hired as secretaries
- Black women were "last hired, first fired"
- This case begs the question: Is discrimination compound?
- The case was dismissed….

INTERSECTIONAL THEORY

Kimberlé Williams Crenshaw, a civil rights advocate and scholar, is known for introduction and development of intersectional theory

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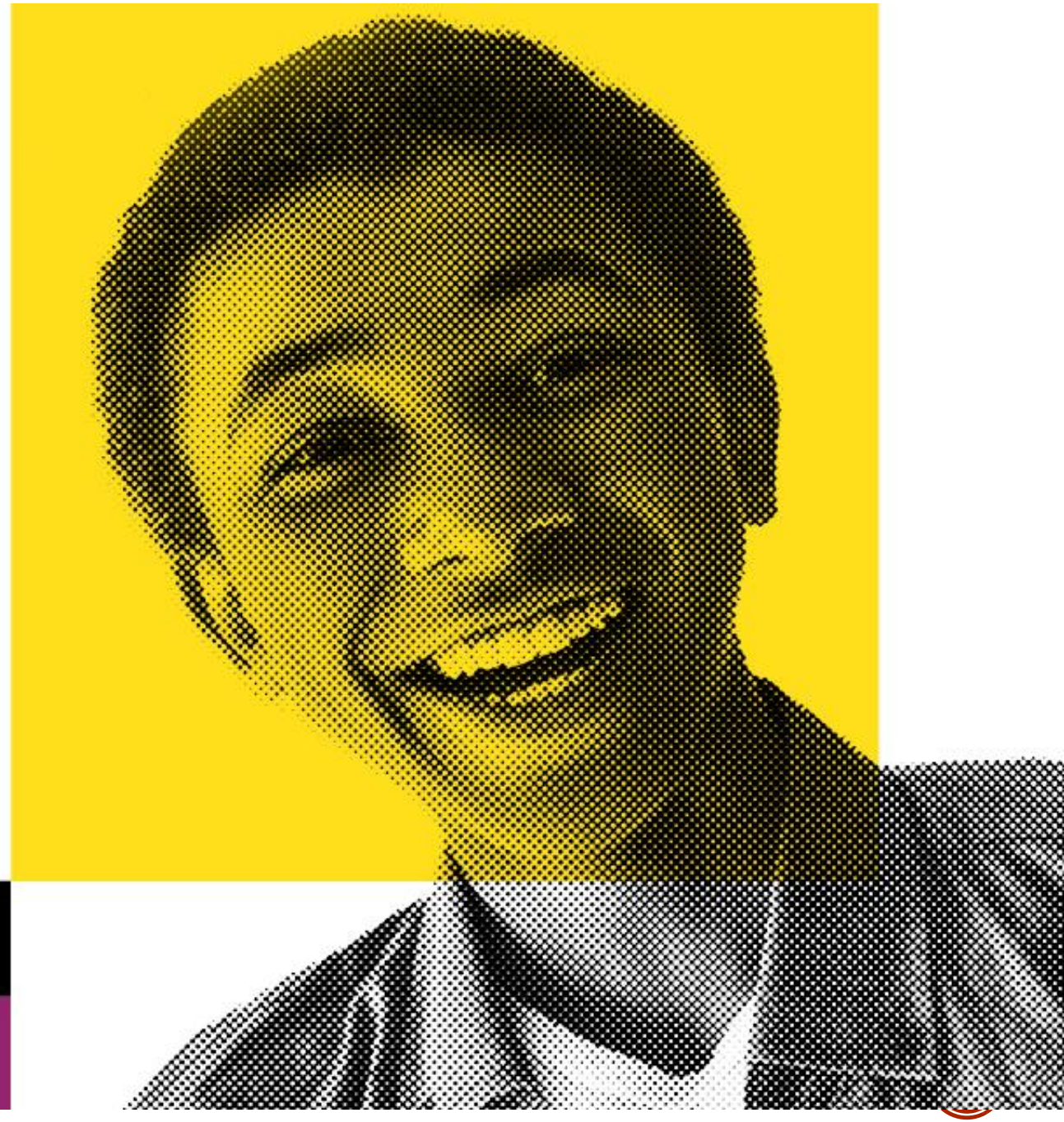
HUMAN RIGHTS CAMPAIGN FOUNDATION

2019 Black & African American LGBTQ YOUTH REPORT



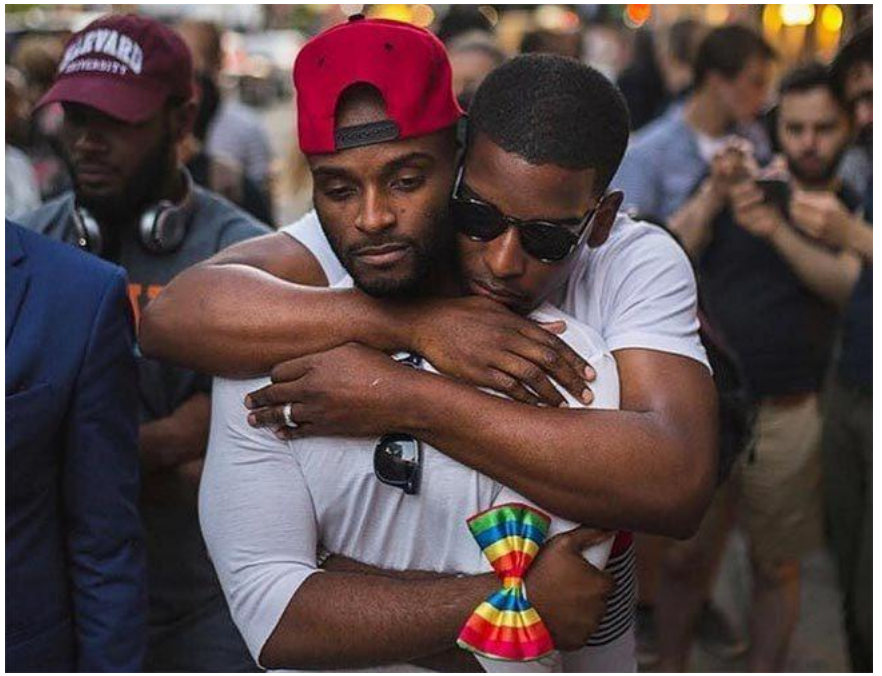
Eighty percent "usually" feel depressed, down, worried, nervous or panicked. **Nearly half** feel critical of their LGBTQ identities.

Sixty-seven percent of respondents -- and **82 percent** of transgender and gender-expansive youth -- have been verbally insulted because of their LGBTQ identity.

Ninety percent of respondents have experienced racial discrimination, and **only five percent** believe Black and African American people are regarded positively in the U.S.

Sixty-three percent of Black and African American transgender and gender-expansive youth try to avoid using the restroom during the school day.

More than three-fourths of Black and African American LGBTQ youth who responded to the survey have heard family members say negative things about LGBTQ people, and **nearly half** have been taunted or mocked by family for being LGBTQ.

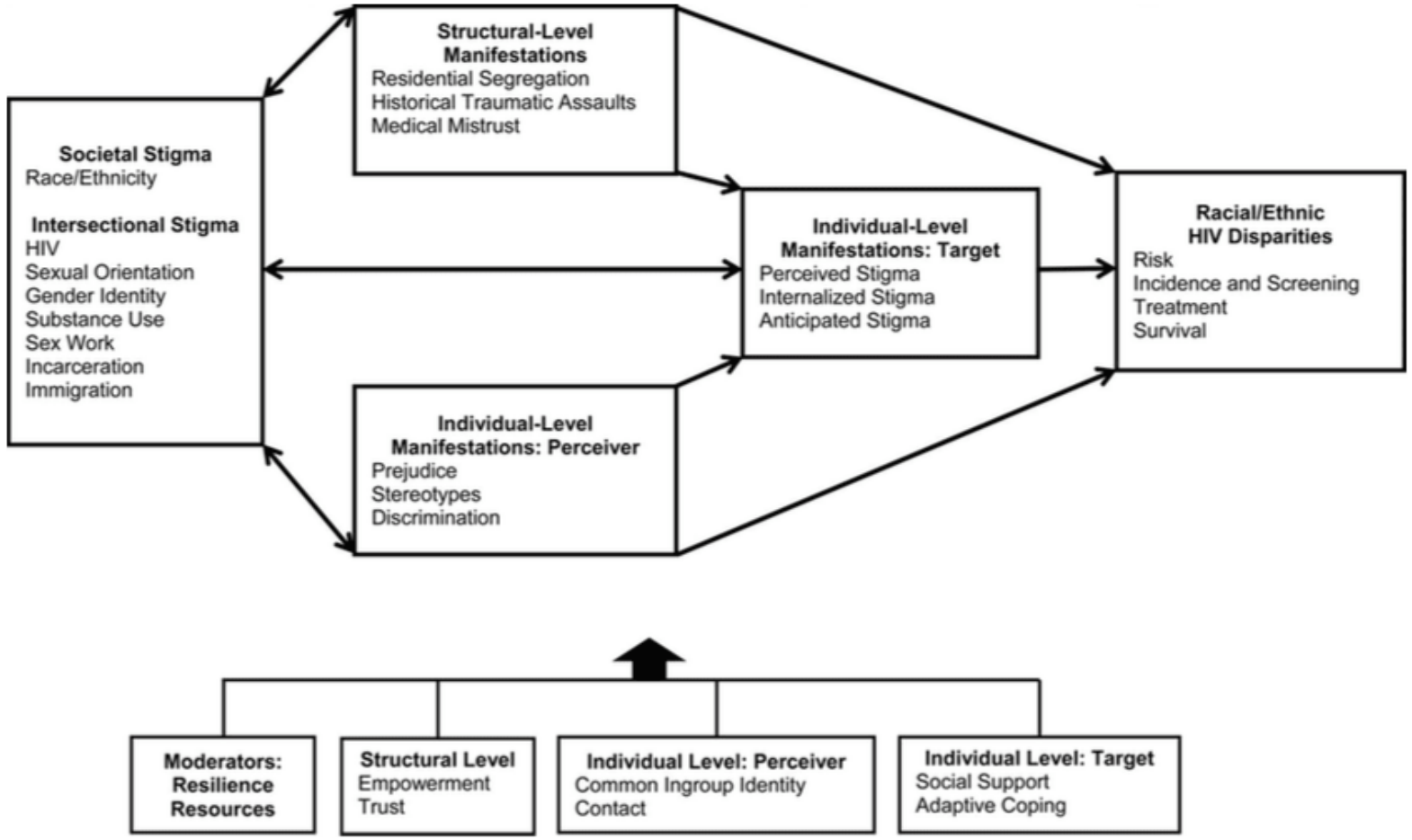


"Messages that reinforce stigma and shame, racist rhetoric from elected officials, and inequitable systems of care complicate the ability of Black and African American LGBTQ youth to fully express and explore their intersecting racial and LGBTQ identities."

-Ellen Kahn, HRC Foundation Director of the Children, Youth & Families Program

STIGMA AND HIV

Figure 1
Stigma and HIV Disparities Model



Earnshaw et al 2013

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Implicit Bias,

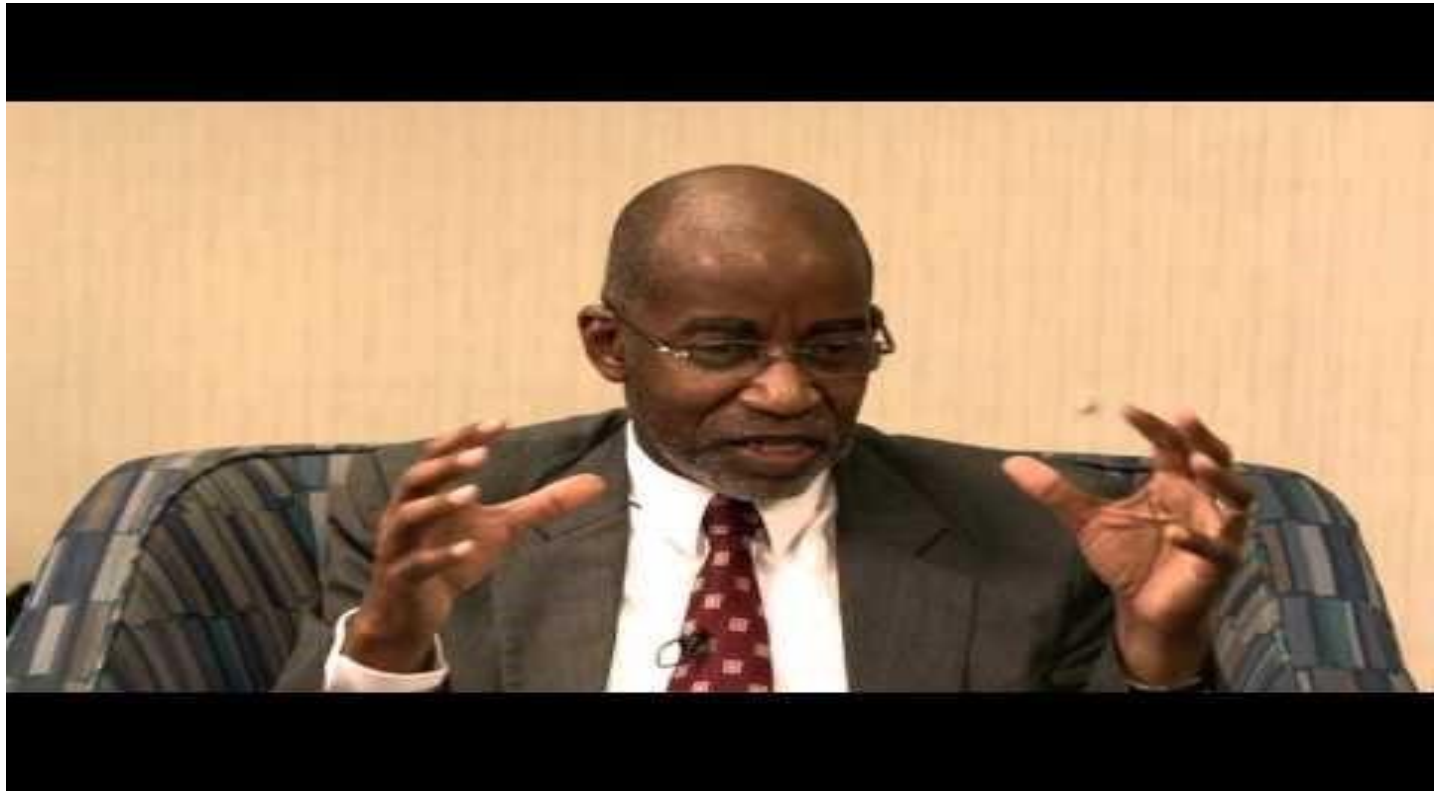
sometimes called unconscious bias, happens when we allow our own attitudes, feelings, stereotypes, or beliefs to impact our judgment or understanding of other people.

What we consciously or subconsciously assume about our patients has an impact on the health care we provide.

Implicit bias may contribute to a health care system that marginalizes and harms individuals and communities by perpetuating systems of oppression through racism, homophobia, transphobia etc.

THIS MEANS US

HOW CAN PROVIDERS REDUCE UNCONSCIOUS BIAS?



Source: IHI: Institute for Healthcare Improvement
http://www.ihi.org/education/IHIOpenSchool/resources/Pages/AudioandVideo/David-Williams-Don-Berwick-How-Can-Providers-Reduce-Unconscious-Bias.aspx

COMMUNITIES MARGINALIZED BY HEALTH CARE

- Disabled people
- People of color
- Indigenous/first nations people
- LGBTQ
- Undocumented
- Incarcerated
- Women

Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites

PNAS April 19, 2016 vol 113 no 16 p 4296-4301

Item	General	1st year	2nd year	3rd year	Residents
Blacks age more slowly than white	23	21	28	12	14
Blacks' nerve endings are less sensitive than whites'	20	8	14	0	4
Black people's blood coagulates more quickly than whites	39	29	17	3	4
Whites have larger brains than blacks	12	2	1	0	0
Whites have a better sense of hearing than blacks	10	3	7	0	0
Blacks' skin is thicker than whites	58	40	42	22	25
Blacks have a more sensitive sense of smell than whites	20	10	18	3	7
Whites have a more efficient respiratory system than blacks	16	8	3	2	4
Black couples are significantly more fertile than white couples	17	10	15	2	7
Blacks are better at detecting movement than whites	18	14	15	5	11
Blacks have stronger immune systems than whites	14	21	15	3	4

Percentage of white participants endorsing beliefs about biological differences between blacks and whites. (Courtesy of PNAS/Hoffman et al)

"What we found is those who endorsed more of those false beliefs showed more bias and were less accurate in their treatment recommendations," Hoffman said.

- "Tuskegee Study of Untreated Syphilis in the Negro Male" 1932-1972*

The New York Times

Syphilis Victims in U.S. Study Went Untreated for 40 Years

By JEAN HELLER
The Associated Press

WASHINGTON, July 25—For 40 years the United States Public Health Service has conducted a study in which human beings with syphilis, who were induced to serve as guinea pigs, have gone without medical treatment for the disease and a few have died of its late effects, even though an effective therapy was eventually discovered.

The study was conducted to determine from autopsies what the disease does to the human body.

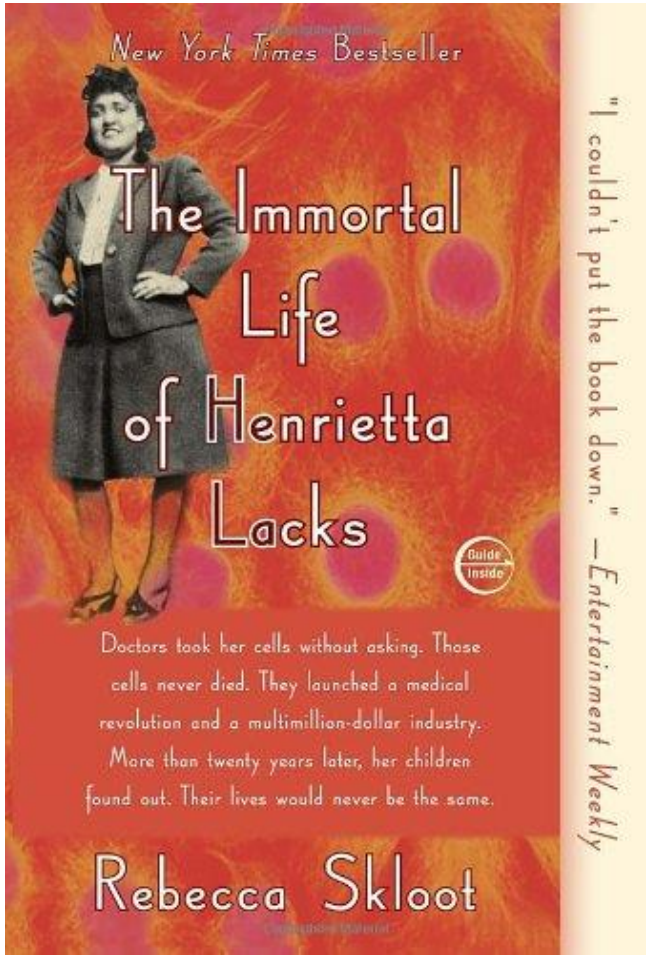
Officials of the health service who initiated the experiment have long since retired. Current officials, who say they have serious doubts about the morality of the study, also say that it is too late to treat the syphilis in any surviving participants.

Doctors in the service say they are now rendering whatever other medical services they can give to the survivors while the study of the disease's effects continues.

Dr. Merlin K. DuVal, Assistant Secretary of Health, Education and Welfare for Health and Scientific Affairs, expressed shock on learning of the study. He said that he was making an immediate investigation.

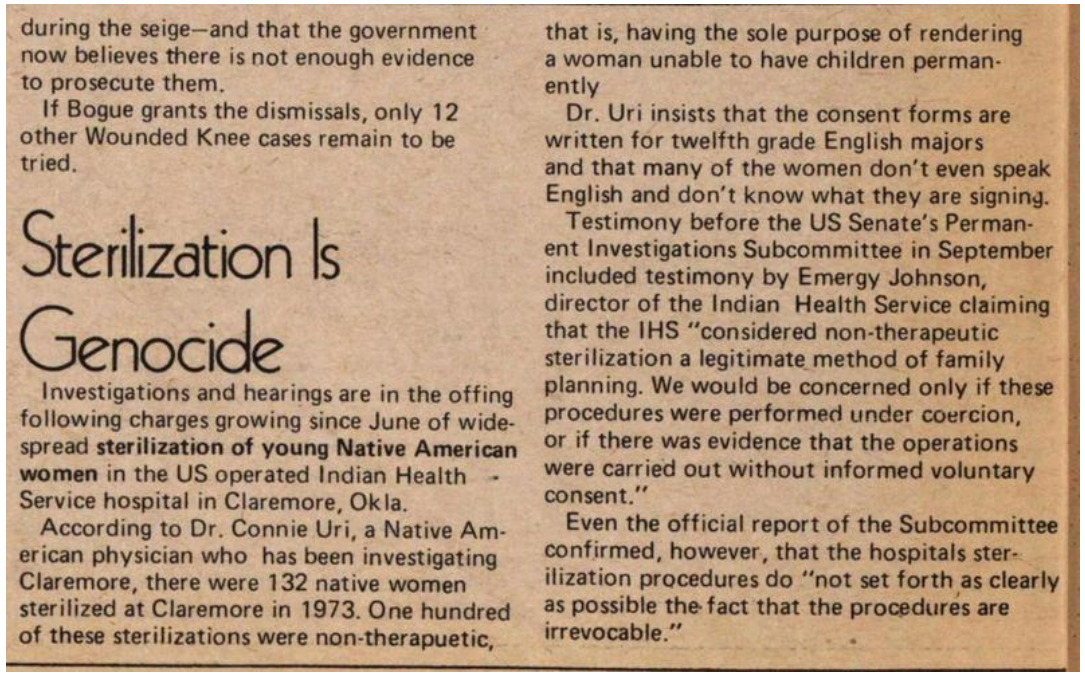
The experiment, called the Tuskegee Study, began in 1932 with about 600 black men,

- HeLa Cells 1951-present **



*US Public Health Service Syphilis Study at Tuskegee
http://www.cdc.gov/tuskegee/timeline.htm
**HeLa Cells: A New Chapter in an Enduring Story
https://directorsblog.nih.gov/2013/08/07/hela-cells-a-new-chapter-in-an-enduring-story/

- Native American/Indigenous People
  - Forced sterilization of native women by US Government 1973-1976*



during the seige—and that the government now believes there is not enough evidence to prosecute them.

If Bogue grants the dismissals, only 12 other Wounded Knee cases remain to be tried.

Sterilization Is Genocide

Investigations and hearings are in the offing following charges growing since June of widespread **sterilization of young Native American women** in the US operated Indian Health Service hospital in Claremore, Okla.

According to Dr. Connie Uri, a Native American physician who has been investigating Claremore, there were 132 native women sterilized at Claremore in 1973. One hundred of these sterilizations were non-therapuetic, that is, having the sole purpose of rendering a woman unable to have children permanently

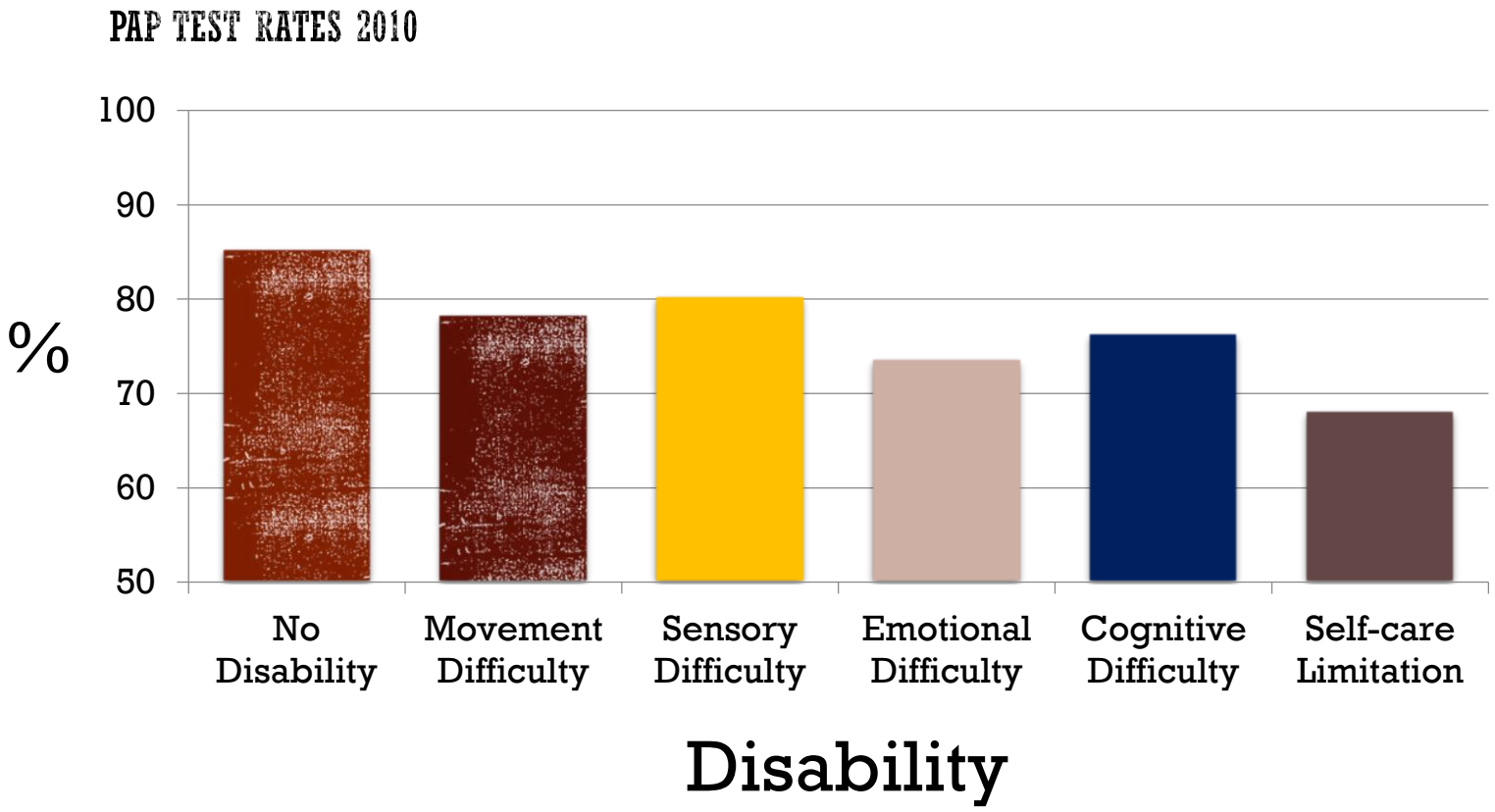
Dr. Uri insists that the consent forms are written for twelfth grade English majors and that many of the women don't even speak English and don't know what they are signing.

Testimony before the US Senate's Permanent Investigations Subcommittee in September included testimony by Emergy Johnson, director of the Indian Health Service claiming that the IHS "considered non-therapeutic sterilization a legitimate method of family planning. We would be concerned only if these procedures were performed under coercion, or if there was evidence that the operations were carried out without informed voluntary consent."

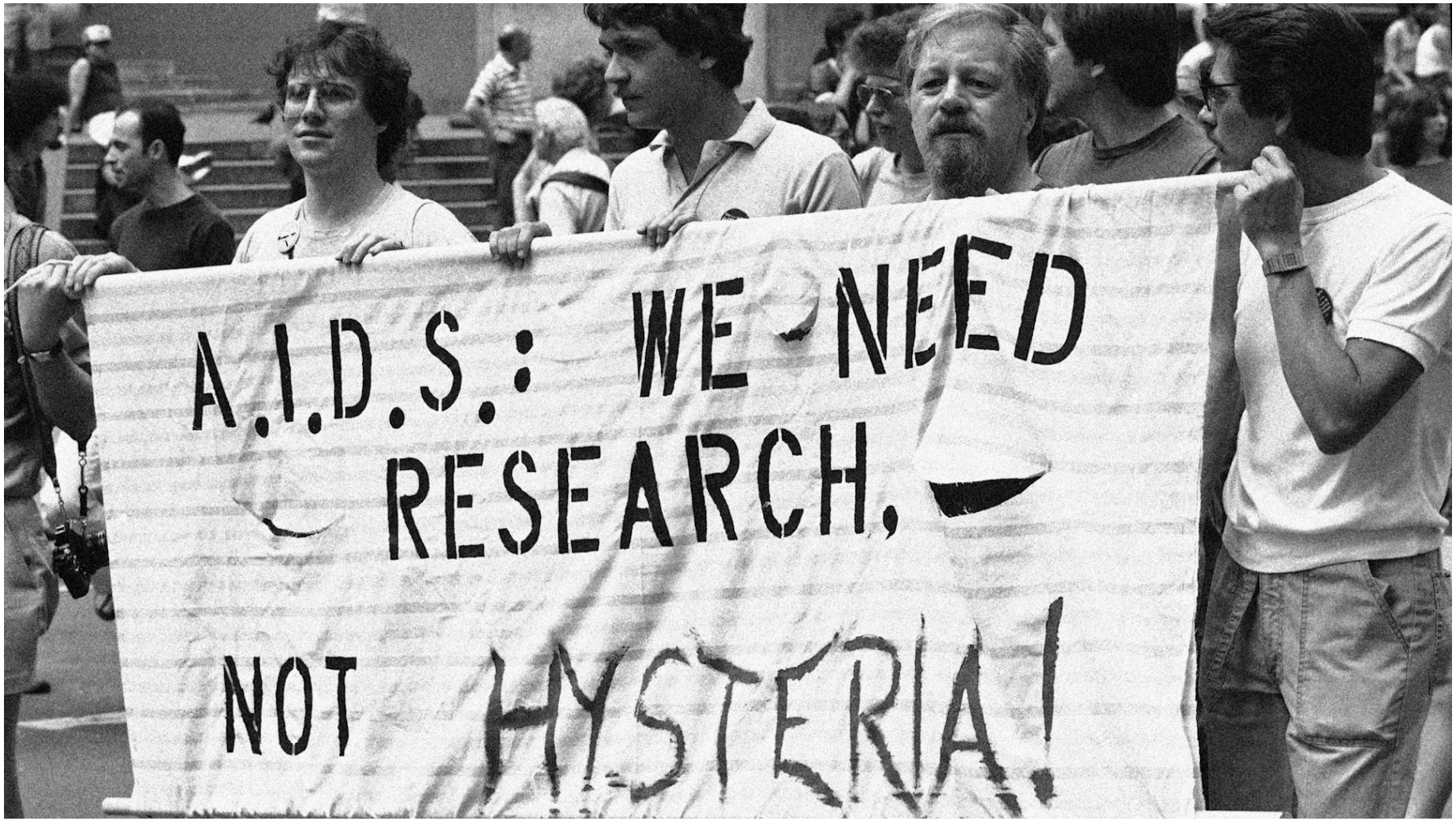
Even the official report of the Subcommittee confirmed, however, that the hospitals sterilization procedures do "not set forth as clearly as possible the fact that the procedures are irrevocable."

*National Library of Medicine: Native Voices
https://www.nlm.nih.gov/nativevoices/timeline/543.html

People With Disabilities



Iezzoni L.I. MD (2016) Make No Assumptions. Used with permission.


A.I.D.S.: WE NEED
RESEARCH,
NOT HYSTERIA!

The New York Times

When Doctors Refuse to Treat AIDS

LEAD: Fear of AIDS has produced its most painful symptom yet: doctors and dentists who refuse to treat patients they believe to be infected with the AIDS virus.

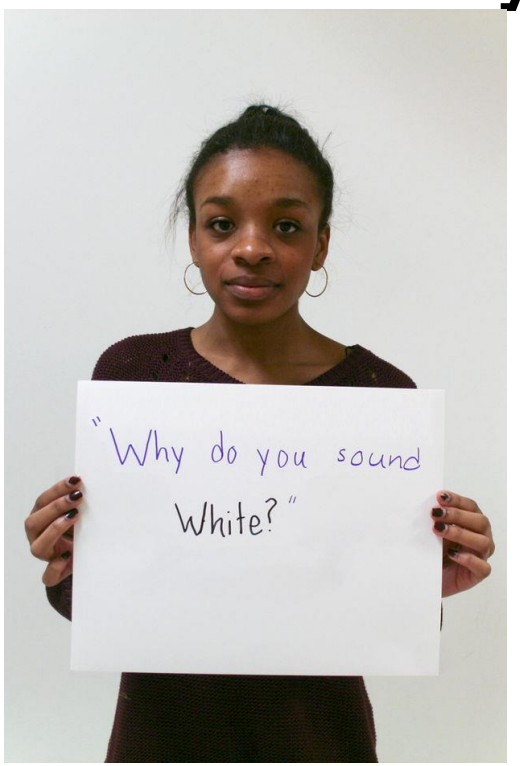
August 3, 1987

A.M.A. Rules That Doctors Are Obligated to Treat AIDS

LEAD: The American Medical Association declared today that doctors had an ethical obligation to care for people with AIDS as well as for those who had been infected with the virus but showed no symptoms.

November 13, 1987

Microaggression: a statement, action, or incident regarded as an instance of indirect, subtle, or unintentional discrimination against members of a marginalized group such as a racial or ethnic minority.



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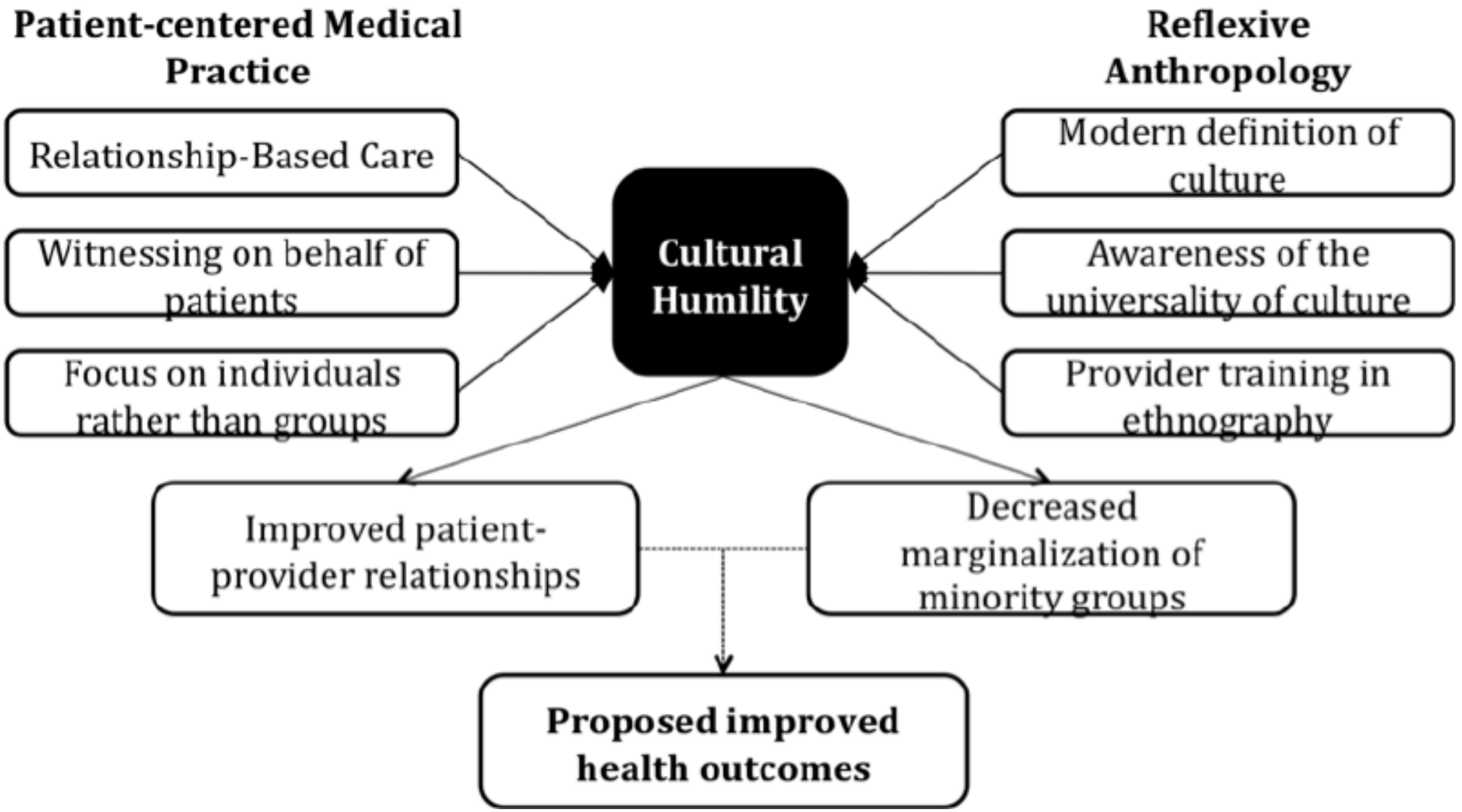
CULTURAL HUMILITY

"It is a process that requires humility…as individuals continually engage in self-reflection and self-critique as lifelong learners and reflective practitioners…to redress power imbalances to develop mutually beneficial non-paternalistic partnerships in care"

(Tercalon & Garcia, 1998, p117)


Patient-centered Medical Practice
Relationship-Based Care
Witnessing on behalf of patients
Focus on individuals rather than groups
Reflexive Anthropology
Modern definition of culture
Awareness of the universality of culture
Provider training in ethnography
Cultural Humility
Improved patient-provider relationships
Decreased marginalization of minority groups
Proposed improved health outcomes

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TERMS TO KNOW

- **Natal/Biologic gender:** Gender assigned at birth; body parts, hormones, biology.
- **Gender Identity:** The understanding of one's self (Female, male, transgender, gender non-conforming, genderqueer, non-binary, gender fluid, cisgender)
- **Gender Expression:** Ways in which a person acts, presents self, and communicates gender within a given culture
- **Gender Non Conforming/non-binary/genderqueer:** A person who views their gender on a spectrum rather than fitting into society's binary categories of male/female.
- **Cisgender:** denoting or relating to a person whose sense of personal identity and gender corresponds with their birth sex
- **Transgender:** denoting or relating to a person whose sense of personal identity and gender does not correspond with their birth sex

TERMS TO KNOW

- **Sexual orientation:** sexual concept of one's self based on feelings, attractions and desires
- **LGBTQ+:** Lesbian, Gay, Bisexual, Transgender, Queer/Questioning
- **Pansexual:** Fluid sexual attraction to people of any sex or gender
- **Asexual or ACE:** A person who does not experience sexual attraction
- **Queer:** An umbrella term that may include the entire LGBT community and also people who fit outside social norms of sexual identity and gender expression; emphasized fluid and experience-based identifies and attractions.
- **Sexual behaviors:** Men who have sex with men (MSM), women who have sex with women (WSW)

TERMS TO UN-KNOW

- Offensive: "homosexual" (n. or adj.)
  Preferred: "gay" (adj.); "gay man" or "lesbian" (n.); "gay person/people"
- Offensive: "homosexual relations/relationship," "homosexual couple," "homosexual sex," etc.
  Preferred: "relationship," "couple" (or, if necessary, "gay couple"), "sex," etc
- Offensive: "sexual preference"
  Preferred: "sexual orientation" or "orientation"
- Offensive: Transvestite- An outdated term that is associated with the medical community's negative view of transgender people and people who "cross-dress".
- Offensive: "Alternative lifestyle"
- **More: https://www.glaad.org/reference/offensive**

REMEMBER…

- Gender identity and sexual orientation are separate and often unrelated.
- Sexual orientation does not always line up with sexual behaviors.

LEARNING TO ADDRESS IMPLICIT BIAS TOWARDS LGBTQ PATIENTS: CASE SCENARIOS

Source: National LGBT Health Education Center

https://www.lgbthealtheducation.org/wp-content/uploads/2018/10/Implicit-Bias-Guide-2018_Final.pdf

CASE 1: LEE

Lee presents to the health center for his annual checkup. The health center includes sexual orientation and gender identity questions on the registration forms. Lee notes that he is "heterosexual/straight" on the intake form. Later, during the exam, the primary care provider asks as part of the sexual history, "Are you using condoms, or comfortable with the idea of a partner getting pregnant?" Lee, who has only had male partners for the past year, answers "I have been sleeping with men lately." The primary care provider then says, "Oh, it says here you are straight. You must have filled out the form incorrectly." Lee responds, "No, I didn't."

What assumption did Lee's primary care provider make?

Why was it incorrect?

Lee's primary care provider assumed Lee identified as gay because he has sex with men. Although we commonly think of people who have same-gender partners as being gay or bisexual, studies have found that at as many as 10% of men who have sex with men may identify as straight.

This apparent discrepancy between behavior and identity could be due to the stigma attached to being gay, and/or to cultural variations in sexual identity. For example, some cultures do not recognize gay identities; some define gay men only as those who appear to act in traditionally feminine ways; and some feel that the term "gay" only applies to white people.

It is also possible that Lee is in the process of coming out, but is not yet ready to identify as gay, bisexual, or another sexual orientation. For this and other reasons, it is important to routinely ask about sexual orientation (and gender identity).

What should Lee's primary care provider have done instead?

The primary care provider should have asked Lee to tell him the gender of his sexual partner(s).

He should not have assumed Lee only had sex with women, even though Lee thinks of himself as heterosexual.

When he hears that Lee has sex with men, it is, however, acceptable for the provider to ask about sexual orientation again, as a way to validate the data. One way to ask would be, “It says in your record that you identify as heterosexual. Is that correct?”

CASE 2: MARLEY

Marley, who identifies as transmasculine, is being prepped for a gynecology exam by a medical assistant. The assistant says to Marley, "Please change into this robe, with the opening in the front. You need to remove your bra and panties because you are due for a breast exam and Pap smear."

What did the medical assistant say that might make Marley feel uneasy?

When the medical assistant referred to a bra, breast exam, and panties, she was using words traditionally associated with female gender.

Some transgender people experience dysphoric feelings about parts of their body that do not align with their gender identity.

Hearing these words can make an already uncomfortable exam even more distressing.

What could the medical assistant have said instead?

Marley would likely feel more respected if the medical assistant used words like underwear and chest that apply to all genders and anatomies.

The medical assistant could have said "The doctor will be performing a chest exam and cancer screening, and asks that you please remove all of your clothes, including any underwear. You should wear the robe with the opening in the front."

In addition, medical providers should ask transgender patients what words the patients use to describe their external and internal organs, and then use those words consistently.

RESOURCES

- The National LGBT Health Education Center - www.lgbthealtheducation.org
- Health Equality Index from the Human Rights Campaign - www.hrc.org/hei
- Center of Excellence for Transgender Health - www.transhealth.ucsf.edu
- World Professional Association for Transgender Health - www.wpath.org
- The Fenway Guide to LGBT Health, 2nd Edition https://store.acponline.org/ebizatpro/Default.aspx?TabID=251&ProductId=21572
- Project Implicit - https://implicit.harvard.edu/implicit/

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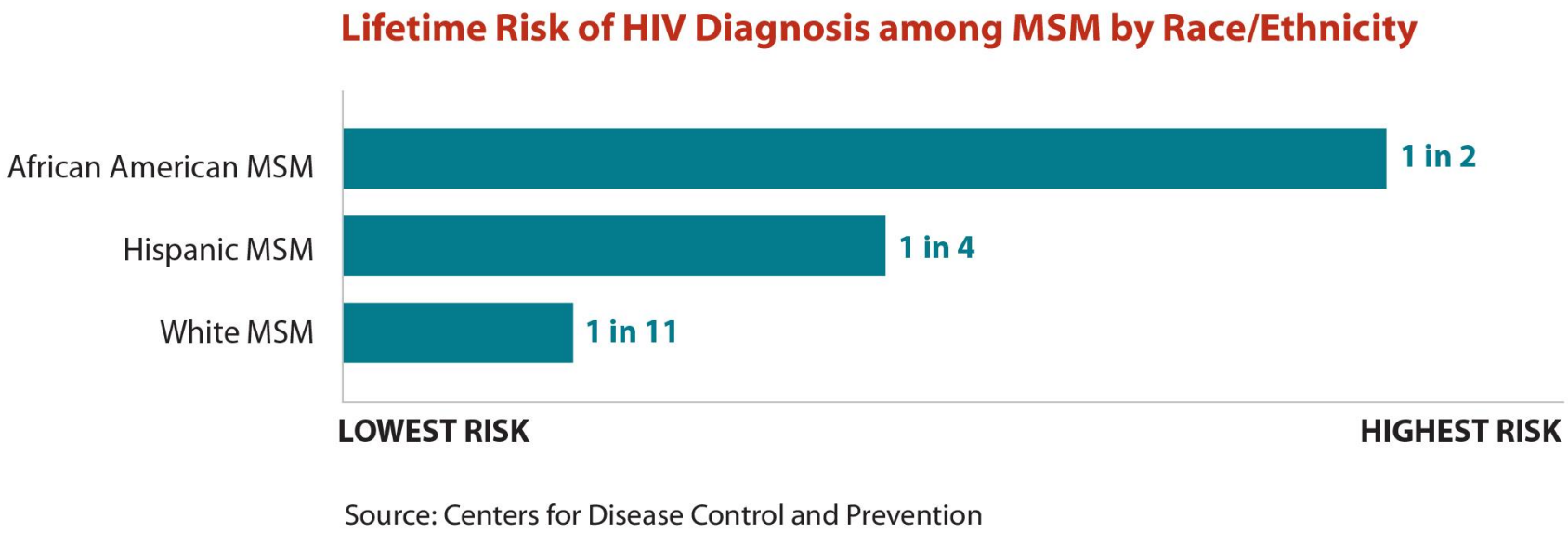


"If we fail to end AIDS in the Black Community…we fail to end AIDS."

-Phil Wilson, President and CEO of the Black AIDS Institute

"I want folks who read the report to walk away knowing that we are not in this epidemic due to our sexual proclivities. This epidemic we are facing is a direct response to systemic issues such as lack of insurance, education, employment, **access to friendly and respectful treatment**, and the list continues."

-Daniel Driffin, co-founder of the Southeast HIV/AIDS Research and Evaluation (SHARE) Project from: "Black gay men reject 'lifetime HIV risk estimate' in new CDC report". *Georgia Voice* February 24, 2016

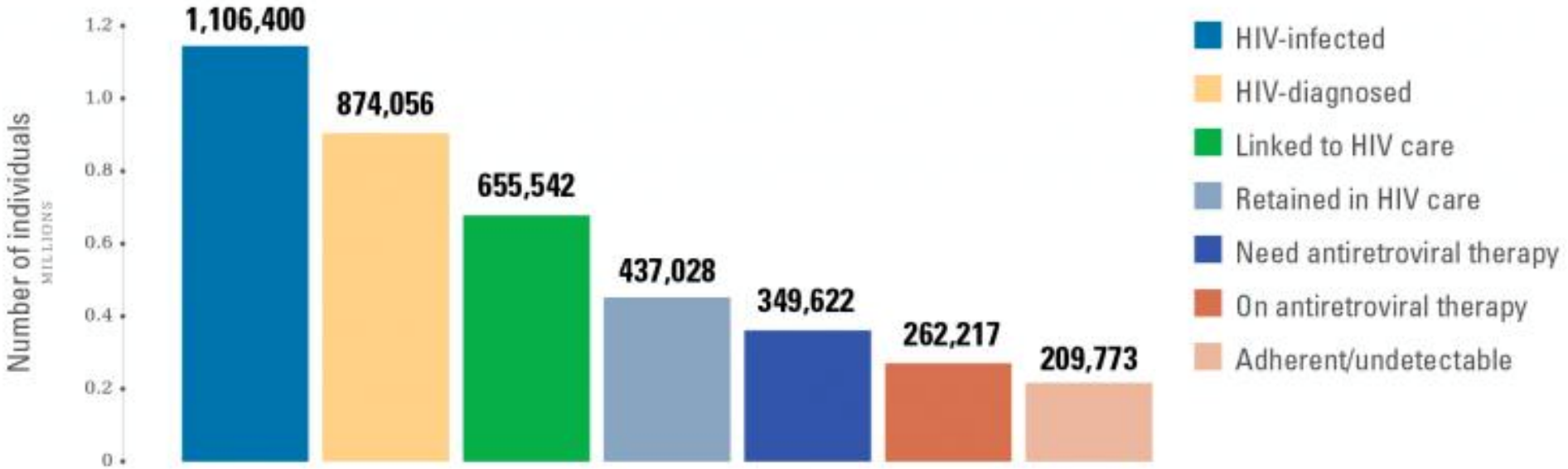
HIV SCREENING REVIEW

- "Opt-Out" as of 2006*
  - Testing should be routine unless patient refuses
  - Pre and post counseling no longer required
- 4th Generation Ag/Ab Testing
  - Rapid vs Serum
- Communication of results
  - In person vs phone or email
- CDC recommends screening:**
  - At least once for all people 13-64 years old
  - All pregnant people
  - At least annually for sexually active MSM

*AIDS.gov "Opt-Out Testing"
https://www.aids.gov/hiv-aids-basics/prevention/hiv-testing/opt-out-testing/
**CDC 2015 STD Treatment Guidelines
http://www.cdc.gov/std/tg2015/screening-recommendations.htm

Estimated Engagement in the HIV Care Cascade in the US

It is estimated that only 19 percent of HIV-positive people in the US have an undetectable viral load. Similar patterns in the care cascade exist around the world.



Source: EM Gardner et al. "The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection," Clin Infect Dis. (2011) 52 (6): 793-800.

AVAC Report 2012: Achieving the End – One Year and Counting, www.avac.org/report2012.

ADULTS AND ADOLESCENTS LIVING WITH DIAGNOSED HIV INFECTION, BY POPULATION OF AREA OF RESIDENCE AND REGION, YEAR-END 2014—UNITED STATES

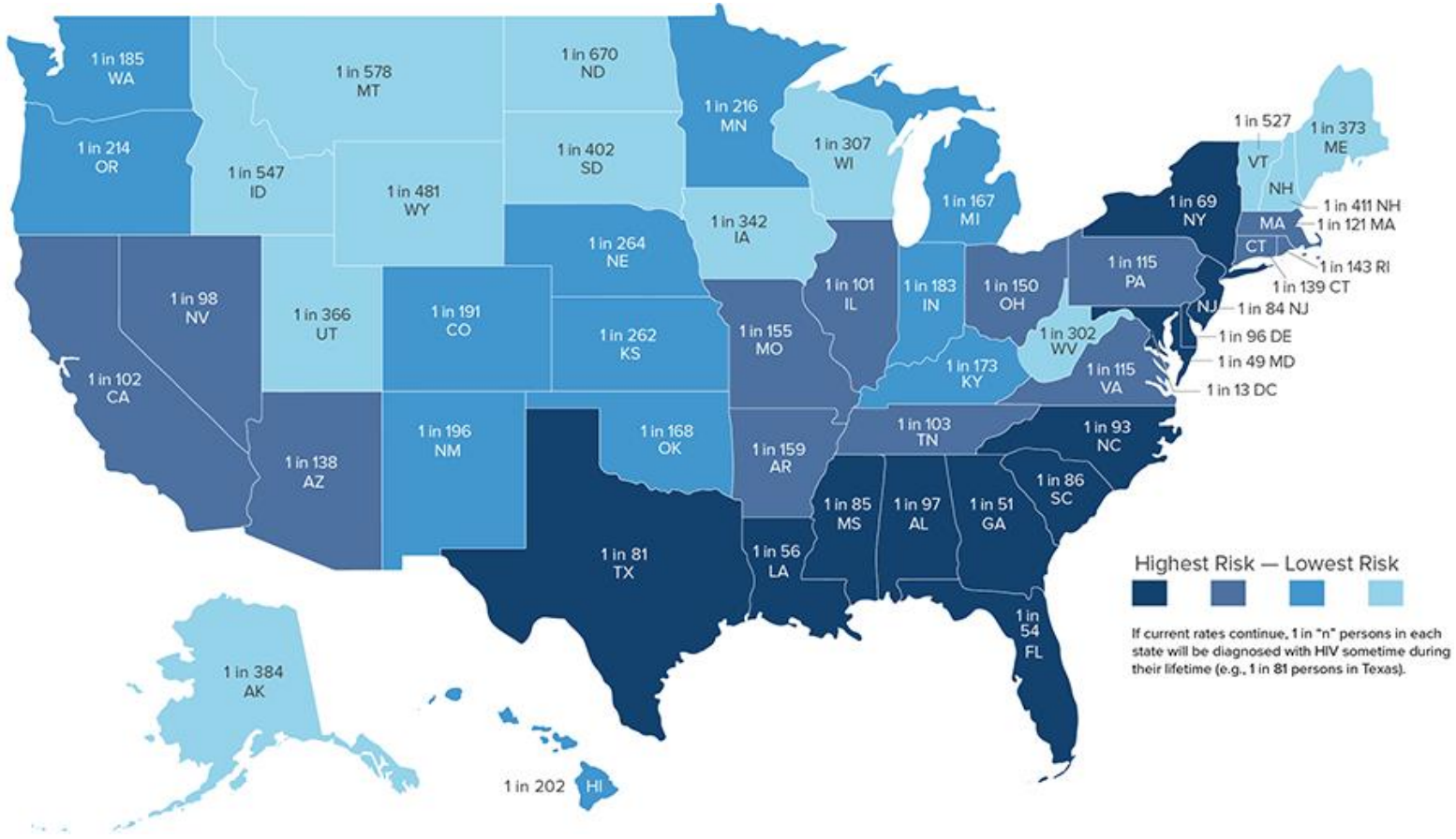
MSA: Metropolitan Statistical Area

Region of residence	MSA of ≥500,000		MSA of 50,000-499,999		Non-metropolitan	
	No.	Rate	No.	Rate	No.	Rate
Northeast N = 224,942	207,655	536.6	11,658	232.3	5,629	141.0
Midwest N = 107,200	85,060	267.6	14,208	117.9	7,932	62.3
South N = 381,718	295,667	475.1	52,807	253.5	33,244	200.7
West N = 179,906	161,542	344.0	13,360	135.8	5,004	90.4

Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data are based on address of residence as of December 31, 2014 (i.e., most recent known address). Data exclude persons whose county of residence is unknown. Rates are per 100,000 population.

HIV in the Southern USA
CDC Issue Brief
May 2016

Diagnosis rates for people in the South are higher than for Americans overall. Eight of the 10 states with the highest rates of new HIV diagnoses are in the South, as are the 10 metropolitan statistical areas (MSAs) with the highest rates.



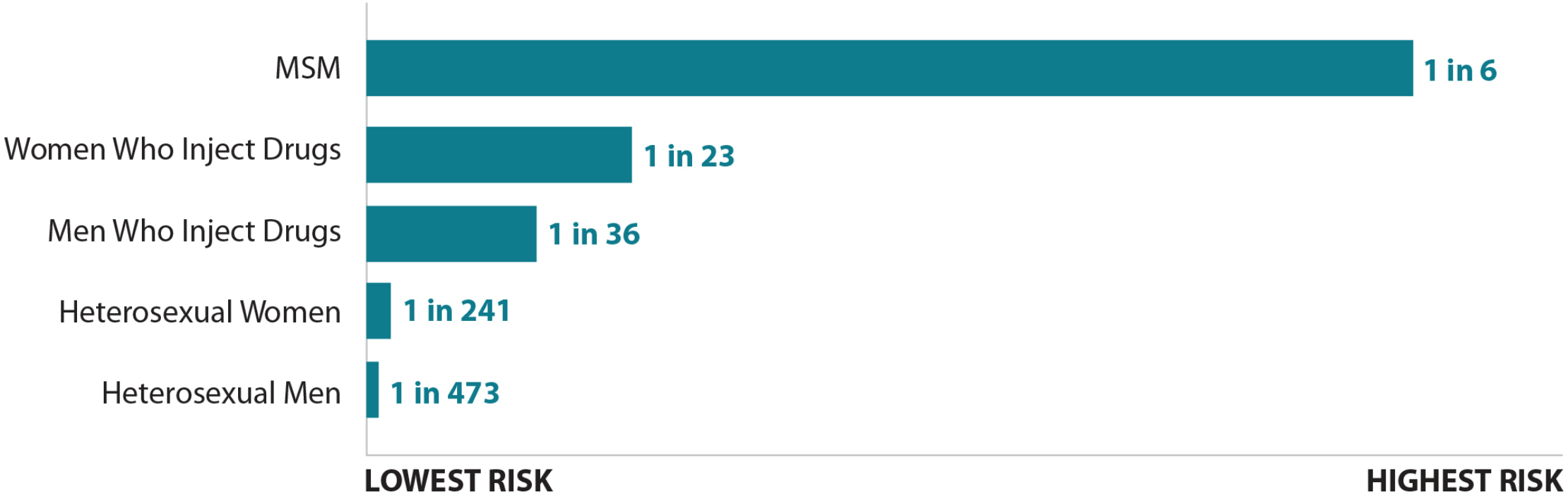
The heavy burden of HIV in the South is driven in part by unique socioeconomic factors. Income inequality, poverty, and poorer health outcomes have long been more widespread in southern states, compared to the rest of the nation.

…and southern states generally continue to have the highest numbers of people without health insurance. The four states with the highest proportions of people without health insurance are in the South: Texas (18.8%), Oklahoma (18.1%), Georgia (17.5%), and Florida (17.2%).

Cultural factors may also play a key role. Issues such as homophobia and transphobia, racism, and general discomfort with public discussion of sexuality may be more widespread in the South and can lead to higher levels of stigma, which may limit people's willingness to seek HIV testing, care, or prevention services.

Another challenge is that southern states have not yet widely adopted new HIV prevention advances, such as antigen/antibody combination HIV tests that can detect infection in its early, or acute, stages when it is most easily transmitted.

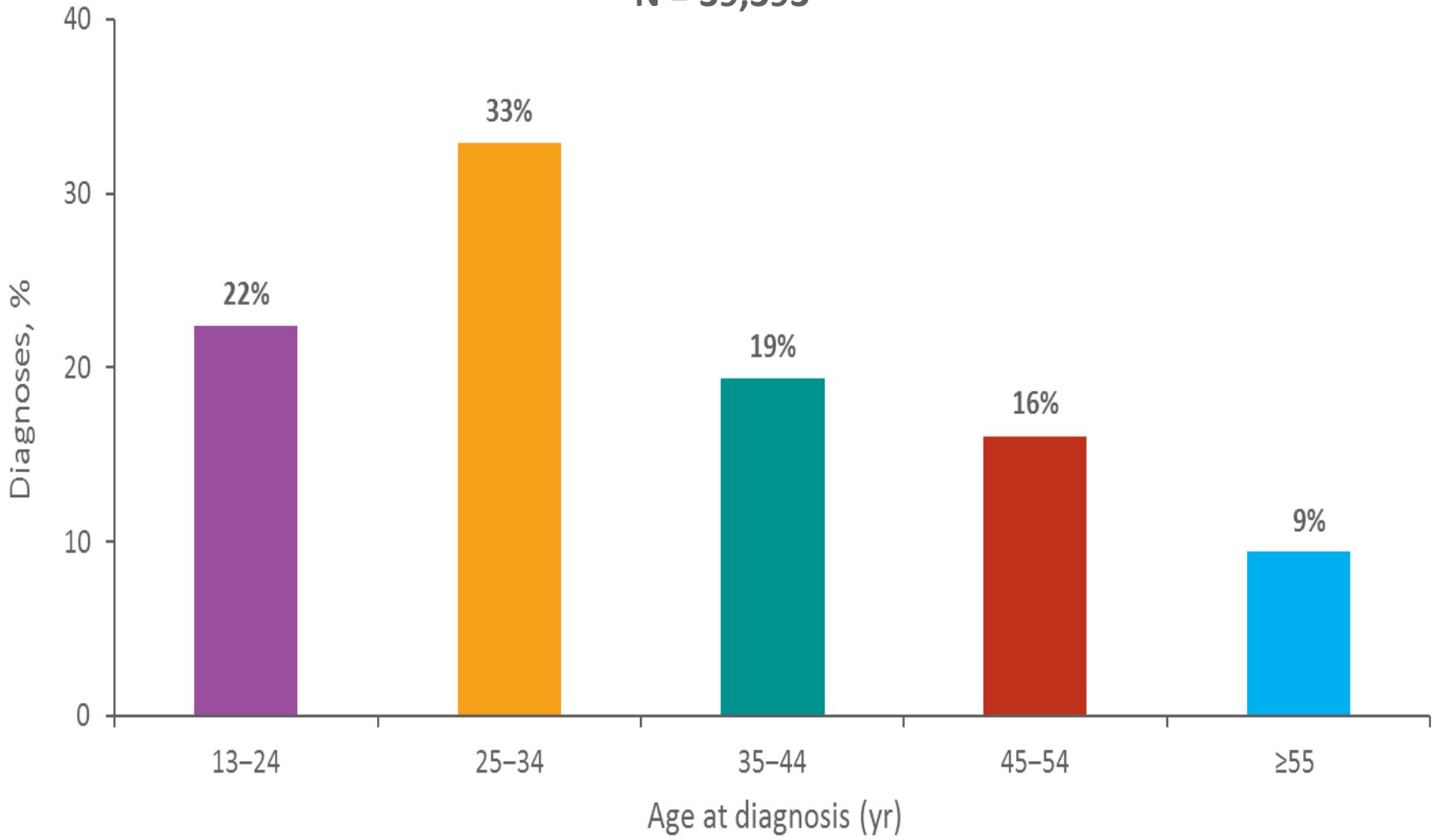
Lifetime Risk of HIV Diagnosis by Transmission Group



Source: Centers for Disease Control and Prevention

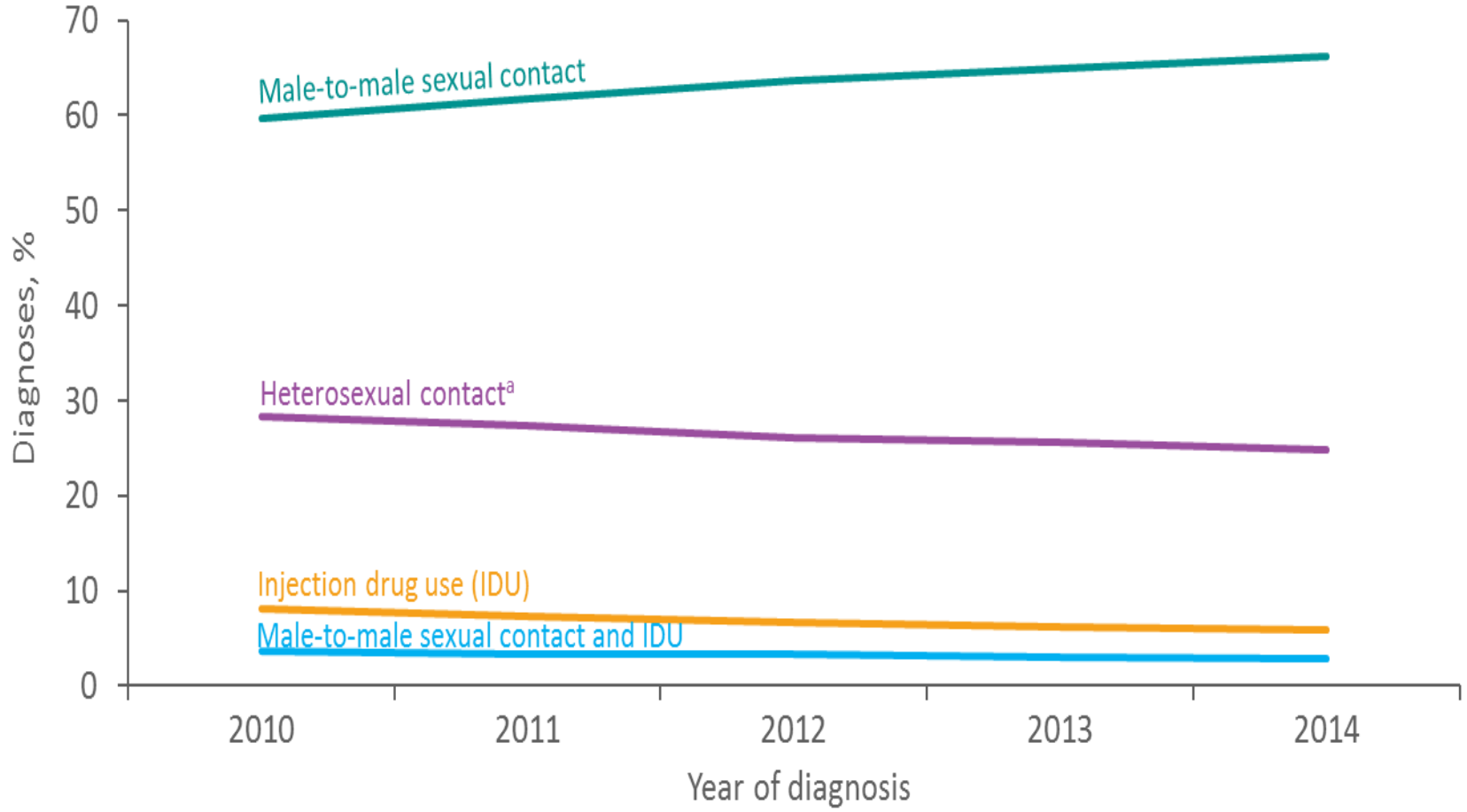
DIAGNOSES OF HIV INFECTION AMONG ADULTS AND ADOLESCENTS BY AGE AT DIAGNOSIS, 2015—UNITED STATES

N = 39,393



Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data for the year 2015 are preliminary and based on 6 months reporting delay.

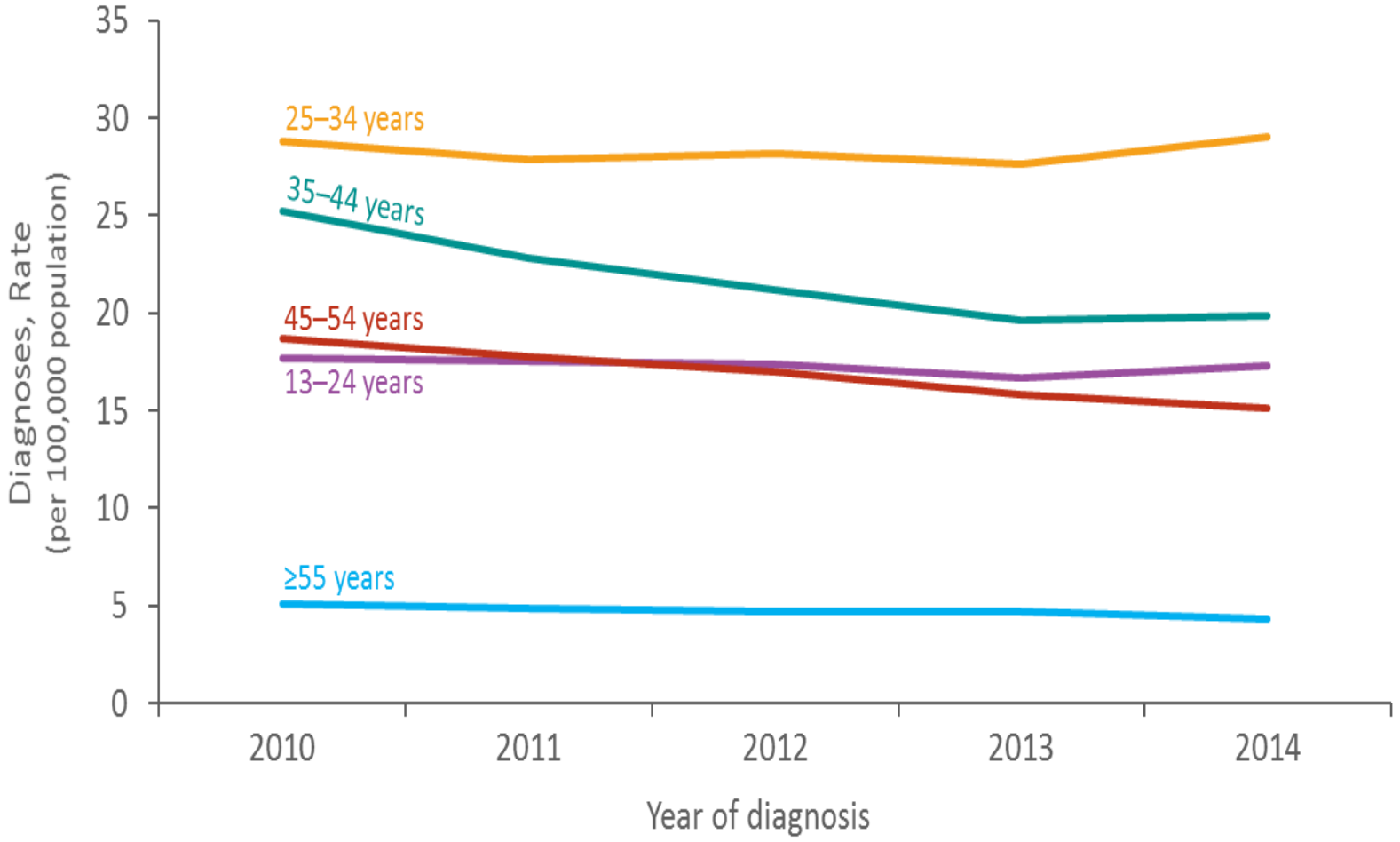
DIAGNOSES OF HIV INFECTION AMONG ADULTS AND ADOLESCENTS, BY TRANSMISSION CATEGORY, 2010–2014—UNITED STATES AND 6 DEPENDENT AREAS



Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data have been statistically adjusted to account for missing transmission category. "Other" transmission category not displayed as it comprises less than 1% of cases.

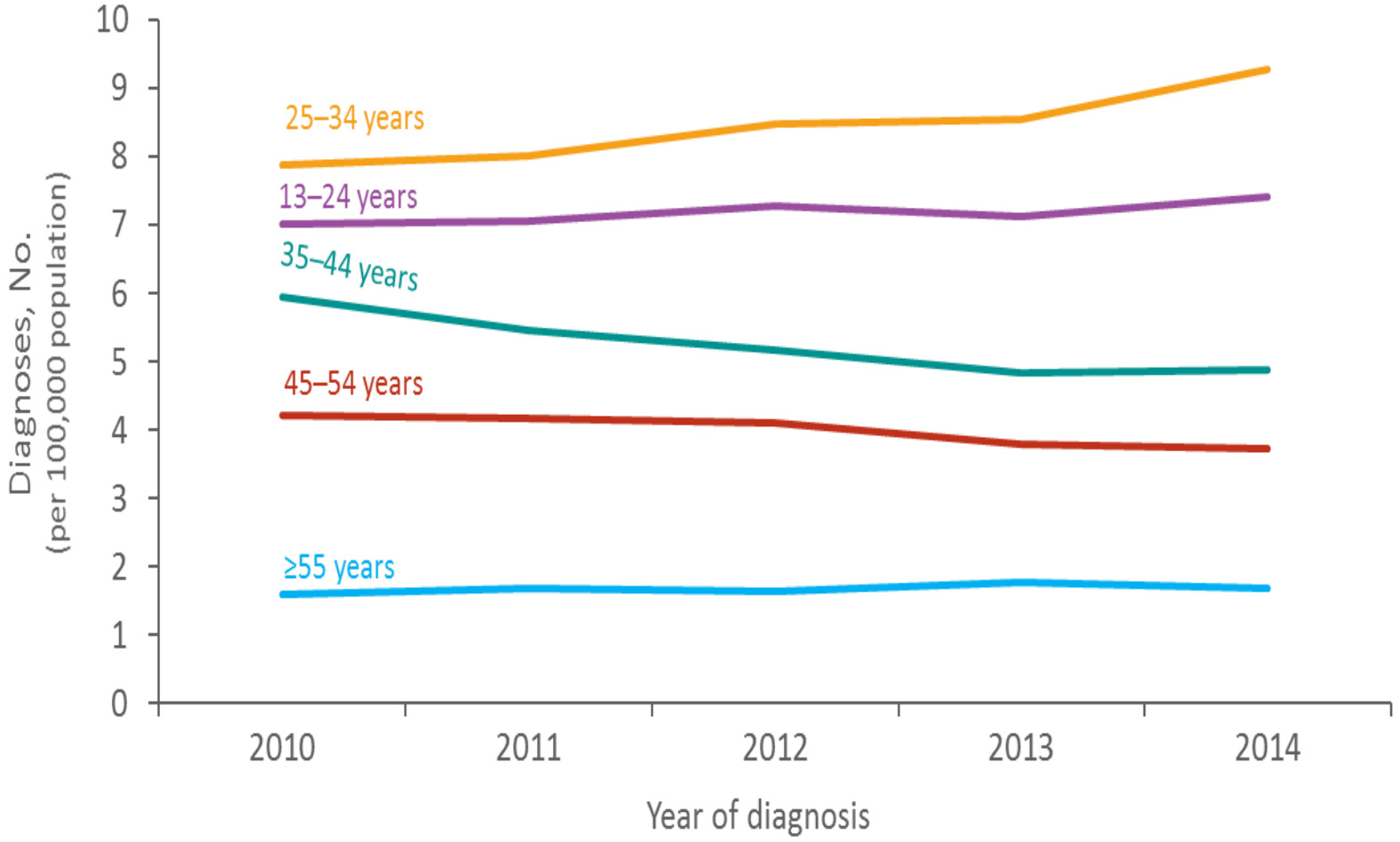
[a] Heterosexual contact with a person known to have, or to be at high risk for, HIV infection.

RATES OF DIAGNOSES OF HIV INFECTION AMONG ADULTS AND ADOLESCENTS BY AGE AT DIAGNOSIS, 2010–2014—UNITED STATES



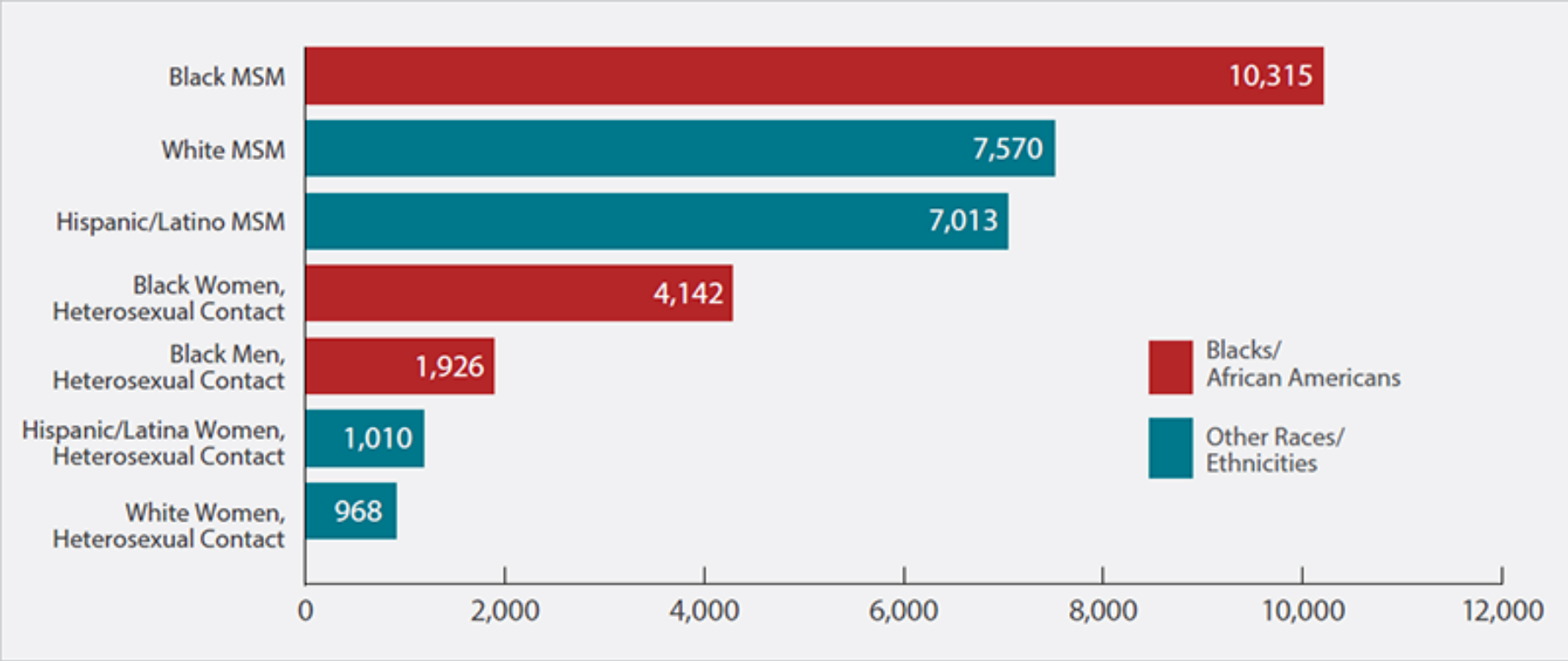
Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis.

DIAGNOSES OF HIV INFECTION AMONG MEN WHO HAVE SEX WITH MEN, BY AGE AT DIAGNOSIS, 2010–2014—UNITED STATES AND 6 DEPENDENT AREAS



Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. Data have been statistically adjusted to account for missing transmission category. Data on men who have sex with men do not include men with HIV infection attributed to male-to-male sexual contact *and* injection drug use.

HIV Diagnoses in the United States for the Most-Affected Subpopulations, 2015



*CDC HIV Surveillance Report 2016;27

OBJECTIVES

- Intersectionality
- Role of stigma
- Implicit biased
- Cultural humility
- Terms
- HIV overview
- Prep overview

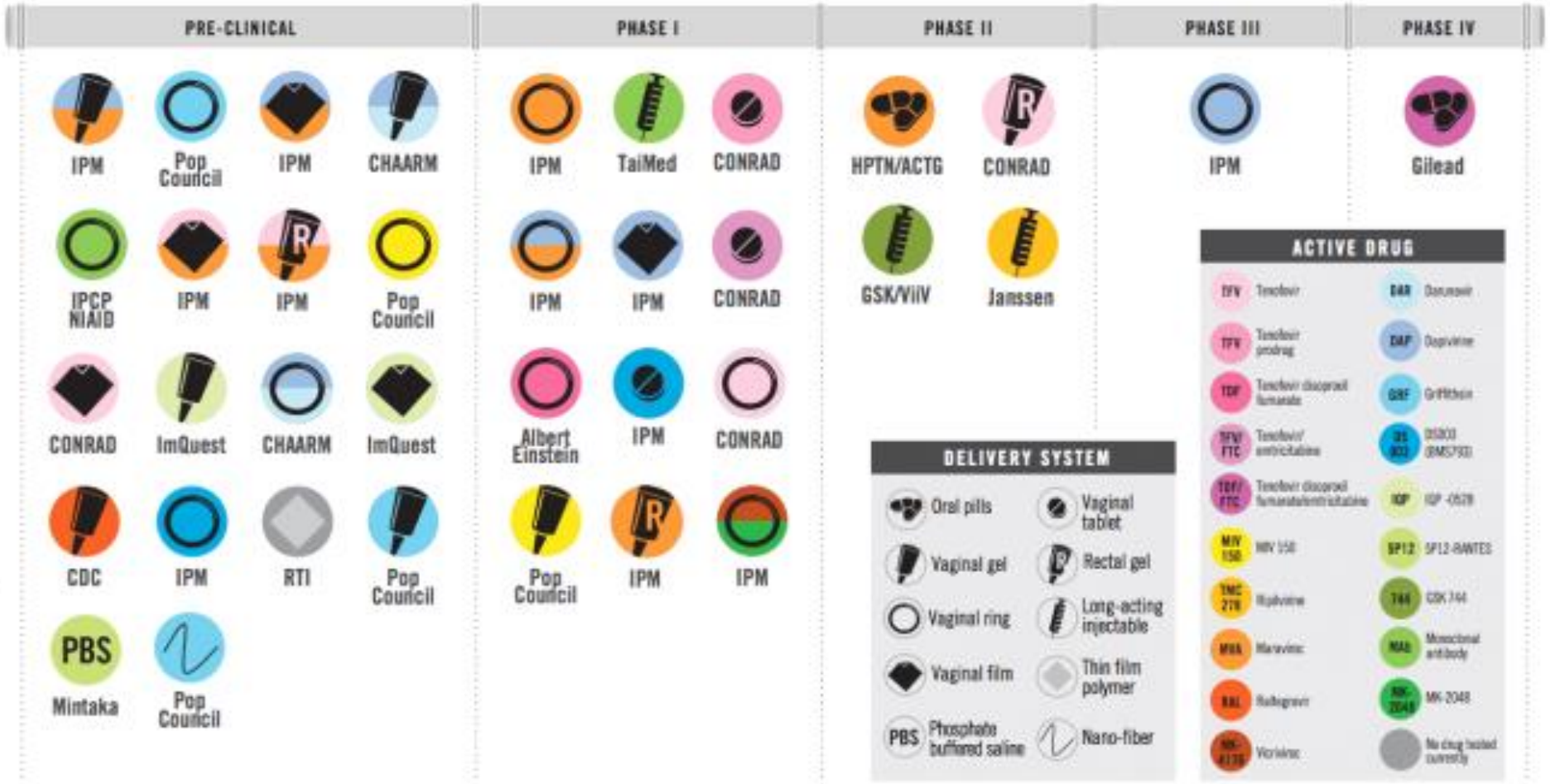
Pre Exposure Prophylaxis

Right now PrEP is mostly used synonymously with Truvada, however, there are many more PrEP options in development…

ARV-Based Prevention Pipeline

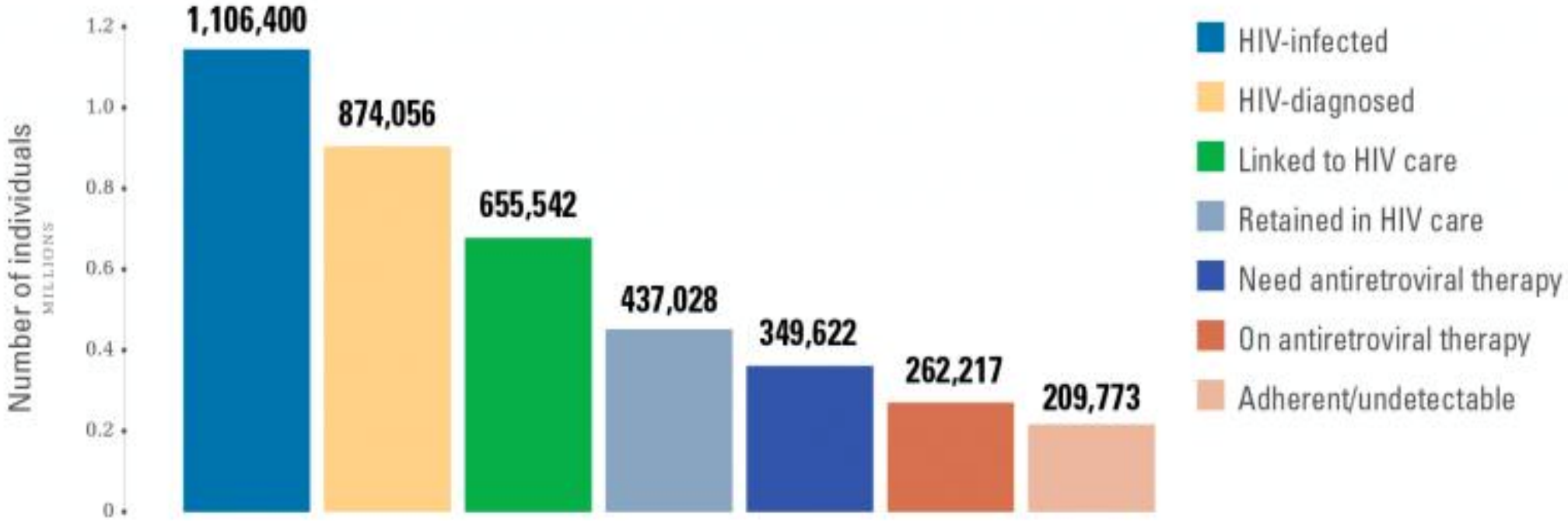
The pipeline of ARV-based prevention products includes oral pills, vaginal rings, vaginal and rectal gels, vaginal films, long-acting injectable ARVs. Not pictured are a range of multipurpose technologies in development that aim to reduce women's risk of HIV and STIs, and provide effective contraception.

For up-to-date information on the ARV-based prevention pipeline, visit the HIV Prevention Research Database at www.avac.org/pxrd.



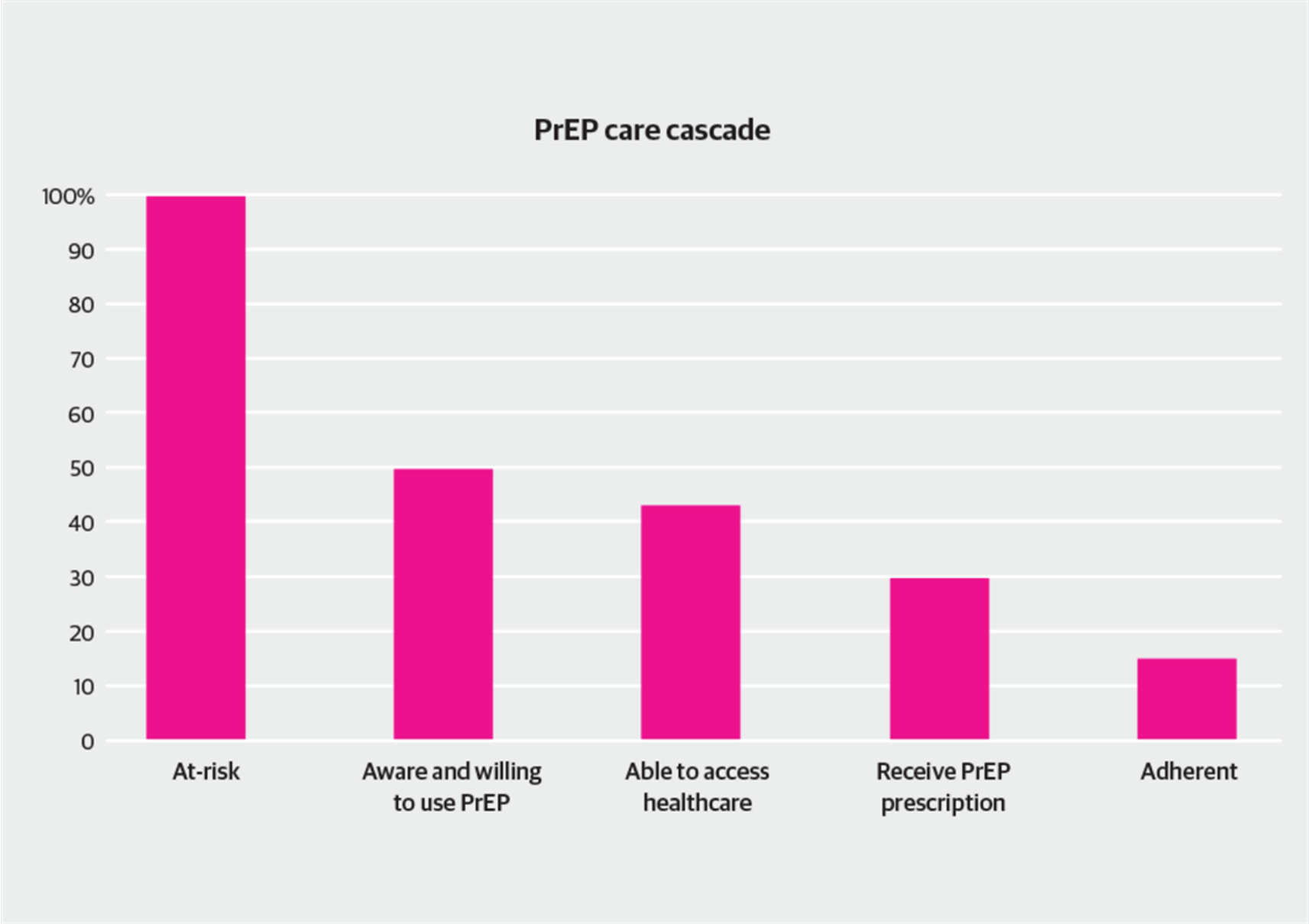
Estimated Engagement in the HIV Care Cascade in the US

It is estimated that only 19 percent of HIV-positive people in the US have an undetectable viral load. Similar patterns in the care cascade exist around the world.

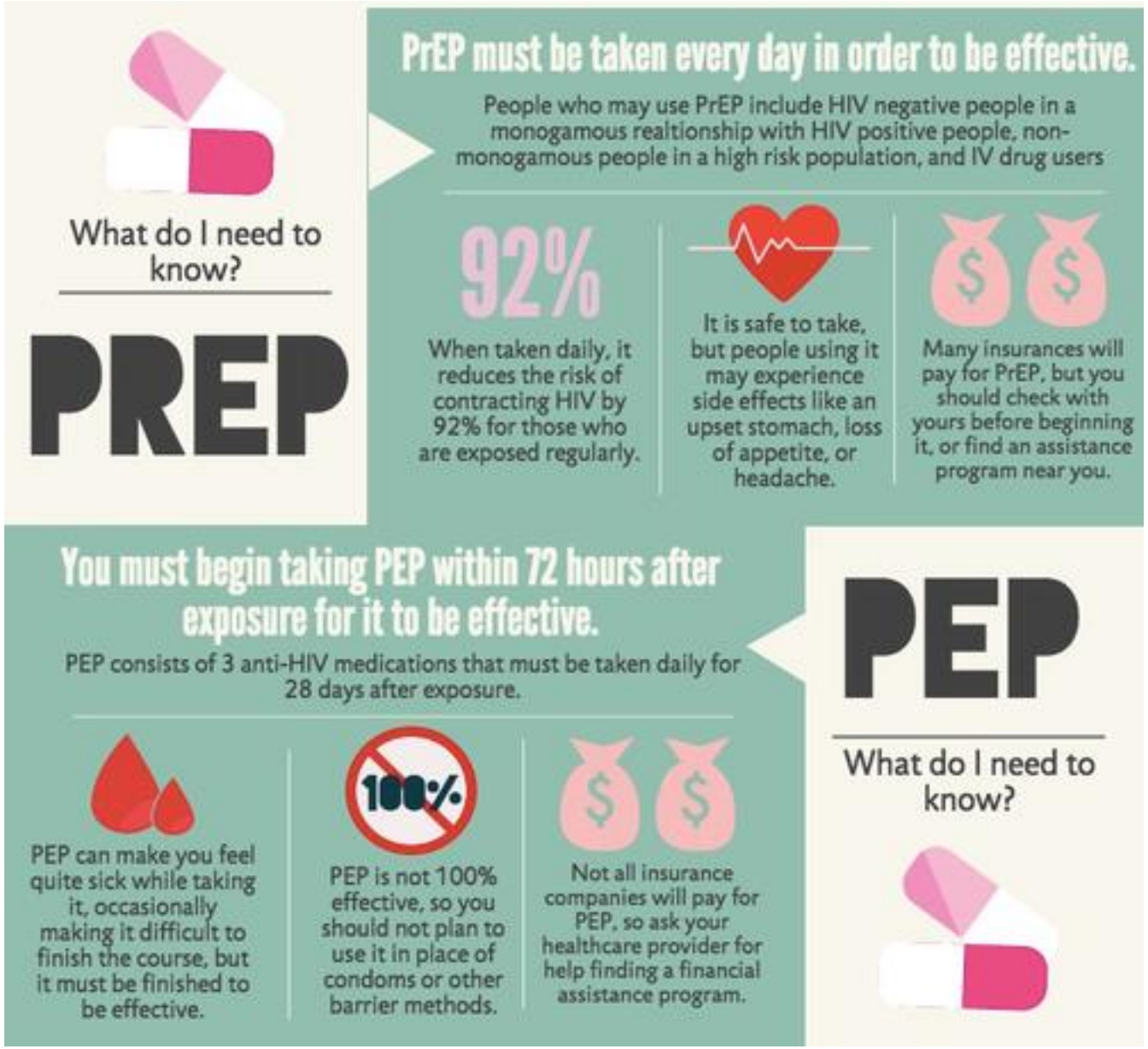


Source: EM Gardner et al. "The Spectrum of Engagement in HIV Care and its Relevance to Test-and-Treat Strategies for Prevention of HIV Infection," Clin Infect Dis. (2011) 52 (6): 793-800.

AVAC Report 2012: Achieving the End – One Year and Counting, www.avac.org/report2012.



http://www.aidsmap.com/US-PrEP-care-cascade-analysis-suggests-that-major-structural-barriers-need-to-be-addressed-for-PrEP-to-have-an-impact/page/2997511/



http://www.nextbigfuture.com/2017/01/40-lower-hiv-infections-in-london-using.html

Understanding PrEP

Search Search

Home What's PrEP Sexual health and HIV For patients For providers Resources About us Log out

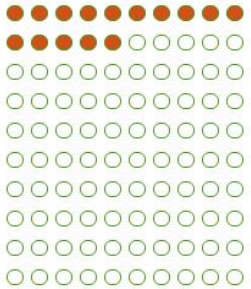
A decision tool for men and their health providers

Step 2:
Chances of getting HIV, with and without PrEP

This is an estimate of your chances of becoming HIV-positive over one year.

Without PrEP

If 100 men who answered like you **are not taking PrEP**

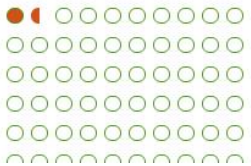


15 men
will become HIV-positive

85 men
will stay HIV-negative

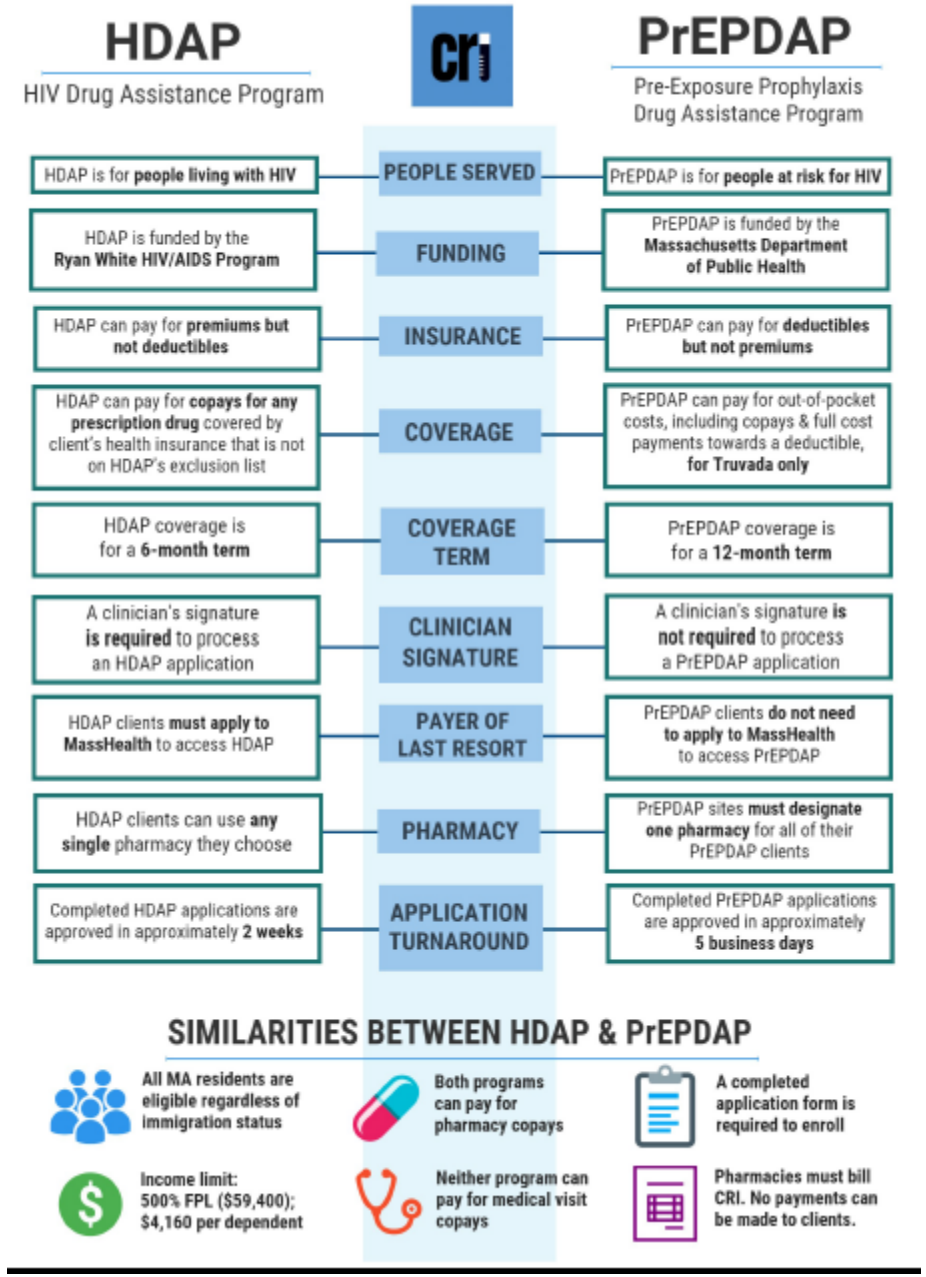
With PrEP

If 100 men who answered like you **are taking PrEP**



1-2 men
will become HIV-positive

98-99 men
will stay HIV-negative


HDAP
HIV Drug Assistance Program
cri
PrEPDAP
Pre-Exposure Prophylaxis Drug Assistance Program
HDAP is for people living with HIV
PEOPLE SERVED
PrEPDAP is for people at risk for HIV
HDAP is funded by the Ryan White HIV/AIDS Program
FUNDING
PrEPDAP is funded by the Massachusetts Department of Public Health
HDAP can pay for premiums but not deductibles
INSURANCE
PrEPDAP can pay for deductibles but not premiums
HDAP can pay for copays for any prescription drug covered by client's health insurance that is not on HDAP's exclusion list
COVERAGE
PrEPDAP can pay for out-of-pocket costs, including copays & full cost payments towards a deductible, for Truvada only
HDAP coverage is for a 6-month term
COVERAGE TERM
PrEPDAP coverage is for a 12-month term
A clinician's signature is required to process an HDAP application
CLINICIAN SIGNATURE
A clinician's signature is not required to process a PrEPDAP application
HDAP clients must apply to MassHealth to access HDAP
PAYER OF LAST RESORT
PrEPDAP clients do not need to apply to MassHealth to access PrEPDAP
HDAP clients can use any single pharmacy they choose
PHARMACY
PrEPDAP sites must designate one pharmacy for all of their PrEPDAP clients
Completed HDAP applications are approved in approximately 2 weeks
APPLICATION TURNAROUND
Completed PrEPDAP applications are approved in approximately 5 business days
SIMILARITIES BETWEEN HDAP & PrEPDAP
All MA residents are eligible regardless of immigration status
Both programs can pay for pharmacy copays
A completed application form is required to enroll
Income limit: 500% FPL ($59,400); $4,160 per dependent
Neither program can pay for medical visit copays
Pharmacies must bill CRI. No payments can be made to clients.

THANK YOU!