

# Stigma, discrimination, awareness, activism



## The HIV Epidemic in the United States

Theodore Gideonse, PhD

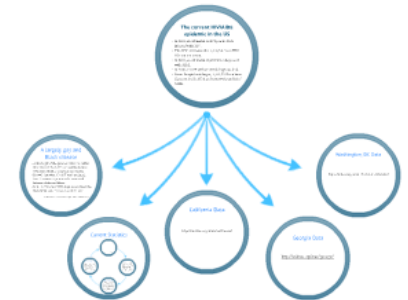
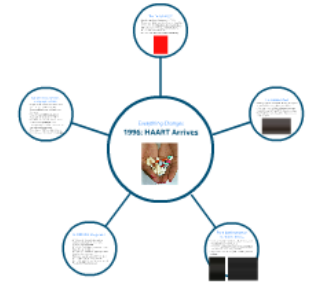
September 4, 2014

"The AIDS epidemic has rolled back a big rotting log and revealed all the squirming life underneath it, since it involves, all at once, the main themes of our existence: sex, death, power, money, love, hate, disease, and panic."

Edmund White in

States of Desire: Travels in Gay America (1986)

# How HIV came to the United States



# INTRODUCTION The two HIV/AIDS epidemics



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## INTRODUCTION

# The two HIV/AIDS epidemics

### United States vs. Sub-Saharan Africa

- In many African countries, the HIV/AIDS epidemic is largely heterosexual and female.
- In the US, HIV/AIDS is largely concentrated among MSM, though in some places, the epidemic resembles Africa's demographics.

### Responses

- In both areas (everywhere, in fact), stigma has made prevention and treatment difficult.
- The US's economic power has enabled most people with HIV to get free or low cost treatment.
- In the US, AIDS deaths per 100,000 is 3.4.
- In South Africa, where AIDS deaths have decreased 50% since 2005 because of increased treatment, AIDS deaths per 100,000 is 627.

sources: AIDSVC; WHO, World Health Statistics, 2011

### So what?

- These difference arose from differing social, historical, and economic contexts and processes.
- While pathogens don't care about culture or history, we must care about these things to tailor responses to specific situations.
- The epidemic in the US is in managed well compared to poorer nations, but still: 50,000 become infected with HIV each year in the US and 15,000 die of AIDS.

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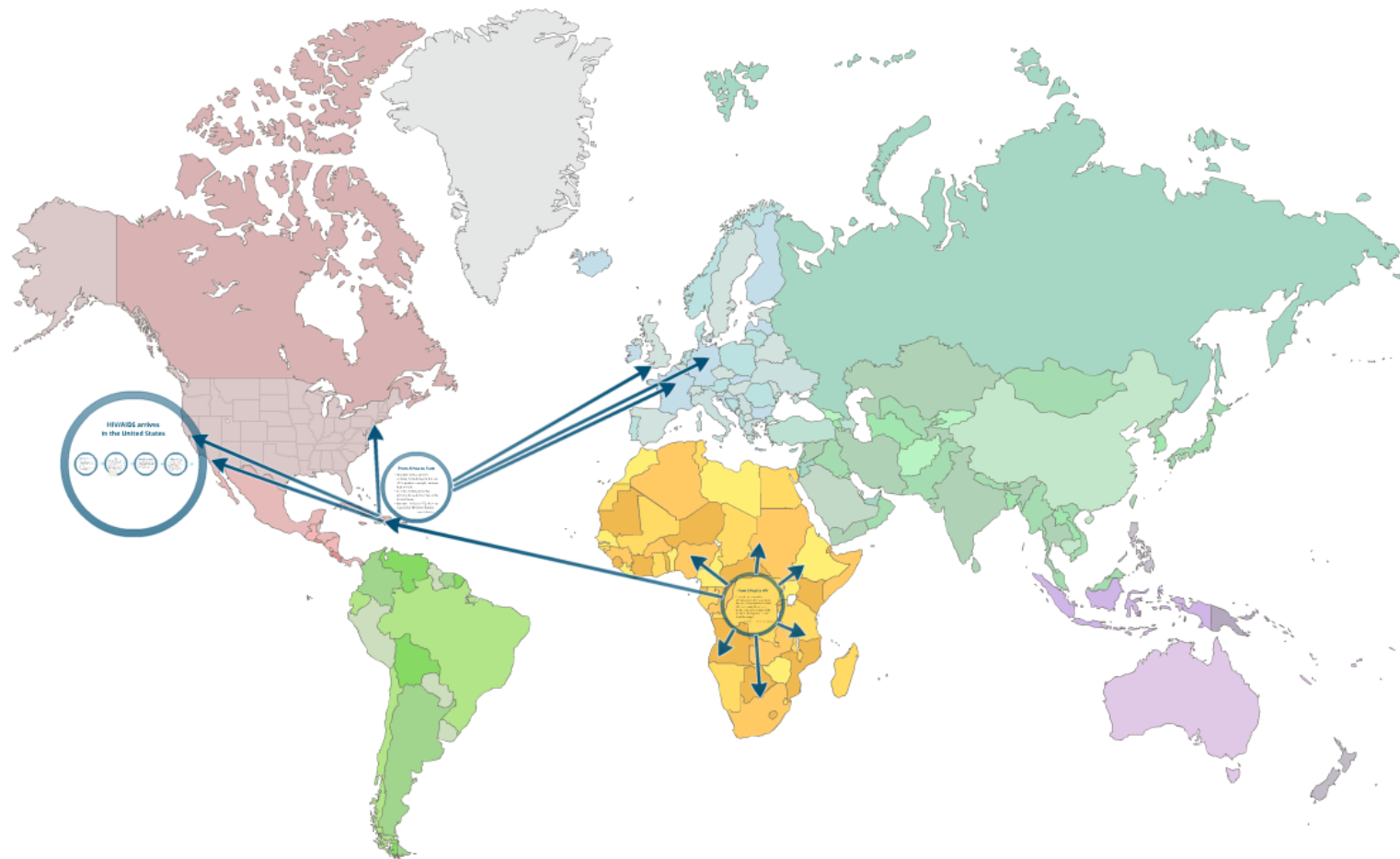
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# How HIV came to the United States



A stylized map of the African continent is shown in the background, rendered in shades of orange and yellow. Overlaid on this map is a thick, dark green circular band that encircles the continent. Several blue lines, some straight and some curved, cross the green band and the map, possibly representing rivers or major roads. The overall design is graphic and modern.

## From SIVcpz to HIV

- A mostly harmless simian immunodeficiency virus jumped to humans and mutated into the lethal HIV in the early 20th century.
- In the 1960s, cases of what would be called AIDS appeared in Zaire (now the Congo).

sources: Gao, et al., 1999; Vangroenweghe, 2001

## From Africa to Haiti

- Hundreds of Haitian men studying in the Congo in the late 1960s probably brought the virus back to Haiti.
- In 1969, American tourists probably brought the virus to the United States.
- Between 1969 and 1972, the virus migrated to Northern Europe.

source: Gilbert, 2007

# HIV/AIDS arrives in the United States

## Isolated, pre-1981 cases

- Genetic studies show that HIV probably entered the US in 1966.
- Teen-aged boy in St. Louis died of AIDS in 1969.
- In 1977, a prostitute in San Francisco gave birth to the first of three children with HIV.

source: Kelso, 1987; Sklar, 1987

## 1981

- Gottlieb, et al report five cases of gay men in Los Angeles with PCP in MMWR.
- A month later, MMWR reports 26 case of KS in gay men in New York.
- Doctors called the syndrome Gay Related Immune Deficiency, or GRID.
- Gay men in New York found Gay Men's Health Crisis (GMHC) in response to what is seen as inaction by the government.



source: Sklar, 1987

## Discovered in more groups

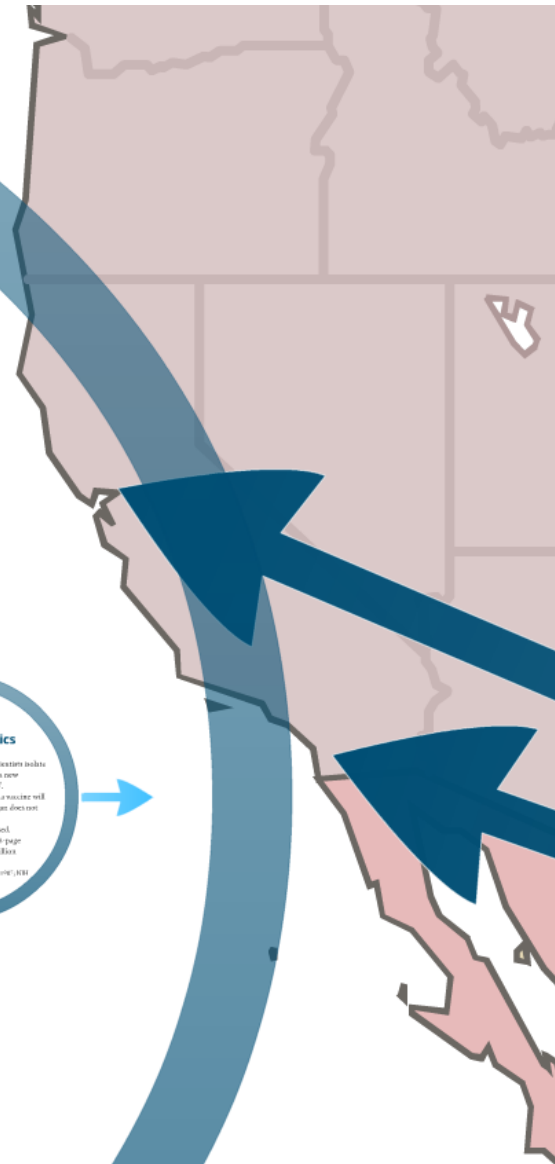
- Cases are found in hemophiliacs, injection drugs users, Haitian immigrants, blood transfusion recipients, women, and infants.
- CDC names Acquired Immune Deficiency Syndrome, or AIDS.
- By the end of 1982, in the US 771 cases were reported and 618 people had died.

source: Sklar, 1987 and PAH

## Science and politics

- In 1984, after French and American scientists isolate a virus in AIDS patients, they agree this new retrovirus causes AIDS; they call it HIV.
- Sec. of HHS Margaret Heckler predicts a vaccine will be ready in two years, while Pres. Reagan does not comment on AIDS while in office.
- In 1985, a the first test for HIV is licensed.
- 1986, Surgeon General Kohn reads an 8-page version of his report of AIDS to 107 million American homes.

source: Sklar, 1987, 1981



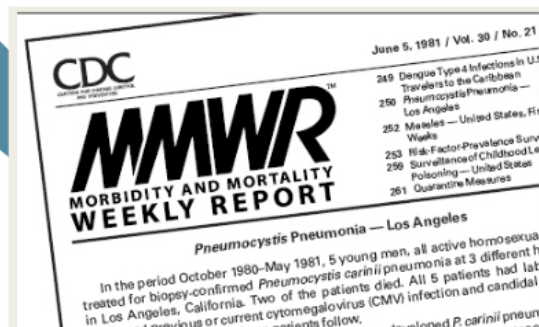
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source: Kolata, 1987; Shilts, 1987

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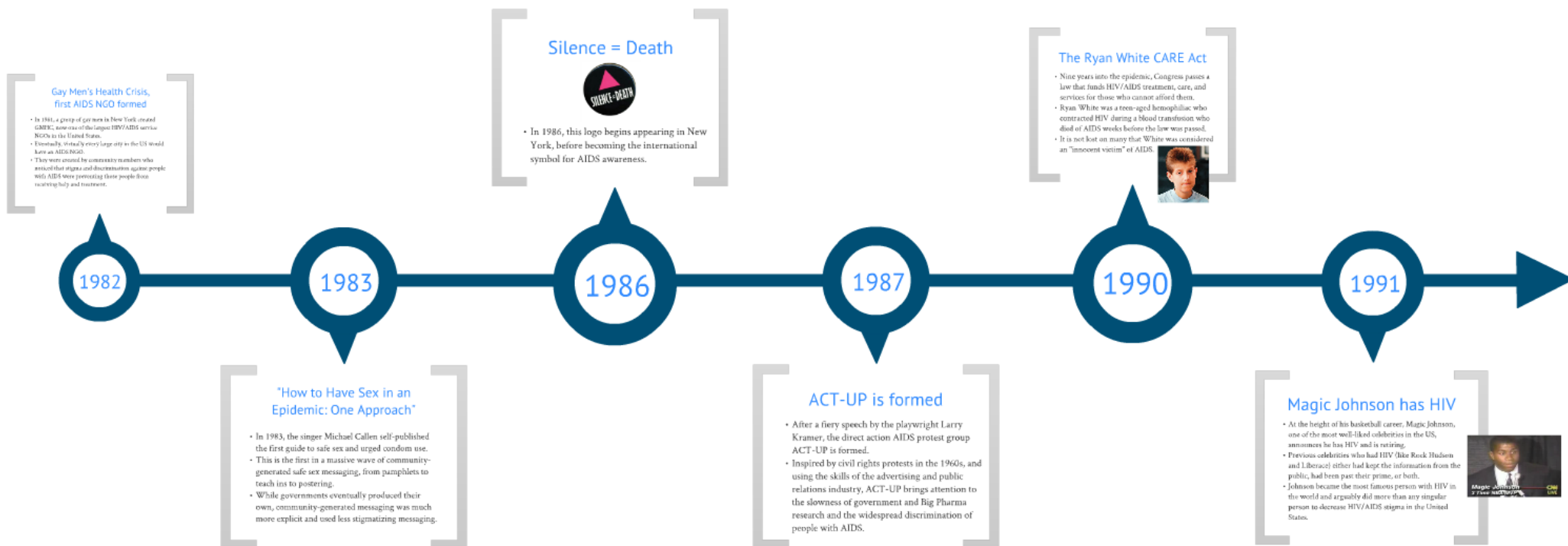


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# Stigma, discrimination, awareness, activism



## Gay Men's Health Crisis, first AIDS NGO formed

- In 1981, a group of gay men in New York created GMHC, now one of the largest HIV/AIDS service NGOs in the United States.
- Eventually, virtually every large city in the US would have an AIDS NGO.
- They were created by community members who noticed that stigma and discrimination against people with AIDS were preventing those people from receiving help and treatment.

1982

32

1983

## "How to Have Sex in an Epidemic: One Approach"

- In 1983, the singer Michael Callen self-published the first guide to safe sex and urged condom use.
- This is the first in a massive wave of community-generated safe sex messaging, from pamphlets to teach ins to posterings.
- While governments eventually produced their own, community-generated messaging was much more explicit and used less stigmatizing messaging.

## Silence = Death



- In 1986, this logo begins appearing in New York, before becoming the international symbol for AIDS awareness.

1986

1



1987

## ACT-UP is formed

- After a fiery speech by the playwright Larry Kramer, the direct action AIDS protest group ACT-UP is formed.
- Inspired by civil rights protests in the 1960s, and using the skills of the advertising and public relations industry, ACT-UP brings attention to the slowness of government and Big Pharma research and the widespread discrimination of people with AIDS.

## The Ryan White CARE Act

- Nine years into the epidemic, Congress passes a law that funds HIV/AIDS treatment, care, and services for those who cannot afford them.
- Ryan White was a teen-aged hemophiliac who contracted HIV during a blood transfusion who died of AIDS weeks before the law was passed.
- It is not lost on many that White was considered an "innocent victim" of AIDS.



1990

1

1990

1991

## Magic Johnson has HIV

- At the height of his basketball career, Magic Johnson, one of the most well-liked celebrities in the US, announces he has HIV and is retiring.
- Previous celebrities who had HIV (like Rock Hudson and Liberace) either had kept the information from the public, had been past their prime, or both.
- Johnson became the most famous person with HIV in the world and arguably did more than any singular person to decrease HIV/AIDS stigma in the United States.



## Everything Changes 1996: HAART Arrives



### The End of AIDS?

- At the International Conference on AIDS in Vancouver in 1996, scientists including Dr. David Ho presented data that showed that HIV could be treated with combinations of drugs, or Highly Active Antiretroviral Treatment (HAART).
- Rates of deaths from AIDS declines dramatically.



### But infections continue, and people still die

- Yearly, 50,000 Americans become infected with HIV and 15,000 die of AIDS.
- Rates for MSM, blacks, and Latinos are increasing.
- Large numbers of HIV infections are diagnosed at the same time as AIDS.
- Infections and deaths are concentrated in socioeconomically disadvantaged communities, where education, healthcare, and other services are weak.
- The roll-out of PrEP may help, but access, publicity, and community debates are issues.

### The Lazarus Effect

- Many people near death were able to leave hospitals in weeks and survive, perhaps until old age.
- Shocking to them and also to the country, which began to increasingly see AIDS as less of a problem.
- But: Early drugs were toxic, didn't always work, and very expensive.



### Is AIDS still a big deal?

- With less people dying and looking sick, the urgency to practice safer sex is diminished, particularly for younger MSM.
- While funding for developing medications remains high, little focus on prevention.
- Costs for treatment is still very high, but paid for by federal and state governments.
- Wait lists for drugs entire, nearly 8,000 in 11 states were on wait lists in 2011. Money from RHHS decreased that in 2012. In April, 2014, only 16 people were on ADAP wait lists in the US.

### From death sentence to chronic illness

- Instead of managing eventual death, doctors focused on managing a chronic infection.
- "Treatment adherence" becomes as much, and then more than, a focus as "risk prevention."
- Big Pharma advertises drugs with healthy, cheerful models.



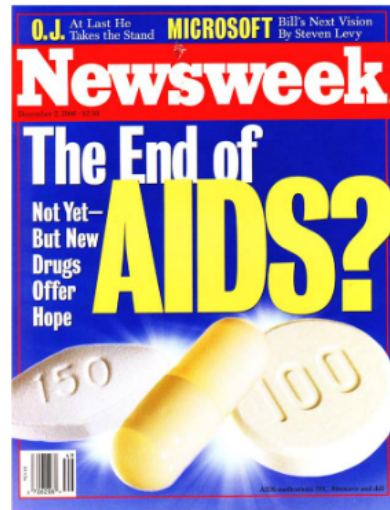
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## The current HIV/AIDS epidemic in the US

- In 2011, an estimated 49,273 people were infected with HIV.
- The CDC estimates that 1,148,200 have HIV; 18% are not aware.
- In 2011, an estimated 32,052 were diagnosed with AIDS.
- In 2010, 15,529 with an AIDS diagnosis died.
- Since the epidemic began, 1,155,792 have been diagnosed with AIDS and 636,000 have died of AIDS.

## A largely gay and Black disease

- At the height of the epidemic (1991-92), whites were 56% of HIV/AIDS cases and blacks were 27%; white MSM over 30 bore the burden.
- By 1995, just when HAART was introduced, infections were beginning to be evenly split between whites and blacks.
- In 2011, 47% of new HIV diagnoses are black; the black MSM under 30 now bear the burden.

source: CDC, HIV Surveillance Reports 1992, 1995, and 2011

## Washington, DC Data

<http://aidsvu.org/state/district-of-columbia/>

## California Data

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## Current Statistics



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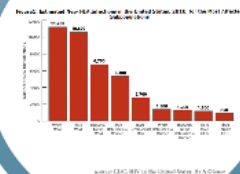
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# Current Statistics



## Heterosexuals and IDUs, 2010

- Heterosexuals are 25% of estimated new infections.
- 85,000 infected through heterosexual sex have died since the epidemic began, with 6,003 in 2010.
- New infections among women are primarily attributed to heterosexual sex (84%) or IDU (16%).
- 9,500 women were infected in 2010 (20% of total), 21% decrease from the 12,000 in 2008.
- IDUs were 8% of new infections in 2010.
- 182,000 IDUs have died of AIDS since the epidemic began, 4,218 in 2010.

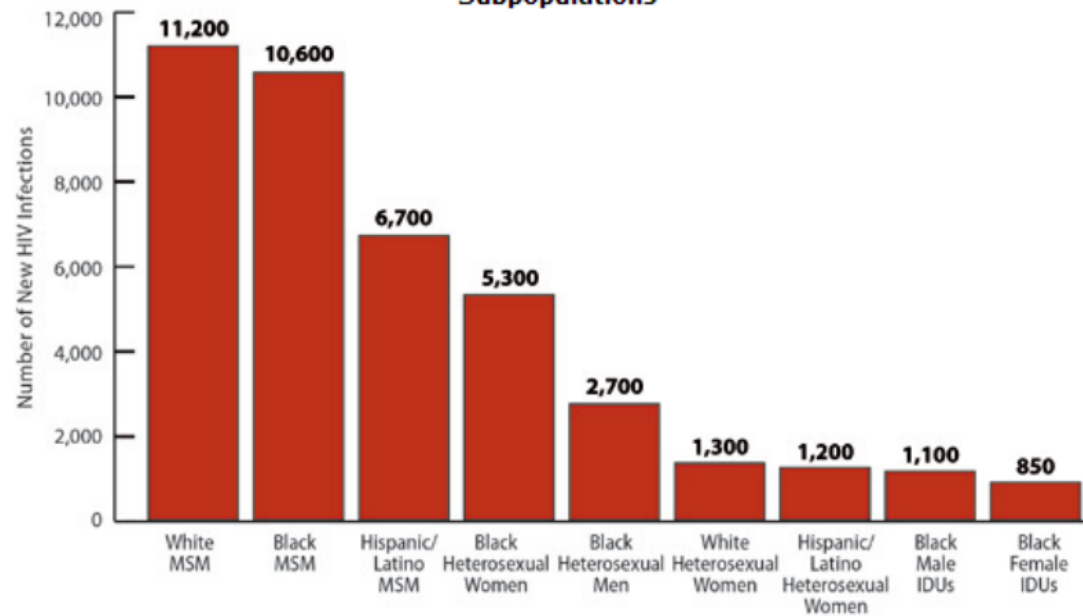
## MSM, 2010

- Estimated number of new HIV infections among MSM was 29,800, up 12% from 2008.
- MSM are 4% of the men in the US, but in 2010 MSM 78% of new HIV infections among men and 63% of all new infections were MSM.
- White MSM have the most new HIV infections (11,200), while black MSM have nearly as many (10,600).
- Broken down by race and age, the most new infections (4,800) were among MSM occurred in young black MSM aged 13-24.

## Blacks and Latinos, 2010

- Blacks are 12% of the U.S. population, but 44% of new infections.
- The CDC: "Unless the course of the epidemic changes, at some point in their lifetime, an estimated 1 in 16 black men and 1 in 33 black women will be diagnosed with HIV infection."
- Hispanics/Latinos are 16% of the population, but 21% of new infections.
- The CDC: "The rate of new HIV infections for Latino males was 2.9 times that for white males, and the rate of new infections for Latinos was 6.2 times that for white females."

**Figure1: Estimated New HIV Infections in the United States, 2010, for the Most Affected Subpopulations**



source: CDC, HIV in the United States: At A Glance

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