# **HIV Prevention Advocacy in the** 2016 Election Year: **Priorities and Challenges**

January 25, 2016

Amy Killelea, NASTAD Cecilia Chung, Transgender Law Center and Positively Trans **Kenyon Farrow, Treatment Action Group** 

**Moderator:** Jeremiah Johnson, Treatment Action Group

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## **Webinar Instructions**

- All attendees are in listen-only mode
- Everyone can submit questions at any time using the chat feature
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- During Q & A segment the moderators will read selected questions that have been submitted
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# Today's Agenda

### **Agenda & Opening Remarks**

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

### **Paying for PrEP**

Amy Killelea, Director of Health System Integration at NASTAD

## **Positively Trans**

Cecilia Chung, Senior Strategist, Transgender Law Center and Chair of the U.S. PLHIV Caucus

## Data to ACTIVISM: 2014 Surveillance Data And Opportunities for **Activism**

- Slides by Kenyon Farrow, US & Global Policy Director, Treatment Action Group
- Presented by Jeremiah Johnson, HIV Prevention Research and Policy Coordinator, **Treatment Action Group**
- Q&A



# Paying for PrEP: Advocacy Priorities and Solutions

Amy Killelea NASTAD



# PrEP as Part of a New Prevention Paradigm

### The Changing Science

US Public Health Service

PREEXPOSURE PROPHYLAXIS

FOR THE PREVENTION OF HIV

INFECTION IN THE UNITED

STATES - 2014

A CLINICAL PRACTICE GUIDELINE

The NEW ENGLAND
JOURNAL of MEDICINE

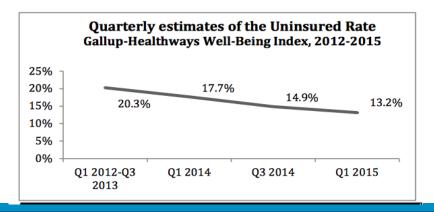
MOME ARTICLES A MULTIMEDIA\* ISSUES\* SPECIALTIES A TOPICS\* FOR AUTHORS\* CME.)

ORIGINAL ARTICLE

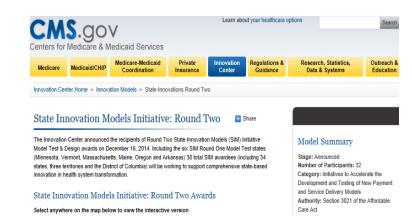
Preexposure Chemoprophylaxis for HIV Prevention in Men Who
HAVE Sex with Men

### The Coverage Landscape

**16.4** million people have gained health insurance coverage through the ACA



# New Attention to **Population Health** by Medicaid and Insurance



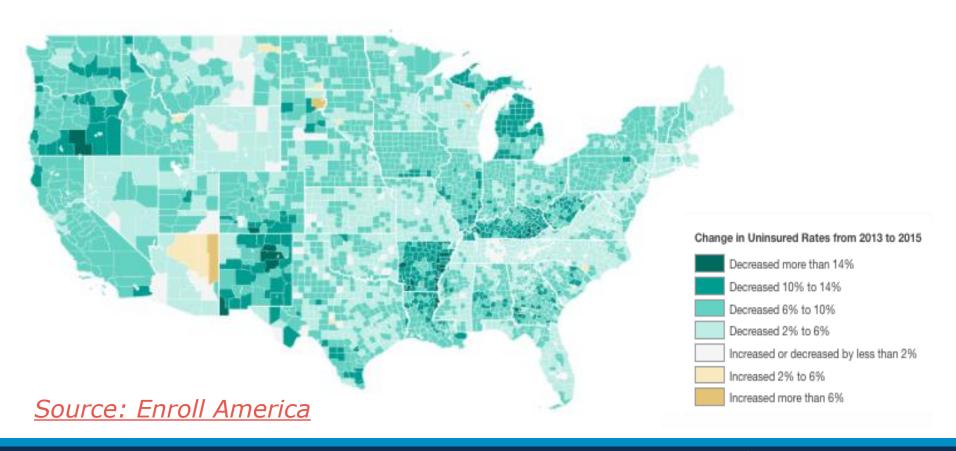
### **A Math Problem**

- CDC and HRSA do NOT cover PrEP (the medication)
- We cannot fight an epidemic with discretionary funding alone



## A New Insured Landscape Nationwide

Changing Uninsured Rates by County: 2013-2015





## The Financing Conundrum

### **PrEP Services**

- PrEP medication access
- Laboratory services
- Primary care visits (LGBT health)
- Linkage to social support services
- Mental illness & substance use/abuse services
- Adherence counseling and support
- Health insurance enrollment and plan navigation
- HCV, HIV and STI screening
- HIV Risk Reduction Counseling

#### CDC

Will not pay for medication and labs

### **Ryan White Program**

Can pay for limited services for HIV negative individuals

### **Medicaid**

> 19 states have still not expanded

### **Private insurance**

Co-pays are still expensive!



## Financing Considerations

- Enroll eligible individuals into insurance coverage
- Assess insurance plan options and plug affordability gaps
- Build off of existing Ryan White/ADAP infrastructure to create public health PrEP program
- Create a PrEP Public Health Safety Net



## 1) Enrollment into New Coverage

## Messages and Messengers Matter

#### Most Important Motivators for People Under 30

Here are the top three messages that motivate young Americans to learn more about the new health coverage options through the Health Insurance Marketplace:

- If you or a family member gets sick, you won't have to worry about big medical bills or going bankrupt.
- You will be able to find a plan that fits your budget.
- The insurance plan you choose will be there to cover the care you need.

#### Best Messengers

- Someone like them
- Someone their age and who has experienced the process of applying for health insurance
- Family member (mom)
- Doctor

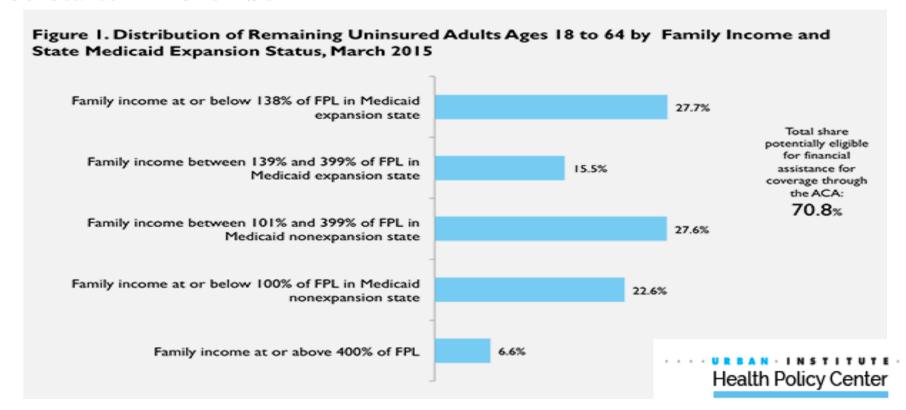




# It's Getting Harder to Identify and Enroll the Remaining Uninsured

Oct 21, 2014 News Release

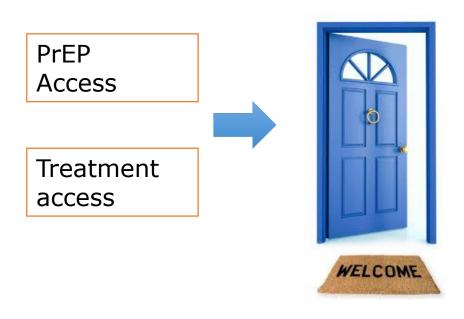
Nine in Ten Uninsured Unaware that the Affordable Care Act's Second Open Enrollment Period Starts in November





# Insurance Education and Assistance is a New Prevention Activity

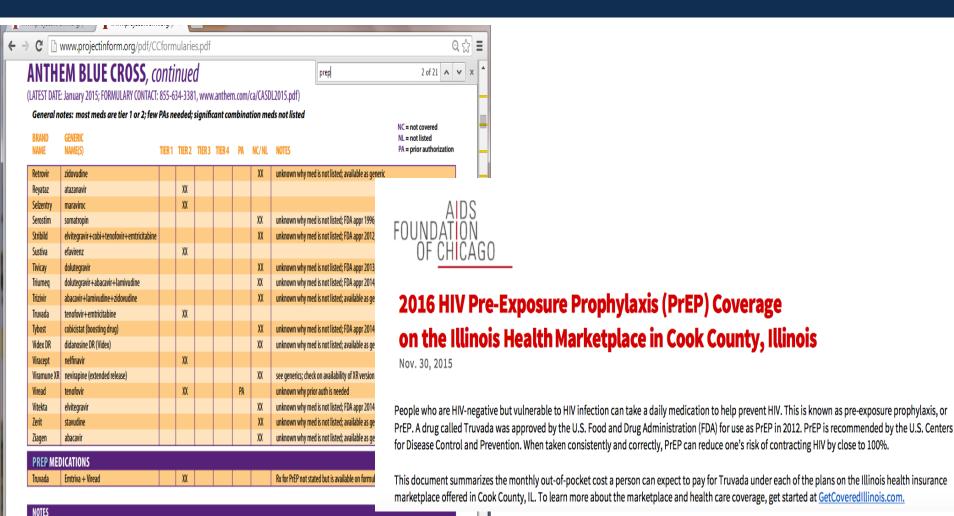
 DIS, HIV linkage staff, and other frontline prevention staff are first touch to both prevention and overall health and wellness



Primary care; insurance coverage; health and wellness



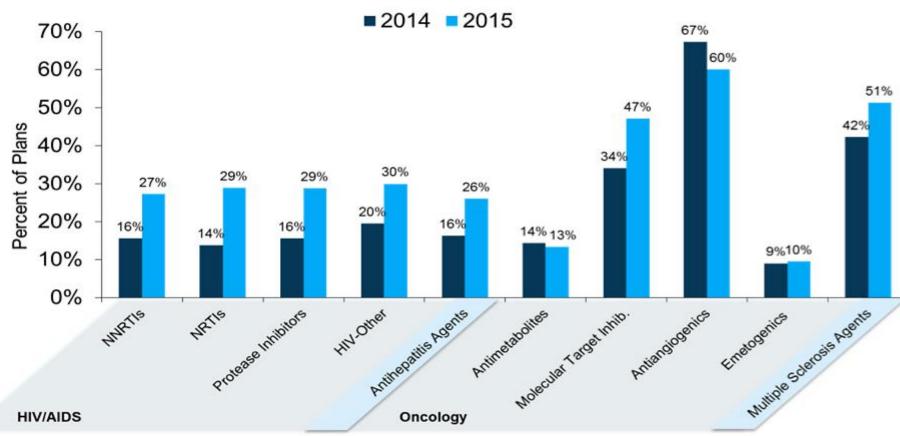
# Insurance Assistance as PrEP Strategy





# 2) Assessing Affordability and Coverage and Filling Gaps





# Assessing QHP Metal Tiers and OOP Plan Costs

QHP Metal Tiers	What It Means
Bronze	Plan pays 60% of costs (on average)/enrollee pays 40%
Silver	Plan pays 70% of costs (on average)/enrollee pays 30%
Gold	Plan pays 80% of costs (on average)/enrollee pays 20%
Platinum	Plan pays 90% of costs (on average)/enrollee pays 10%

Lower premiums, but less generous



Higher premiums, but more generous



# Putting It Together: Comparing Costs Across Plans

# John

- Makes
   ~\$17,000
   per year
   (150% FPL)
- Gets \$202/month in APTC
- Prescribed Truvada

	Bronze Plan	Silver Plan (with CSR)	<b>Gold Plan</b>
Individual premium contribution (after tax credit)	\$13/month	\$53/month	\$130/month
Annual OOP cap	\$6,850	\$2,250	\$6,850
Cost sharing	Tier 2: 30% ~\$385/mo.	Tier 2: 20% ~\$257/mo.	Tier 2: \$35
Deductible	\$6,850	\$2,000	\$500

Industry Co-pay Assistance Programs Can Help



## PrEP Access is a Part of Broader Advocacy around Affordability

HIV Health Care Access Working Group (HHCAWG) Asked and the Center for Medicaid Medicare Services (CMS) Listened!

Abigail Wood | April 16, 2014

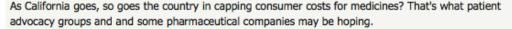
#### "I AM ESSENTIAL" COALITION URGES IMPROVEMENTS TO **ESSENTIAL HEALTH BENEFITS**



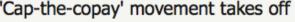
### 'Cap-the-copay' movement takes off

May, 26 2015

By: Anthony Brino



Covered California has become the first state health insurance exchange to require health plans to cap outof-pocket costs for speciality drugs. The exchange's board voted to adopt a limit of \$150 to \$500 per month for speciality medications that treat arthritis, cancer, HIV/AIDS, diabetes, hepatitis C and other complex conditions.







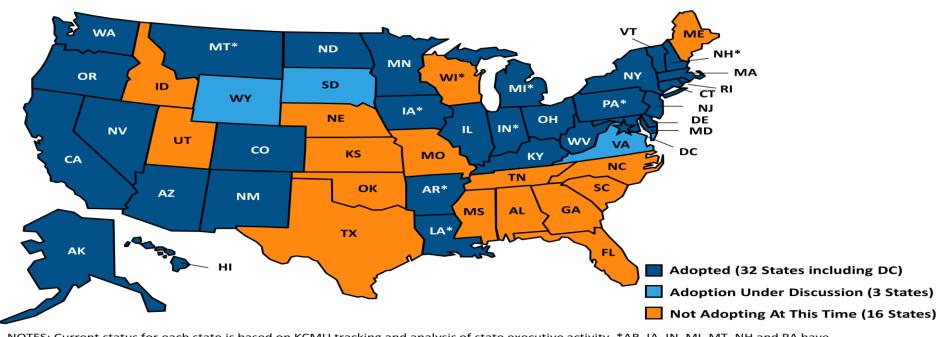
# 3) Building off of RW/ADAP Infrastructure to Create a PrEP Safety Net

- PrEP Drug Assistance Programs
  - E.g., Washington and Colorado
    - Using ADAP infrastructure and purchasing PrEP medication and insurance for HIV negative individuals with state funds
    - BUT, purchasing at full price (no 340B discount)
- Ryan White Program flexibility
  - Purchasing family plans that include an HIV negative partner
  - Limited flexibility for EIS/EIHA to include PrEP



## Medicaid Expansion = PrEP Access X Factor

### **Current Status of State Medicaid Expansion Decisions**



NOTES: Current status for each state is based on KCMU tracking and analysis of state executive activity. \*AR, IA, IN, MI, MT, NH and PA have approved Section 1115 waivers. Coverage under the PA waiver went into effect 1/1/15, but it has transitioned coverage to a state plan amendment. Coverage under the MT waiver went into effect 1/1/2016. LA's Governor Edwards signed an Executive Order to adopt the Medicaid expansion on 1/12/2016, but coverage under the expansion is not yet in effect. WI covers adults up to 100% FPL in Medicaid, but did not adopt the ACA expansion. See source for more information on the states listed as "adoption under discussion." SOURCE: "Status of State Action on the Medicaid Expansion Decision," KFF State Health Facts, updated January 12, 2016. http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/





## Resources

- National Alliance of State & Territorial AIDS Directors (NASTAD), www.NASTAD.org
  - Amy Killelea, <u>akillelea@nastad.org</u>
  - Edwin Corbin-Gutierrez, ecg@nastad.org
  - Xavior Robinson, <u>xrobinson@nastad.org</u>

#### Health Systems Integration resources

- Guttmacher Institute, Medicaid Family Planning Eligibility Expansions, May 2015, http://www.guttmacher.org/statecenter/spibs/spib\_SMFPE.pdf
- HIV Health Reform, <a href="http://www.hivhealthreform.org/">http://www.hivhealthreform.org/</a>
- Treatment Access Expansion Project, <u>www.taepusa.org</u>
- HIV Medicine Association, <u>www.hivma.org</u>
- HRSA/HAB ACA and Ryan White Resources, <a href="http://hab.hrsa.gov/affordablecareact/">http://hab.hrsa.gov/affordablecareact/</a>
- Health Care Reform Resources
  - Center on Budget and Policy Priorities, Beyond the Basics, <u>http://www.healthreformbeyondthebasics.org</u>
  - State Refo(ru)m, <u>www.statereforum.org</u>
  - Kaiser Family Foundation, <u>www.kff.org</u>
  - Healthcare.gov, <u>www.healthcare.gov</u>

#### PrEP Billing and Operations resources:

- PrEP Facts: <u>prepfacts.org</u>
- Project Inform: <a href="http://www.projectinform.org/pdf/PrEP">http://www.projectinform.org/pdf/PrEP</a> Flow Chart.pdf
- Association of Nurses in AIDS Care: <a href="http://www.nursesinaidscare.org">http://www.nursesinaidscare.org</a>
- Cicatelli: <a href="http://caiglobal.co/j\_cba/index.php/available-cba-services">http://caiglobal.co/j\_cba/index.php/available-cba-services</a>





## THANK YOU!





# **Positively Trans**



## Who we are

- National Advisory Board
  - -8 trans women of color and 1 trans men
  - From different cities
  - Majority live with HIV
  - Over half are from Southern states
- Staff
  - -1.5 people
  - -1 trans woman of color, 1 trans man of color



## We Believe

Trans women and men living with HIV are:

Capable of forming our own network

 Telling our own stories and developing our own strategies in addressing the inequities, stigma and discriminations that drive the high rates of HIV and poor health outcomes in our community.



# Among general TGNC population...

- Key Findings
  - Four times more likely to live in poverty
  - 90% experienced discrimination on the job
  - Unemployment is 2 times national average
    - Four times the national average for people of color



# Among general TGNC population:

- Key Findings Health Care (N=6,450)
  - 19% were refused medical care
  - 50% had to "teach my provider" about basic transgender health
  - 28% postponed medical care when sick or injured
  - Four times the national average for HIV (2.64%)
    - African American Transgender Women 50%



# **Positively Trans Survey**

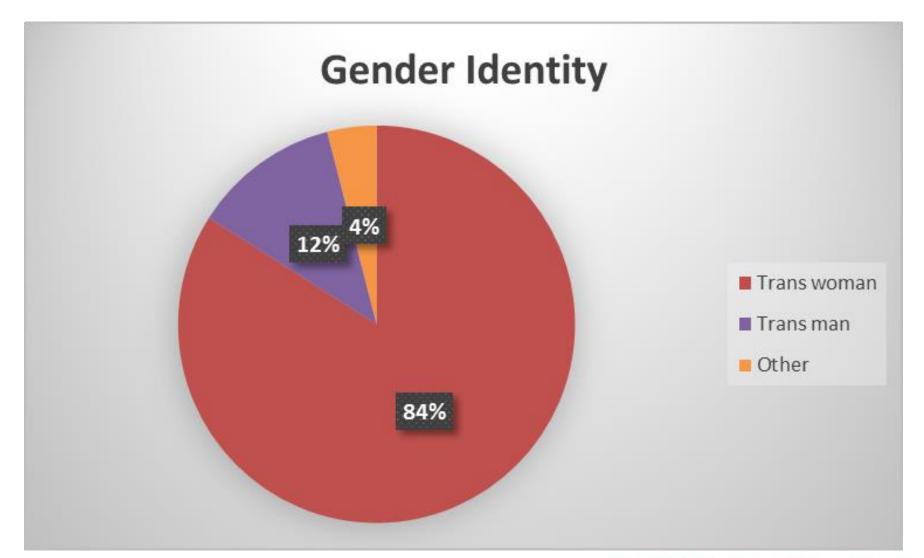
- Assessing the gaps in policy and health care landscapes in which trans people living with HIV live
- Develop our own evidences on how various social determinants affect our health outcomes
- Prioritize unmet legal and health needs



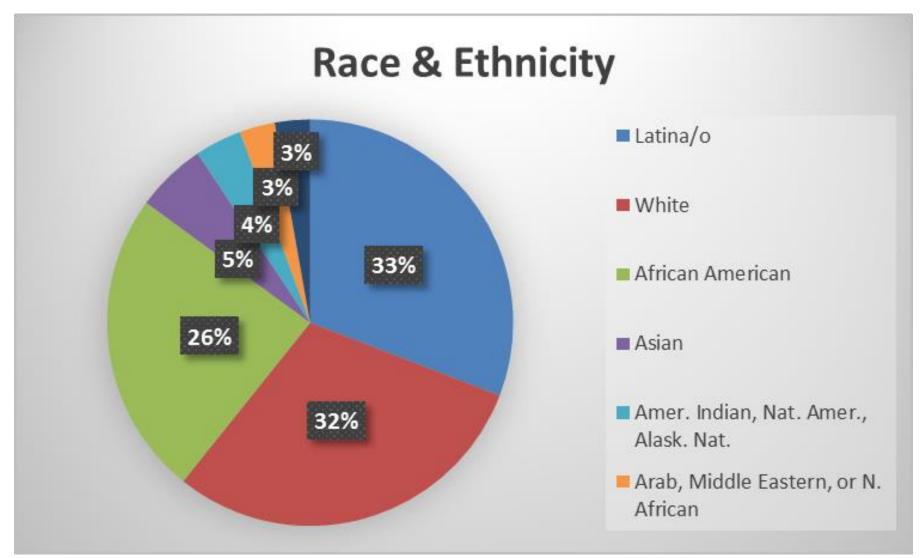
## **Overall**

- 157 complete responses in analytical sample
- 84% transgender women
- 69% people of color
- 43% making less than \$12,000 per year
- Median age: 42
- Median time living with HIV: 12 years
- Median time since coming out as transgender or gender non-conforming: 17 years











## ANALYTICAL DATA



## **TOP 5 HEALTH CONCERNS**

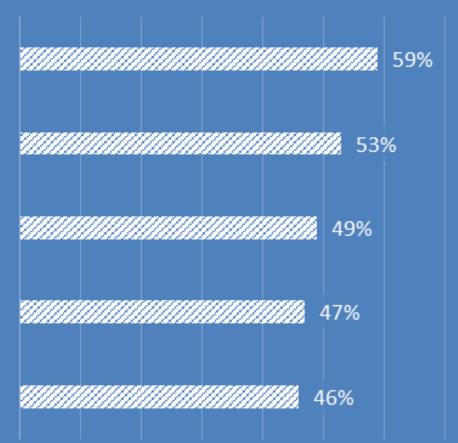
GENDER AFFIRMING AND NON-DISCRIMINATORY HEALTHCARE

HORMONE THERAPY AND SIDE **EFFECTS** 

MENTAL HEALTH CARE, INCLUDING TRAUMA RECOVERY

> PERSONAL CARE (NUTRITION, HEALTHY LIVING, ETC.)

ANTIRETROVIRAL THERAPY AND SIDE **EFFECTS** 

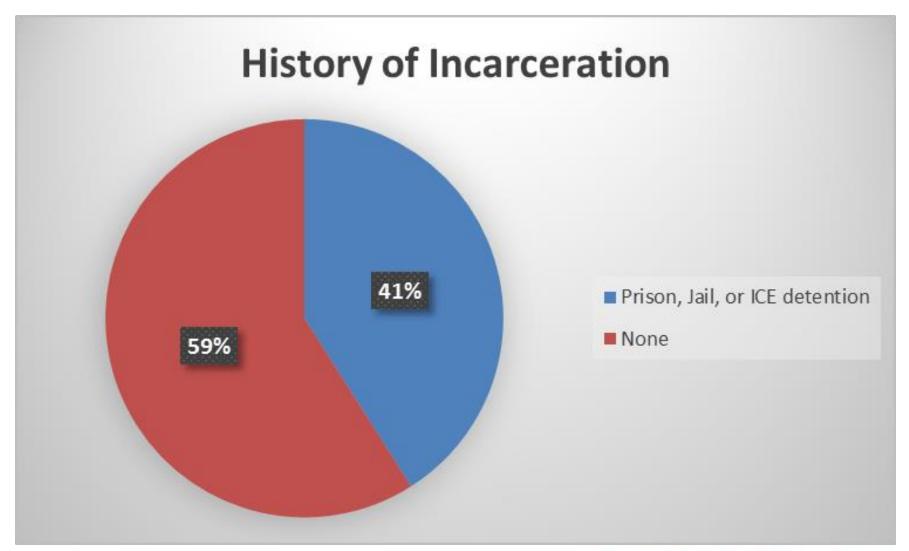




## **TOP 5 LEGAL PRIORITIES**

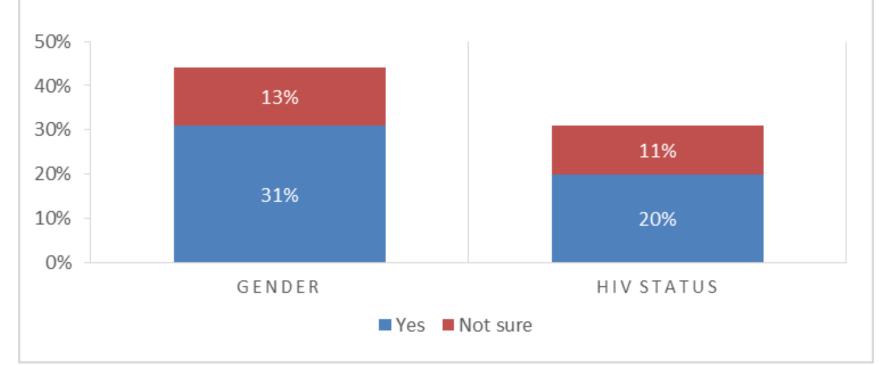




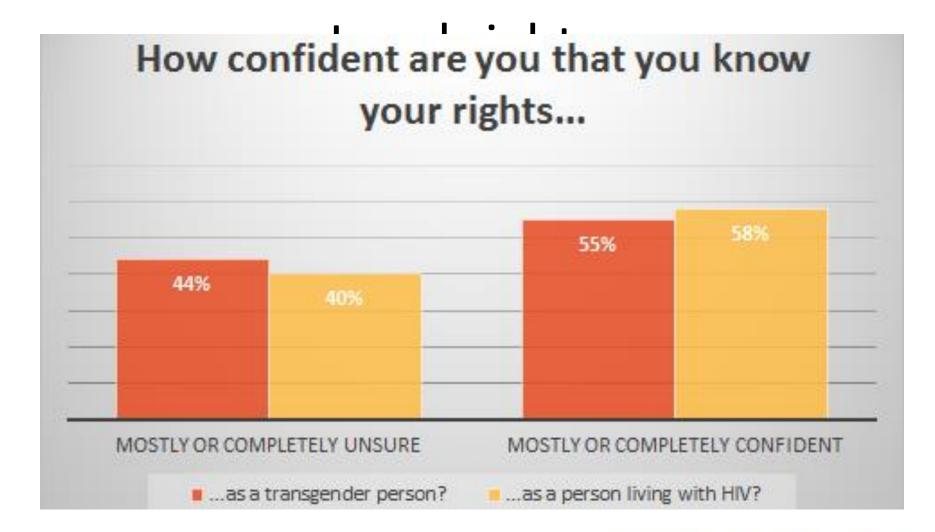




## HAS A HEALTH CARE PROVIDER EVER REFUSED YOU CARE BECAUSE OF YOUR...

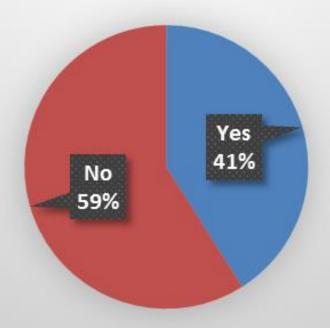








## Have you ever gone more than six months without medical care since your HIV diagnosis?





## Key Focus & Challenges

- Data Collection
- Immigration
- Detention
- Criminalization
- Violence



## Thank you!

More info: www.positivelytrans.org



# DATA TO ACTIVISM: 2014 SURVEILLANCE DATA AND OPPORTUNITIES FOR ACTIVISM

#### **Slides by Kenyon Farrow**

US & Global Policy Director Treatment Action Group

#### **Presented by Jeremiah Johnson**

HIV Prevention Research and Policy Coordinator

# PRIORITIES FOR 2016

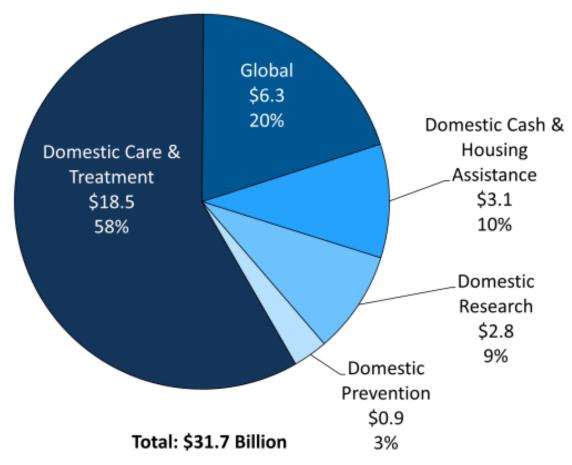
Increase Federal Spending on Prevention
Protecting AIDS Research budget
Mobilizing Public Discourse (How Ending the Epidemic as domestic priority)

Figure 2

U.S. Federal Funding for HIV/AIDS, by Category, FY 2016

Request





NOTE: Categories may include funding across multiple agencies/programs; global category includes international HIV research at NIH. SOURCE: Kaiser Family Foundation, U.S. Federal Funding for HIV/AIDS: The President's FY 2016 Budget Request; February 2015.



Figure 1

# U.S. Federal Funding for HIV/AIDS, FY 2010-FY 2016 Request





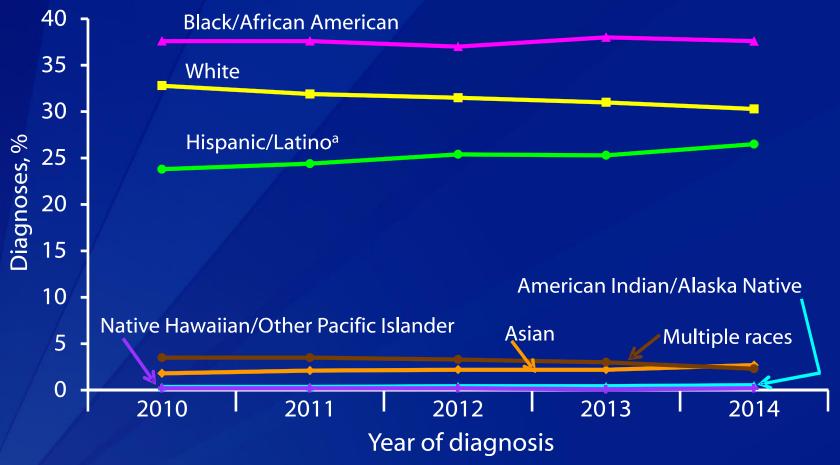
## Increase \$\$ for HIV Prevention FY17

- Likely to get flat-funding in Pres FY17 Budget
- Need budget justifications for increases in prevention \$\$\$, and why flat funding won't help us over the long haul
- We need economic argument for averting new infections, cost savings to USG and state health budgets over time
- Economic arguments for non-Medicaid Expansion states on how Medicaid/insurance coverage will help find previously undiagnosed PLWH, prevent new infections, and what overall cost savings to state will be.

### Threats to AIDS Research

- 10% NIH budget set-aside for AIDS research has been removed from Labor/HHS
- \$2Billion NIH increase in FY16 not likely to be spent on HIV research
- \$100million increase for HIV research may not be allocated to HIV
- Senator Cassidy (R-LA) led an attack on AIDS research in an Oct 2015 NIH hearing, and NIH Director Francis Collins did not vigorously defend OAR

# Diagnoses of HIV Infection among Men Who Have Sex with Men, by Race/Ethnicity, 2010–2014—United States and 6 Dependent Areas

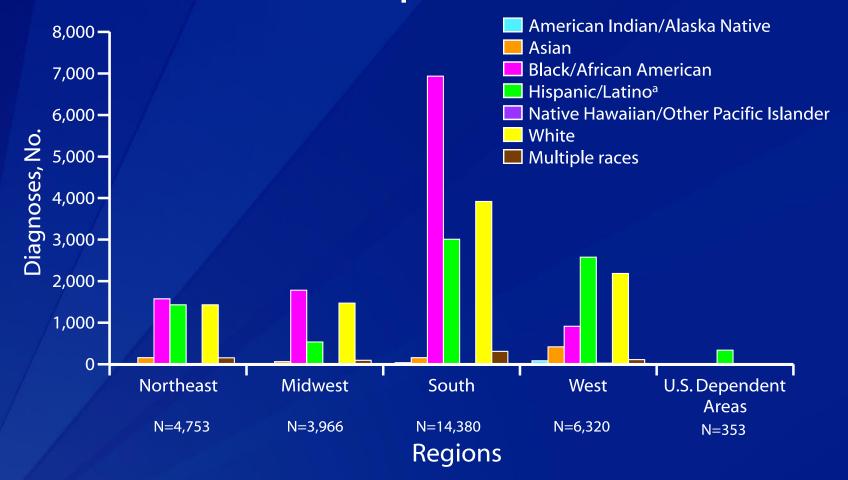


Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays and missing transmission category, but not for incomplete reporting. Data on men who have sex with men do not include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

<sup>a</sup> Hispanics/Latinos can be of any race



# Men, by Region of Residence and Race/Ethnicity 2014—United States and 6 Dependent Areas

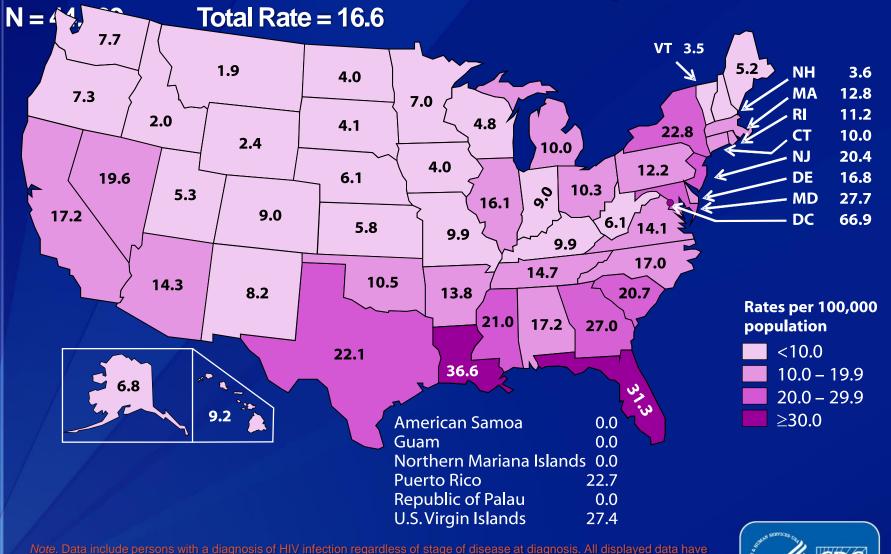


Note. Data include persons with a diagnosis of HIV infection regardless of stage of disease at diagnosis. All displayed data have been statistically adjusted to account for reporting delays and missing transmission category, but not for incomplete reporting. Data on men who have sex with men do not include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



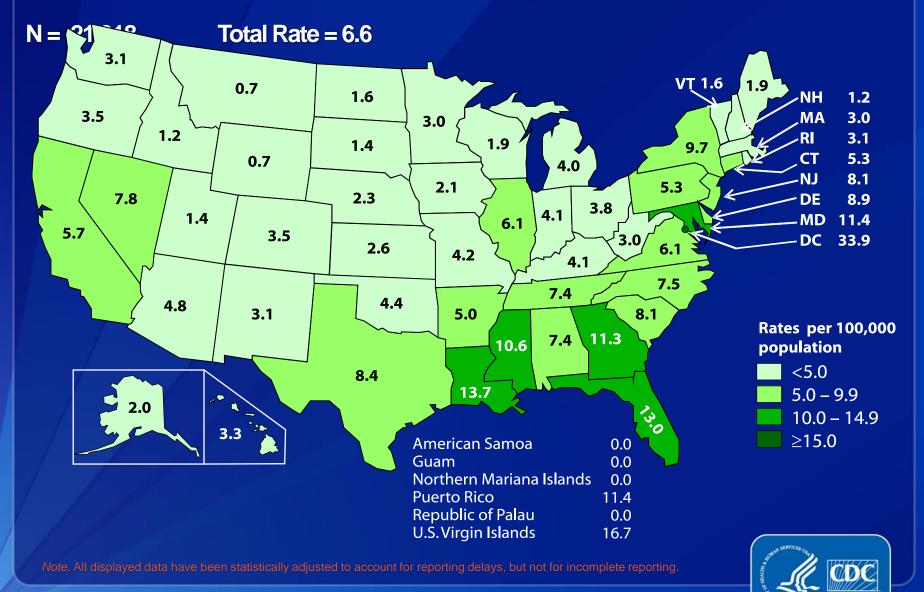


# Rates of Diagnoses of HIV Infection among Adults and Adolescents, 2014—United States and 6 Dependent Areas

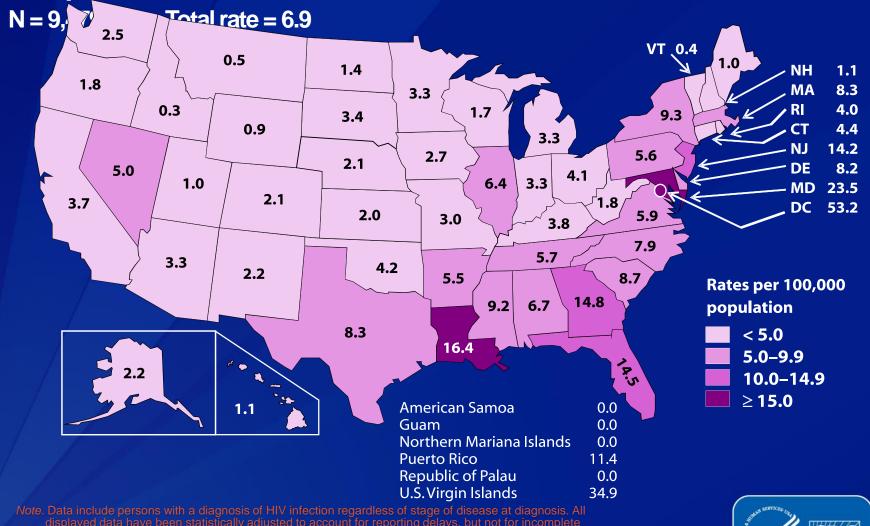


#### Rates of Stage 3 (AIDS) Classifications among Persons with HIV

### Infection, 2014—United States and 6 Dependent Areas

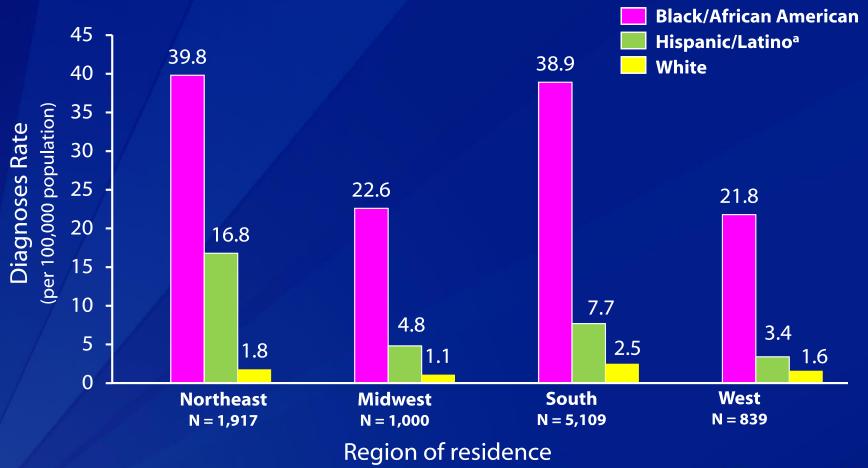


# Females, 2013—United States and 6 Dependent Areas



#### Diagnoses of HIV Infection among Adult and Adolescent

# Females, by Region and Race/Ethnicity 2013—United States



*Note.* All displayed data have been statistically adjusted to account for reporting delays, but not for incomplete reporting <sup>a</sup> Hispanics/Latinos can be of any race.



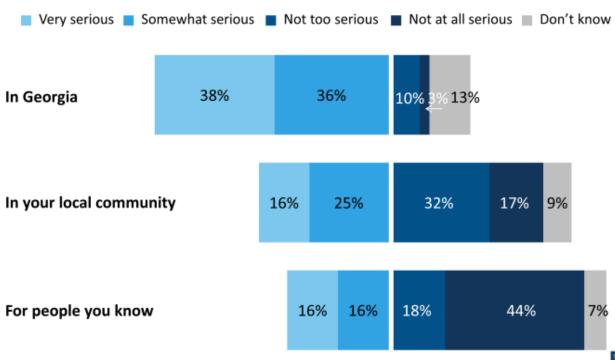
## Understanding New CDC Data

- Push for CDC to release data on where we're seeing success in reductions of new diagnoses among Black women—and study why we're having those successes.
- Need to understand the stabilizing of new diagnosis among Black MSM—are there cities/states with great reductions, but not in others?
- Why are rates among Latino MSM rising—what regions of the country is this happening at a faster rate
- Continue push for better epi on transgender women
- Push for use of incidence data alongside diagnoses changes in diagnoses can mean success in reaching people out of care, and can also mean reductions in testing, or testing the wrong people

## Georgia Survey on HIV

### Most Georgians say HIV/AIDS is a serious issue for state; fewer see as a problem as get closer to home

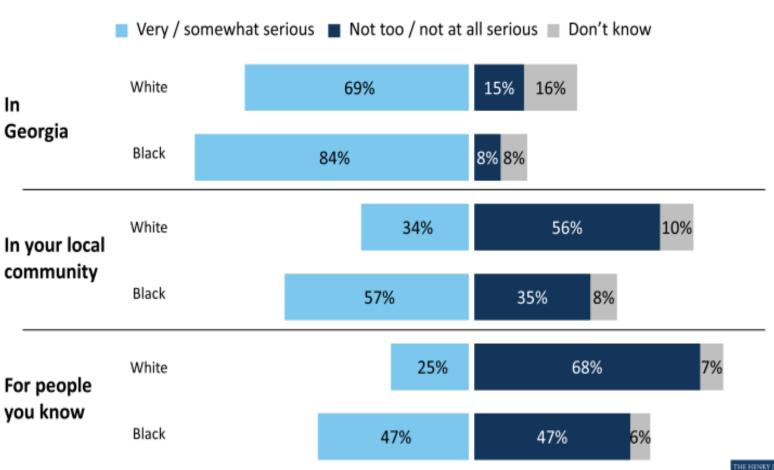
How serious of a problem, if at all, is HIV and AIDS ... today?





# Black Georgians more likely to say HIV/AIDS is a problem where they live and for people they know

How serious of a problem, if at all, is HIV and AIDS... today?





## Many not knowledgeable about advances in HIV treatment and prevention

Yes ■ No ■ Don't know enough to say
Correct Answer for all is "Yes"

Treatment as Prevention: "Antiretroviral drugs, sometimes called ARV or ART, are medications to treat HIV. If someone who has HIV is taking consistent antiretroviral treatment, does this significantly reduce the risk of passing HIV to others, or not, or don't you know enough to say?"

12% 21% 67%

**PrEP:** "Is there a prescription medication that people who do not have HIV can take to lower their risk of getting HIV, or not, or don't you know enough to say?"



#### Maternal to Child Transmission:

"Is there medication that a pregnant woman who has HIV can take to reduce the risk of her baby being born infected, or not, or don't you know enough to say?"





### The Lesson?

- Communities most impacted still care about HIV, and want to do something about
- Surveys that document attitudes, knowledge can be as important as epidemiological data to determine best strategies for mobilizing communities to change policy
- Can we find \$\$\$ to use these kinds of surveys to understand local knowledge, concern and attitudes about HIV? Can we build lists to leverage voter/stakeholder impact on HIV related policy issues, test messages, etc?
- Mobilizing not only PLWH but family members/communities concerned and impacted

- Need to make HIV a part of the election conversation where local, state, federal candidates stand on finishing expanding Medicaid, PrEP access or jurisdictions developing bold plans to end the epidemic? AIDS research as a political issue!
- \$\$\$ for HIV education to update public on new science & PrEP Access (GA survey shows Black Georgians want and need new education, but they think HIV Is a high priority, and how do we capitalize on this?)
- Target high incidence states for collecting voter/civic engagement on HIV issues?

### Questions?

## **Kenyon Farrow**

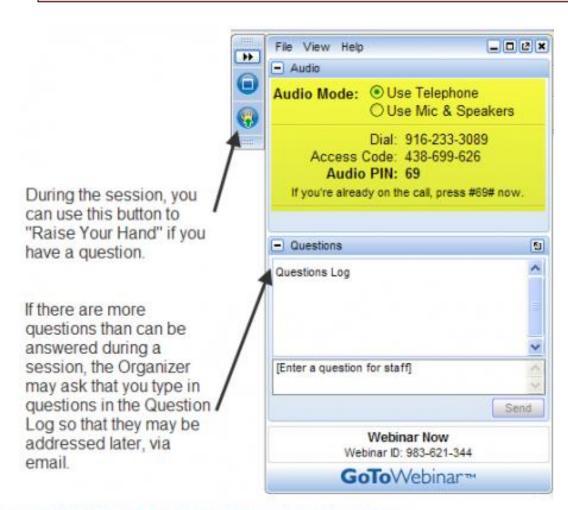
U.S. & Global Health Policy Director

**Treatment Action Group (TAG)** 

Kenyon.farrow@treatmentactiongroup.org

www.treatmentactiongroup.org

#### **Questions?**



You may also email your questions to smadoori@aidschicago.org



Download slides & materials at: www.preventionjustice.org

# Thank you!





