

**2018** NATIONAL  
**RYAN WHITE**  
CONFERENCE ON HIV CARE & TREATMENT



# Heather Hauck

*Deputy Associate  
Administrator*

Health Resources and  
Services Administration,  
HIV/AIDS Bureau



NATIONAL

2018

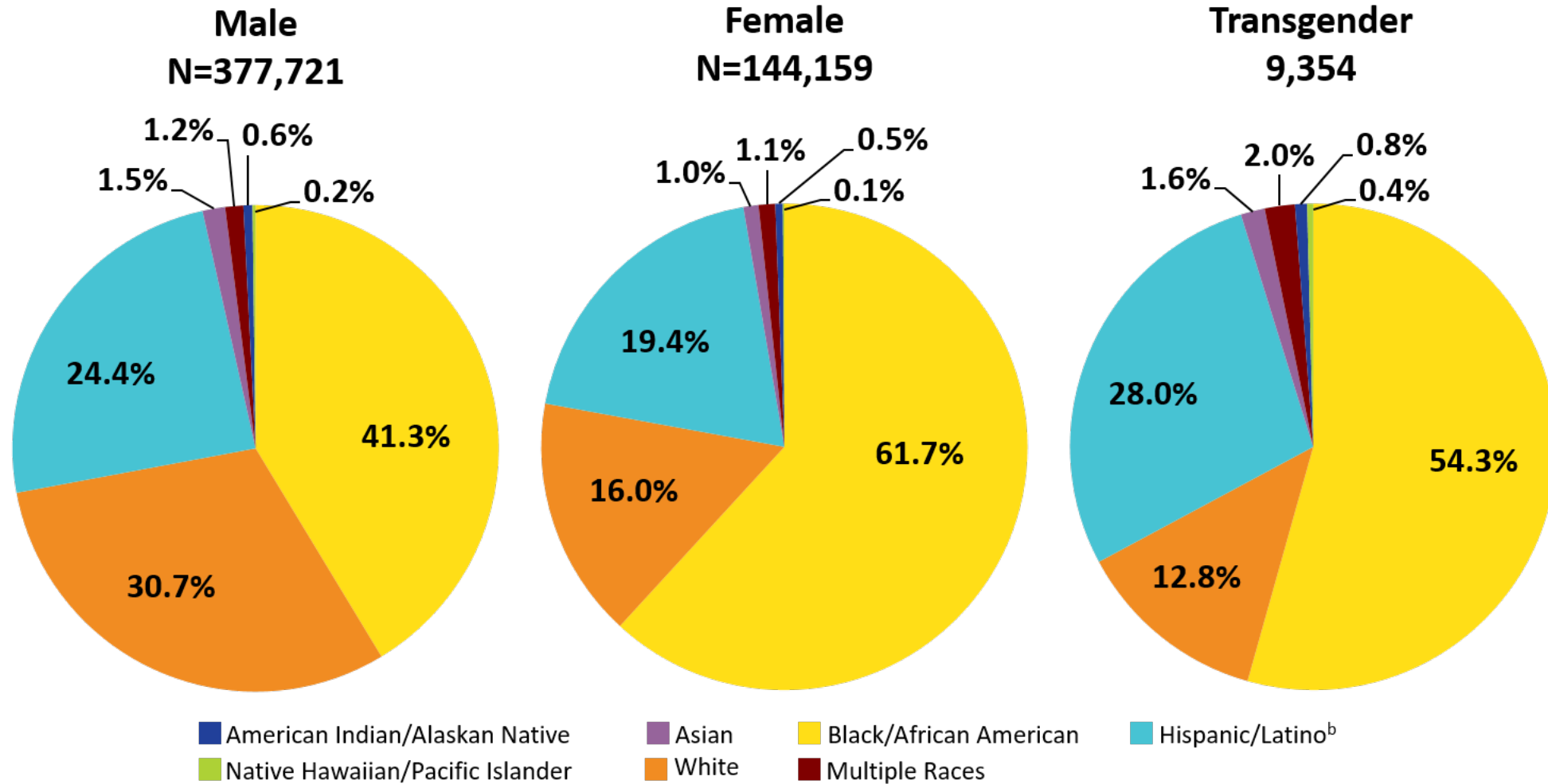
# RYAN WHITE

CONFERENCE ON HIV CARE & TREATMENT

*Catalyzing Success: Advancing Innovation.  
Leveraging Data. Ending the HIV Epidemic.*



# RWHAP Clients, by Gender and Race/Ethnicity, 2017—United States and 3 Territories<sup>a</sup>

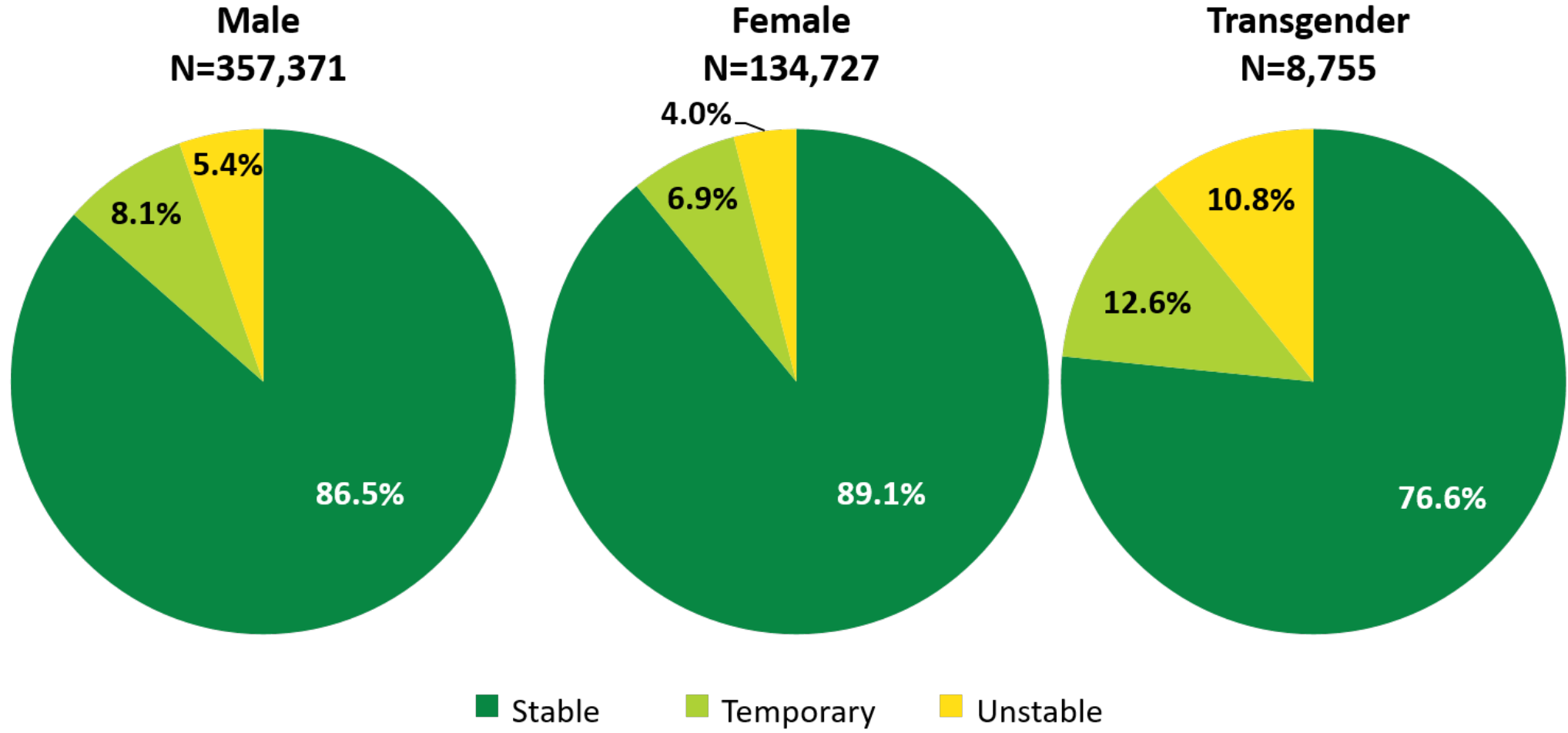


<sup>a</sup> Guam, Puerto Rico, and the U.S. Virgin Islands.

<sup>b</sup> Hispanics/Latinos can be of any race.



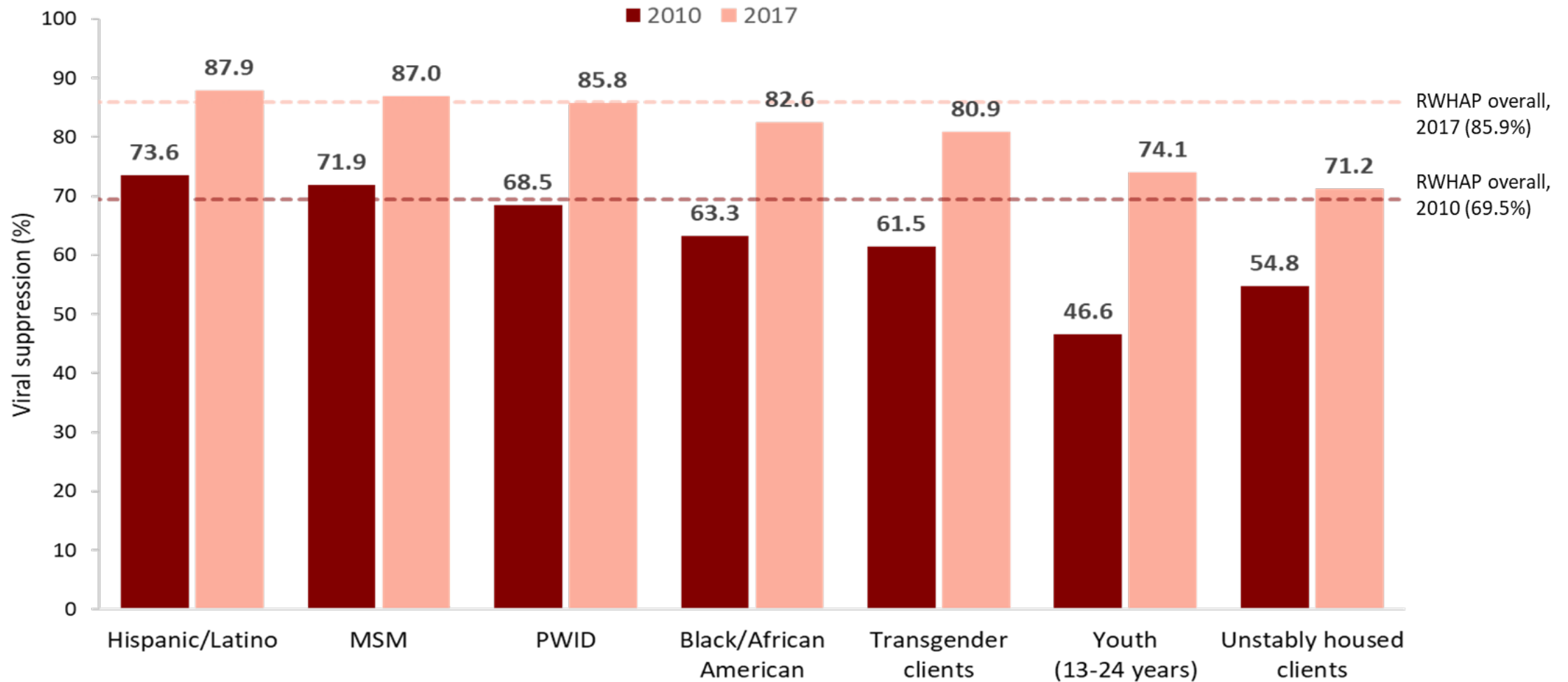
# RWHAP Clients, by Gender and Housing Status, 2017—United States and 3 Territories<sup>a</sup>



<sup>a</sup> Guam, Puerto Rico, and the U.S. Virgin Islands.



# Viral Suppression among Key Populations of RWHAP Clients, 2010 and 2017—United States and 3 Territories<sup>a</sup>



Hispanics/Latinos can be of any race.

Viral suppression:  $\geq 1$  OAHS visit during the calendar year and  $\geq 1$  viral load reported, with the last viral load result  $< 200$  copies/mL.

<sup>a</sup> Guam, Puerto Rico, and the U.S. Virgin Islands.



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# Kyle Foreman

*Director of Data Science*  
Institute for Health Metrics &  
Evaluation, University of  
Washington







# Thomas Williams

*Project Manager/Finance*  
Ryan White HIV/AIDS Program  
Part A, City of Hartford



# Overview of How Hartford Transitional Grant Area Programs Use Data to Locate and Facilitate Linkage to Care for People Co-Infected with HIV and Hepatitis C



**Tom Williams**  
**Project Manager/Finance, Ryan White Part A**  
**City of Hartford Health & Human Services**  
**Hartford CT**



# Hartford Transitional Grant Area Overview

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- The Hartford TGA has 3,428 individuals living with HIV/AIDS in a three county area: Hartford, Tolland and Middlesex.
- Providing services across 12 categories through a partnership with 16 sub-recipients. These includes hospitals, federal qualified health centers, and community based organizations
- Through a SPNS Cooperative Agreement funded through the Secretary's MAI Fund, Project ACCESS (Achieving Comprehensive Coverage Early, Systematically and Sustainably) supports 631 HIV/HCV co-infected individuals partnering with 7 medical sites



# PLWHA Demographic Highlights

- 62% of PLWHA are between the ages of 45 and 62 years old
- 40% are Hispanic, 30% are Black, and 29% are White
- 31% trace their infection to injection drug use; 28% are MSM's, and 25% Heterosexual
- In 2016, 17% were HIV/HCV Co-infected, of which approximately two-thirds were chronic and eligible for treatment



# The History of HCV Services

**Early 2000s:** Early HCV treatment start-up

**2007:** Adoption of Hepatitis HAB Measures into Quality Management plan.

**2014:** Introduction of HCV DAA's (Direct-Acting Antivirals). Providers immediately began linking clients to new treatment, leveraging existing data in CAREWare.

**2016:** HRSA Awarded Hartford TGA a 3-year Cooperative Agreement for HCV Co-infection.

**2016:** Joint HIV/HCV Consent to share implemented for CAREWare, leading to tracking co-infected individuals along the HCV continuum of care and joint provider trainings.

**2008:** All Ryan White Parts in Connecticut convert to CAREWare on one central server.

**2014:** CT enacted legislation for baby boomer HCV screening mandate.

**2016:** HCV was integrated in the Statewide Care & Prevention Plan.

**2016:** Our Part D partner CHCACT received a non-Federal grant to provide technical assistance on data linkage and treatment engagement to community health centers.

**2017:** CAREWare enhancement with HCV data fields and initiating EMR HCV data migration.



# Roadmap to HCV Data-to-Care Linkage for PLWH

## Initial Barriers

- ✓ The State of CT Dept. of Public Health's viral hepatitis surveillance system, *CTEDSS*, is not as robust as needed.
- ✓ Provider noncompliance/reluctance to screen baby boomers and others at risk resulted in underreporting of HCV incidence.
- ✓ Limited rapid testing sites among high risk populations (homeless, PWID and MSM), even among ASOs.

## Response

- ✓ Data Migration from Provider EMR's to CAREWare to augment HCV surveillance.
- ✓ Increased focus on HCV screening of at risk Ryan White clients as a result of Project ACCESS.
- ✓ Expanded rapid testing capacity among providers serving at risk populations.

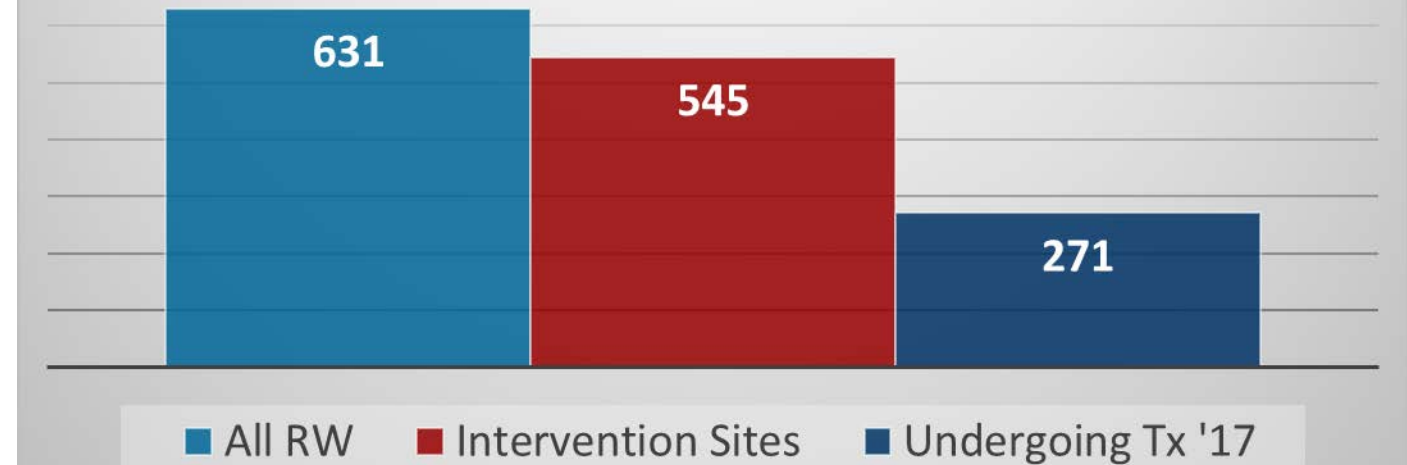


# Evolving Surveillance

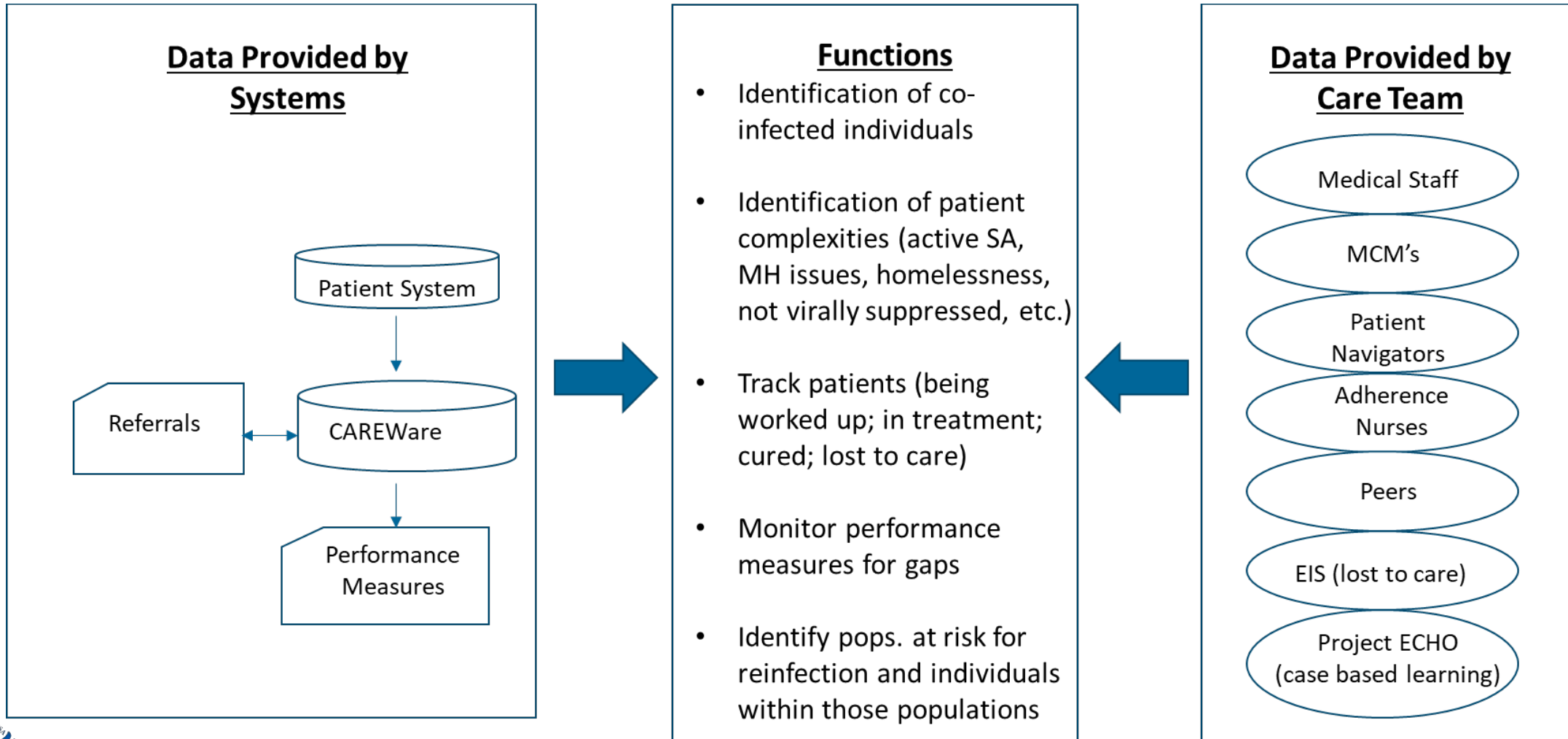
The Viral Hepatitis Action Plan benchmarks **2015** for the national HCV surveillance project

The Hartford TGA benchmarks **July 1, 2016** for its CAREWare HCV surveillance project

### Identifying Co-infected Population in CAREWare 2014 – 2017



# How Data was Used to Locate & Facilitate Linkage to Care





# Lessons Learned

- **HCV Performance Measures** need to be **simple and adaptable** to Ryan White providers
- Invest in **bridging EMR and CAREWare** to allow for clinical staff to maximize direct services provision
- **Adapt Consent to Share** information, and do it early
- Leverage existing technical support (jProg, system analyst, providers, CDC)
- Inform and **update consumers** (Planning Council)
- Seek expertise from others – **build on their successes**
- **Track** those at risk for **reinfection**
- Focus on PWID's **treatment readiness early** in the process to give extra time to successfully treat



# Future Direction

- Include HCV Language into existing Ryan White contracts
- Fold some components of the Patient Navigator function into medical case managers and peer specialists
- Keep close communication with DPH & Yale on statewide surveillance system
- Strengthen educational efforts for individuals who are treated
- Look for funding to treat HCV mono-infected individuals
- Assist Ryan White provider sites in bridging their EMR systems with CAREWare



# Contact Information

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**HCV Coinfection Program Manager**

**Phone: (860) 757-4842**

**[tengc001@hartford.gov](mailto:tengc001@hartford.gov)**





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# Camden Hallmark

*Senior Analyst*  
Houston Department of  
Health and Human Services



# Community Engagement in Cluster Detection and Response

December 12, 2018

**Camden Hallmark**

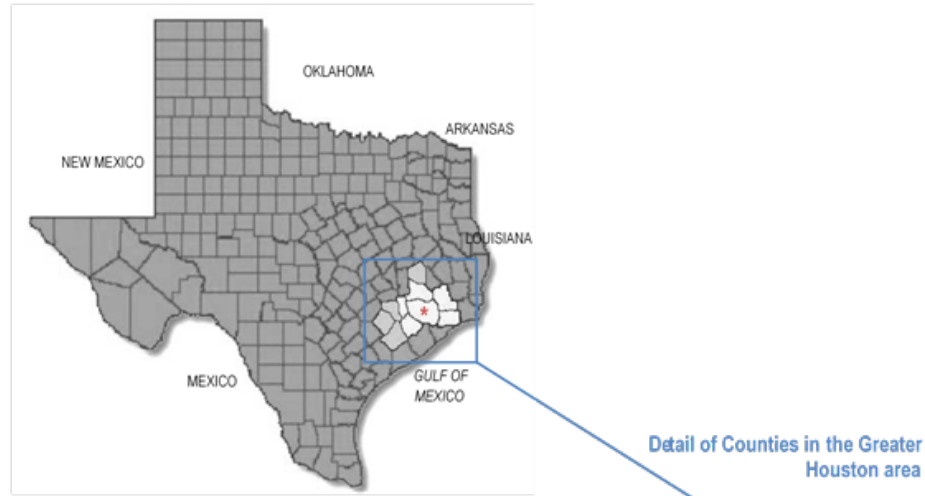
**Senior Analyst, Disease Prevention and Control Division**

**Houston Health Department**

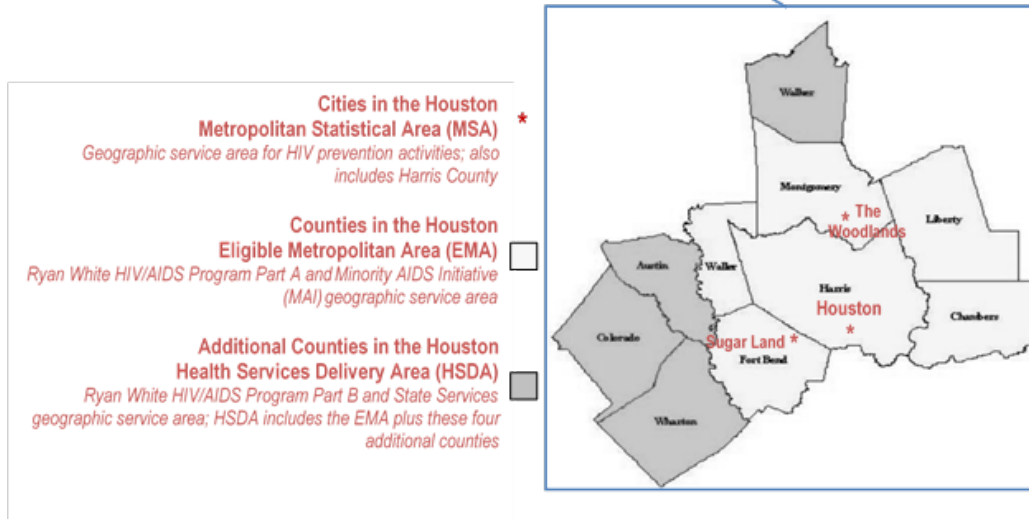


# Overview: Houston Area

Figure 1: Greater Houston area Geographic Service Designations for HIV Prevention and Care



Detail of Counties in the Greater Houston area



The Houston MSA (Houston-The Woodlands-Sugar Land) covers:

- 9 counties
- **8,266 sq. miles**, or 3.2% of the entire state
- Home to **nearly 6.9 million residents**, the majority of whom (68%) reside in Harris County

Harris County= **1,705 sq. miles, over 4.6 million residents**

- Over 70% of the total population are racial/ethnic minorities
- 43% Hispanic, 20% black or African American, 26% foreign born
- 1 in 4 uninsured



# US Department of Health and Human Services

Health Resources and Services Administration (HRSA)  
HIV/AIDS Bureau (HAB)

Division of Metropolitan HIV/AIDS Programs – A  
Division of State HIV/AIDS Programs – B

Division of Community-Based Programs (DCBP)

Ryan White Part A  
Grants to Eligible Metropolitan Areas (EMAs) and Transitional Grant Areas (TGAs)

Harris County Public Health (HCPH) Ryan White Grant Administration (RWGA)

Part A funds services including ambulatory health care, insurance coverage, medications and supportive services to EMAs/TGAs that are most severely impacted by the HIV/AIDS epidemic.

Ryan White Part B  
Grants to All States and Territories

Grants to States and Territories

AIDS Drug Assistance Program (ADAP)

Texas Department of State Health Services Ryan White Part B and State Services\*

HSDAs: Texarkana/Paris, Tyler/Longview, Houston, Beaumont/Port Arthur, Nacogdoches/Lufkin, Galveston

The Houston Regional HIV/AIDS Resource Group

Part B funds services including ambulatory health care, home-based health care, insurance coverage, medications and supportive services. The ADAP program provides medications for treatment of HIV disease.  
\*State Services: Matching funds from the State of Texas.

Ryan White Part C  
Early Intervention Services

Planning Grant Programs

Harris Health System

Harris Health System

Harris Health System

Part C funds services including medical evaluation, ongoing medical, oral health, nutritional, psychosocial and other care services including medical case management to ensure access to services and continuity of care for HIV-infected clients.

Ryan White Part D  
Service for Women, Infant, Children, Youth, and Their Families

Houston WICY Project

Positive VIBE Project

The Houston Regional HIV/AIDS Resource Group

The Houston Regional HIV/AIDS Resource Group

Part D funds medical and supportive services for women, infants, children, and youth living with HIV and their families by addressing the unique needs of these populations.

Centers for Disease Control and Prevention (CDC)  
Coordinating Center for Infectious Disease (CCID)  
National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention (NCHHSTP)

Division of HIV/AIDS Prevention (DHAP)

Division of STD Prevention (DSTDP)

Cooperative Agreements to Ten (10) Local Jurisdictions (Chicago, DC, Houston, Los Angeles, New York, Philadelphia, San Francisco, Baltimore, Fulton County, Broward County)

Houston Health Department (HHD)

Local Community-Based Organizations

HIV Prevention Cooperative Agreements fund services including HIV counseling, testing, and referral (CTR), routine HIV screening, health education/risk reduction (HE/RR), Pre-Exposure Prophylaxis, social marketing, capacity building, and evaluation.

Cooperative Agreements to All States and Territories

Texas Department of State Health Services

Houston Health Department (HHD)

Harris County Public Health (HCPH) Prevention Program

Cooperative Agreements to All States and Territories

Texas Department of State Health Services

Houston

Houston Health Department (HHD)

STD Prevention Cooperative Agreements fund disease intervention services (DIS), partner services (PS), and syphilis elimination.

# US Department of Housing and Urban Development

Office of Community Planning and Development

Division of Special Needs HIV/AIDS Housing

Housing Opportunities for People with AIDS (HOPWA) Program

Funds Distributed to States and Cities by Formula Allocations

Houston

Houston Department of Housing and Community Development

The HOPWA Program was established by HUD to address the specific needs of persons living with HIV/AIDS and their families. HOPWA makes grants to local communities, States, and nonprofit organizations for projects that benefit low income persons medically diagnosed with HIV/AIDS and their families.



# Local Context and Challenges to Engagement

- **Lack of local investment**
  - Hampers sustainability and capacity
- **Changes in local administration**
  - Policy change in hiring temporary staff
  - Procedures in applying for, accepting, and setting up grants
  - Weekly programmatic reporting
- **Political climate**
  - “Bathroom bill”
  - ICE: Lack of awareness among community groups on what government services are “safe”

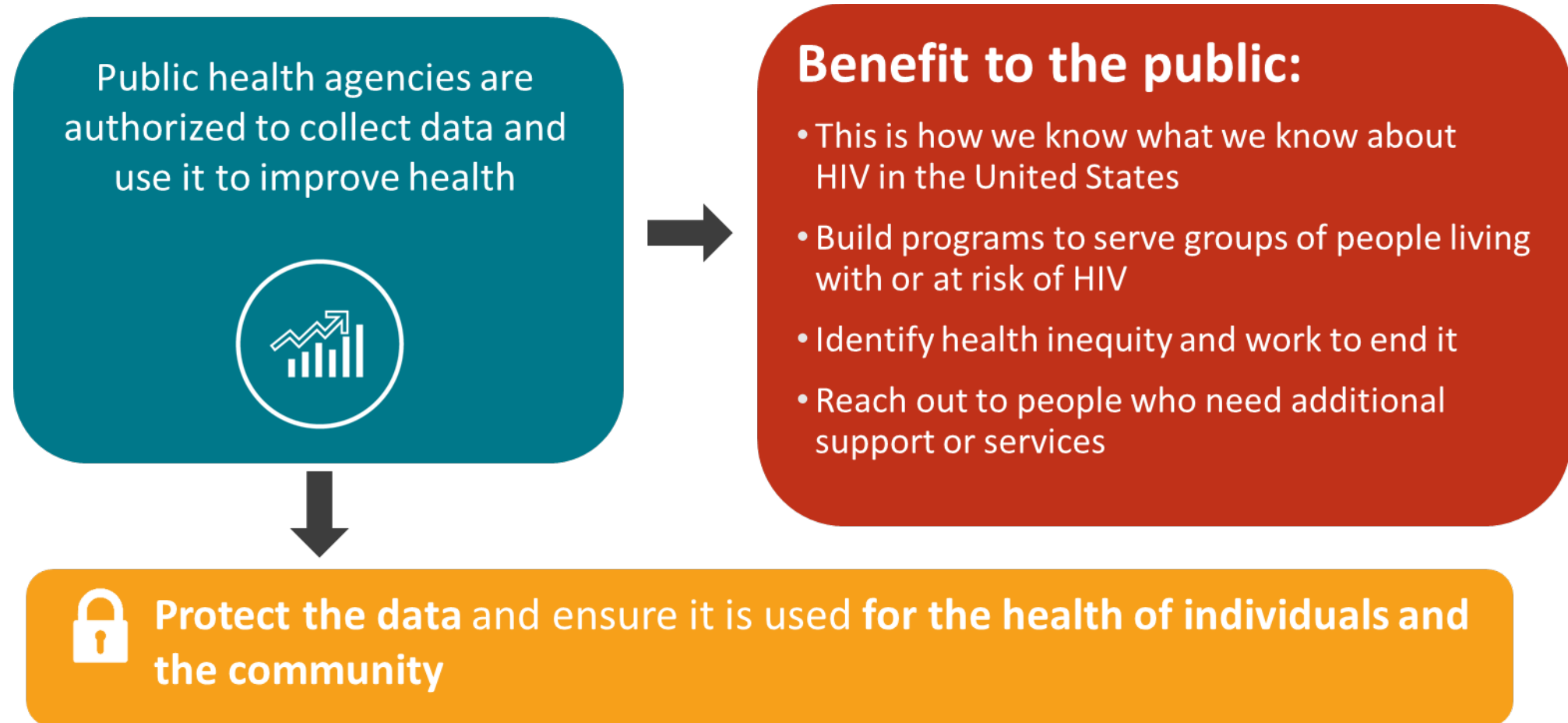
2015/2016 Local Allocation for HIV/STD		
	Allocation	2016 Rank New HIV Diagnoses
NYC	\$37 million	22
San Francisco	\$28.1 million	26
Chicago	\$3.2 million	37
Atlanta	\$629,811	4
Baltimore	\$503,802	14
<b>Houston</b>	<b>\$0</b>	<b>10</b>



Sources: Funding information self-reported by jurisdictions; Ranking from 2016 CDC HIV Surveillance Report, table 28.



# Public Trust is the Foundation of Our Work

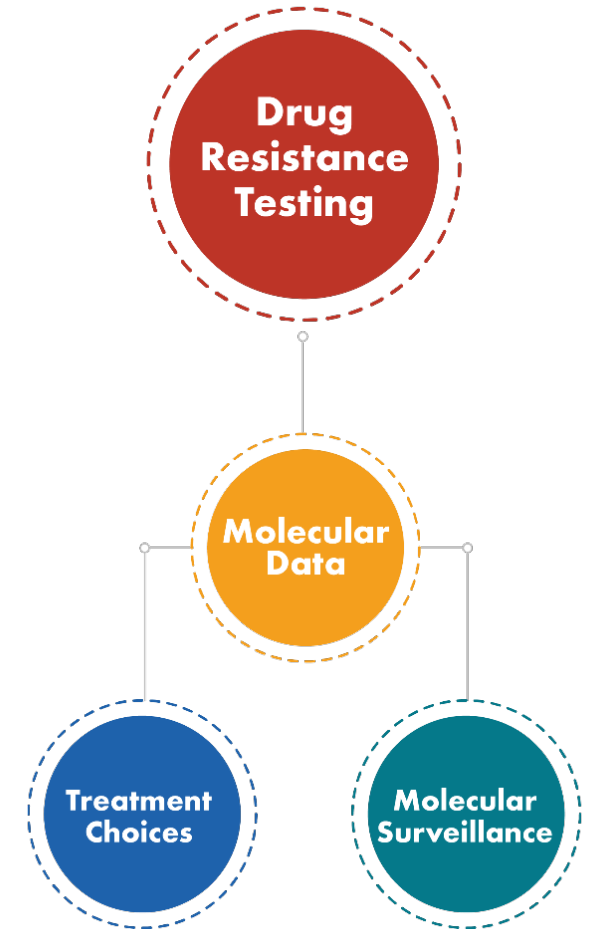


Source: National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Guidance, CDC



# Molecular Data

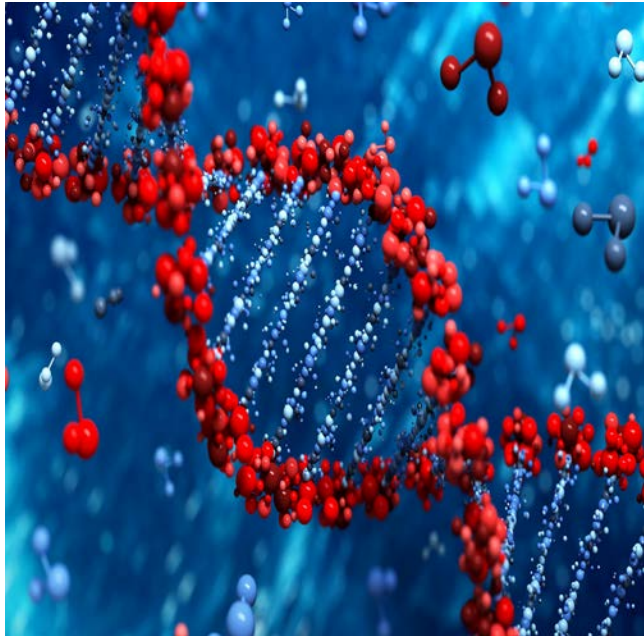
- As part of HIV care, health care providers order testing to learn what treatments will work best for a person's HIV strain
  - Called drug resistance testing
  - This testing involves determining the genetic sequence of the virus (NOT the person)
- We sometimes call the genetic sequences 'molecular data'



Source: National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Guidance, CDC



# What is Molecular HIV Surveillance (MHS)?



- MHS is the **collection, reporting, and analysis of HIV genetic sequences** generated through HIV drug resistance testing.
- Analysis of MHS data reveals that similar viral strains indicate that **transmission probably happened recently and establishes a link between individuals.**
- Molecular surveillance is not new to public health – it has been used for years to track foodborne infections and diseases such as TB. **MHS is quickly becoming a part of routine HIV surveillance and can identify transmission clusters that would otherwise go unrecognized.**

# Limitations of Molecular Analysis

What can we infer when two sequences are closely related?

What can we infer when two sequences are closely related?



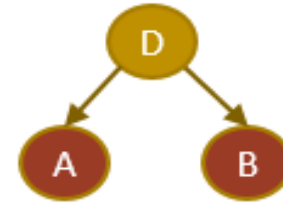
Person A infected person B



Person B infected person A



Person A infected person C, who infected person B



Persons D infected persons A and B

We can infer the presence of a direct OR indirect epidemiologic link;  
we **cannot** infer directionality



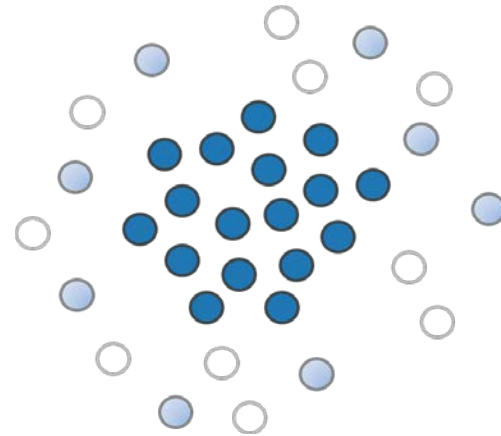
Source: National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Guidance, CDC



# What Public Health Agencies Do With Molecular Data

## What does public health surveillance do?

- Detect developing outbreaks
- Find and help sick people
- Help people at risk to stay well
- Target limited resources to the people and areas that need them most



## Reach out to these networks

- Reach out to these networks
- Provide the services they need
- Understand barriers to care and prevention
- Develop approaches to overcome them



Source: National Center for HIV/AIDS, Viral Hepatitis, STD, and TB Prevention Guidance, CDC



# Collaboration with RWGA and RW Providers

- Educate agency staff and clients about MHS and cluster detection
  - Importance of drug resistance testing
- Cluster members and social/sexual networks at RW agencies
  - Referrals by case managers to the HHD for MHS response project?
- Facilitating linkage and retention together (TasP)
  - Interface to exchange care appointment and prevention data electronically for Linkage Program clients
  - Missing appointments: referrals from RW providers to the HHD (95 in past year)
- Activity alignment with Integrated Plan
- Other prevention interventions (testing and PrEP for social/sexual network)



# Critical Community Meeting

- Pre-meetings with local researchers from the University of Texas School of Public Health (UTSPH) working in social network analysis and genetic modeling techniques
- Invitation letter to planning bodies (CPG, RWPC), CBOs, agencies working with Hispanic/Latinx population
- Available to answer questions: Bureau of Epidemiology, UTSPH researchers
- Requested feedback on *if* the HHD should apply for a cluster detection and response demonstration project and any activities missing or needing revision



CITY OF HOUSTON  
Houston Health Department

Sylvester Turner  
Mayor

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[www.houstontx.gov](http://www.houstontx.gov)  
[www.houstonhealth.org](http://www.houstonhealth.org)

May 8, 2017

Dear Colleague,

With the National HIV/AIDS Strategy as a guiding force, the Bureau of Epidemiology and the Bureau of HIV/STD and Viral Hepatitis at the Houston Health Department (HHD) continue to enhance services and expand our response to the HIV epidemic. As part of this initiative, these Bureaus have sought and continuously been awarded demonstration project funding since 2012. We have been a site of innovation, pushing our response to new levels by harnessing all available tools.

You may be familiar with our current demonstration project that includes new ways of using data to monitor health outcomes and re-engage people into HIV medical care. We have recently become aware of a new funding opportunity that will also rely on the power of data to inform action. The Centers for Disease Control and Prevention (CDC) released a funding opportunity announcement that will "support demonstration projects to use molecular HIV surveillance data to pinpoint networks that include Hispanic/Latino MSM in which active HIV transmission is occurring, and target high-impact HIV prevention services for persons in these networks. Networks with active transmission include persons with diagnosed HIV infection who have genetically similar HIV strains (i.e., molecular clusters); HIV-negative persons at risk for acquiring HIV, and persons with undiagnosed HIV infection."

Although our community can greatly benefit from any activities and capacity that this opportunity may present, we cannot and will not move forward without the insight of our external partners. As the use of surveillance data for prevention and care intervention continues to evolve, we desire to proceed in a thoughtful and meaningful way. Therefore, I am writing this letter to request that you send representatives from your leadership team to an upcoming meeting to discuss this work. On **May 16<sup>th</sup>, 2017 from 9:30-11:00am**, the Bureau of Epidemiology and the Bureau of HIV/STD and Viral Hepatitis will (1) discuss data this grant opportunity harnesses, (2) outline what activities the HHD plans to propose in our response, (3) seek input and ideas from your organization, and (4) request your organization's support for our application.

As you know, Houston is one of the epicenters of the Southern US epidemic. We look forward to your invaluable input and partnership to most effectively respond and increase our capacity to serve this great city. If you should have any questions, please contact Camden Hallmark at 832-393-4545 or [camden.hallmark@houstontx.gov](mailto:camden.hallmark@houstontx.gov).

Sincerely,

A handwritten signature in black ink, appearing to read "Stephen L. Williams".

Stephen L. Williams, M.Ed., MPA  
Director, Houston Health Department





# Facilitator: Transparency and Continuous Community Engagement

- Long history of transparent collaboration
  - Be transparent in new initiatives!
  - Realistic constraints transform community into partners in your prioritization efforts
- Engage with the stakeholders that community engages with (e.g., CAB, providers, CBOs)
  - Cross-representation between CAB and RWPC
- Disseminate project plans/results and encourage others to do so as well



From Research to the Real World:  
**Sharing Science  
Symposium**



HOUSTON HEALTH  
DEPARTMENT

Baylor  
College of  
Medicine



# Additional Challenges

- Lack of awareness among HIV workforce and community on surveillance in general (and nearly none on MHS)
- Nationally, some communities feel implementation already began without community engagement
- **Language matters! Control of messaging- can only control what messages and language used by the HHD**
  - Other health departments and agencies (both government and non-government) may use language that local community finds stigmatizing
  - Challenge: Stigmatizing language is not the same for all communities, all individuals and may change over time



# Community Feedback

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- Criminalization implications
- People-first language in all messaging
- More data and inclusion of the transgender population and sex worker community
- Relief that current methodology does not determine “source” of infection, but this could be useful in halting spread
- Barriers, such as housing and employment, need more resources
  - Medical intervention not only thing needed
  - Community is frequently asked about barriers (focus on creating solutions)
- Continuous communication throughout projects, not just at initiation



# Acknowledgements

**Co-PIs: Marlene McNeese, Kirstin Short**

## **Collaborators**

- UTHealth, School of Public Health
- Community Advisory Board: FLAS, Avenue 360, AAMA
- Ryan White Planning Council
- Community Planning Group
- Ryan White Grants Administration, Harris County Public Health

## **MHS Team**

- Moctezuma Garcia
- Ricardo Mora
- Abbhirami Rajagopal
- Rachel White
- In-Kind: Lupita Thornton, Camden Hallmark



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# Kneeshe Parkinson

*Community Health Navigator/  
Missouri State Lead*

Project ARK at Washington  
University in St. Louis



# Kneeshe's Story

Be

The

Rock

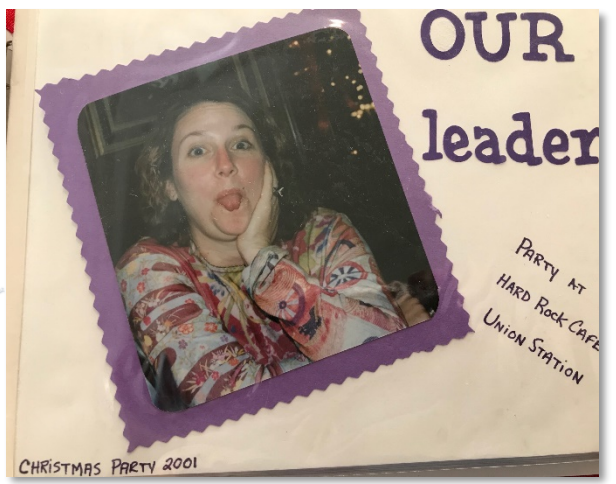
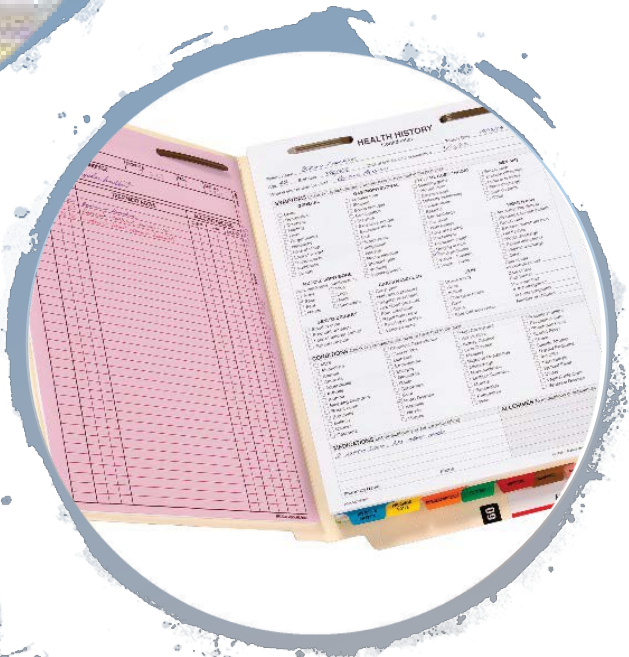


# My Life : Before HIV





# HIV Came into My Life



# The Immediate Aftermath



My Best Friend, Krista



My Sister



Me and My Sister

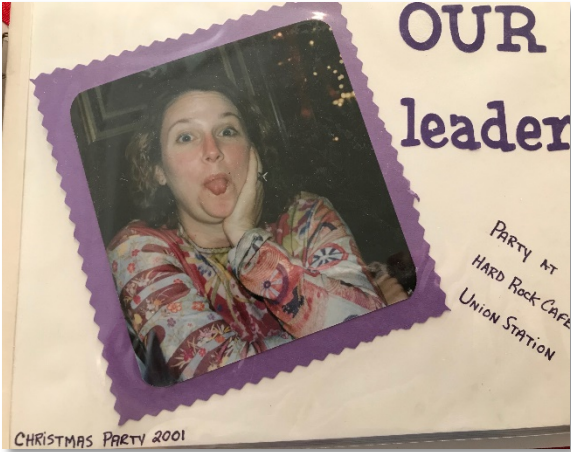
My Mood



# Starting to Get Better



My Clinic



Jessica



Me



# HIV+ Women -Strong ACTIVE Healthy

I want people to look at me and say...



Kneeshe Parkinson


Because of you I don't Hide my... **HIV** Status

**Introduction**

- While treatment has significantly improved the life expectancy of people living with HIV, there are still many challenges to be addressed.
- We continue to explore their lives and how we can better support them with comprehensive treatment for antiretroviral therapy.

**Method**

- Qualitative research was conducted with PLHIV to identify their needs and preferences.
- A steering committee of members and community leaders was formed.
- The study was conducted from July 2017 to January 2018.
- Individual interviews were conducted with participants, and social media was used to reach a wider audience.
- All eligible participants were aged 18 years and older.
- URR link to the study was provided according to the study protocol.
- Data was analyzed using thematic analysis.



love has no labels

®





My Aunt  
Helena Hatch

## THE DENVER PRINCIPLES

(Statement from the advisory committee of the People with AIDS)

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

### What HIV Showed Me About Myself

"I am not a victim. Working and walking in truth, integrity and service takes a lot of courage..."



**BELIEVE**



# Heather Hauck

*Deputy Associate  
Administrator*

Health Resources and  
Services Administration,  
HIV/AIDS Bureau





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