



# HRSA HIV/AIDS Bureau Community Engagement Framework Activities

2022 National Ryan White Conference on HIV Care and Treatment

*August 25, 2022*

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**HIV/AIDS Bureau (HAB)**

**Vision: Healthy Communities, Healthy People**



# Disclosures

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**Tamika Martin** and **Erin Nortrup** have no relevant financial interests to disclose.

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Commercial support was not provided for this activity.



# Community Engagement Institute Learning Objectives

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1. Participants will learn how HRSA's HIV/AIDS Bureau is prioritizing community engagement to improve HIV strategies and outcomes.
2. Participants will explain how storytelling can change decision maker's minds about programs and policy.
3. Participants will describe effective strategies used by RWHAP recipients to make systems changes that are responsive to community needs.



# Health Resources and Services Administration (HRSA)

## Overview



Supports more than 90 programs that provide health care to people who are geographically isolated, economically or medically challenged



HRSA does this through grants and cooperative agreements to more than 3,000 awardees, including community and faith-based organizations, colleges and universities, hospitals, state, local, and tribal governments, and private entities



Every year, HRSA programs serve tens of millions of people, including people with HIV/AIDS, pregnant people, mothers and their families, and those otherwise unable to access quality health care

# HRSA's HIV/AIDS Bureau Vision and Mission

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## Vision

Optimal HIV care and treatment for all to end the HIV epidemic in the U.S.

## Mission

Provide leadership and resources to advance HIV care and treatment to improve health outcomes and reduce health disparities for people with HIV and affected communities.



# HRSA's Ryan White HIV/AIDS Program (RWHAP) Overview

- Provides a comprehensive system of HIV primary medical care, medications, and essential support services for low-income people with HIV.
- Funds grants to states, cities, counties, and local community-based organizations to improve health outcomes and reduce HIV transmission.
  - Recipients determine service delivery and funding priorities based on local needs and planning process.
- Provided services to nearly 562,000 people in 2020—more than half of all people with diagnosed HIV in the United States.
- 89.4% of RWHAP clients receiving HIV medical care were virally suppressed in 2020, exceeding national average of 64.6%<sup>i</sup>.



# Agenda

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- Community Engagement institute overview
- Community Engagement institute learning objectives
- HAB's Community Engagement activities
- Community Engagement framework
- Recipient spotlight
  - Virginia Department of Health
  - City of Newark, New Jersey
  - Miami-Dade County, Florida Ryan White Parts A & B



# Why is Community Engagement Important?

- The voices of people with HIV, their communities, and the greater communities that support people with HIV have been the cornerstone of the HRSA RWHAP since its passage by Congress in 1990.
- While the RWHAP has successfully provided care, support, and treatment for more than 561,000 people with HIV in 2020, there remains hundreds of thousands of people who have HIV but are not diagnosed or are inconsistently in care.
- With a renewed focus on community engagement to meet the goals for Ending the HIV Epidemic in the U.S. initiative, our collective success depends on how well communities are involved in the planning, development, and implementation of HIV care and treatment strategies.



# Community Engagement in HAB's Notices of Funding Opportunities (NOFOs)

- RWHAP Part A
  - Recipients should work with their community and public health partners to improve outcomes across the HIV care continuum.
  - HRSA and CDC support activities that facilitate collaboration and/or develop a joint planning body to address prevention and care.
  - Community engagement is an essential component for planning comprehensive, effective HIV prevention and care programs in the United States.
- RWHAP Part B and Part C
  - Recipients are encouraged to assess the outcomes of their programs along the HIV care continuum and work with their community and public health partners to improve outcomes so that individuals diagnosed with HIV are linked to and engaged in care and started on antiretroviral therapy (ART) as early as possible.



# Community Engagement in HAB's Notices of Funding Opportunities (NOFOs)

- RWHAP Part D
  - Recipients should work with community and public health partners to integrate awareness, universal education, and intimate partner violence (IPV) screening, counseling, and referral across the WICY population.
- RWHAP Part F Dental
  - Recipients should work with their community and public health partners to improve outcomes across the HIV care continuum.
- EHE Cooperative Agreements
  - Proposed activities may include, but are not limited to: community engagement, etc.
  - Recipients should work with their community and public health partners to improve outcomes across the HIV care continuum.



# Community Engagement Framework: Where We Began



# Community Engagement Framework: Where We Are Today



## Community Engagement Guiding Principles

“voices of the community from beginning to end”



# Contact Information

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# Virginia Department of Health

Ryan White Part B

# CONSUMER ENGAGEMENT in Virginia RWHAP B through Quality Management

Kimberly Scott

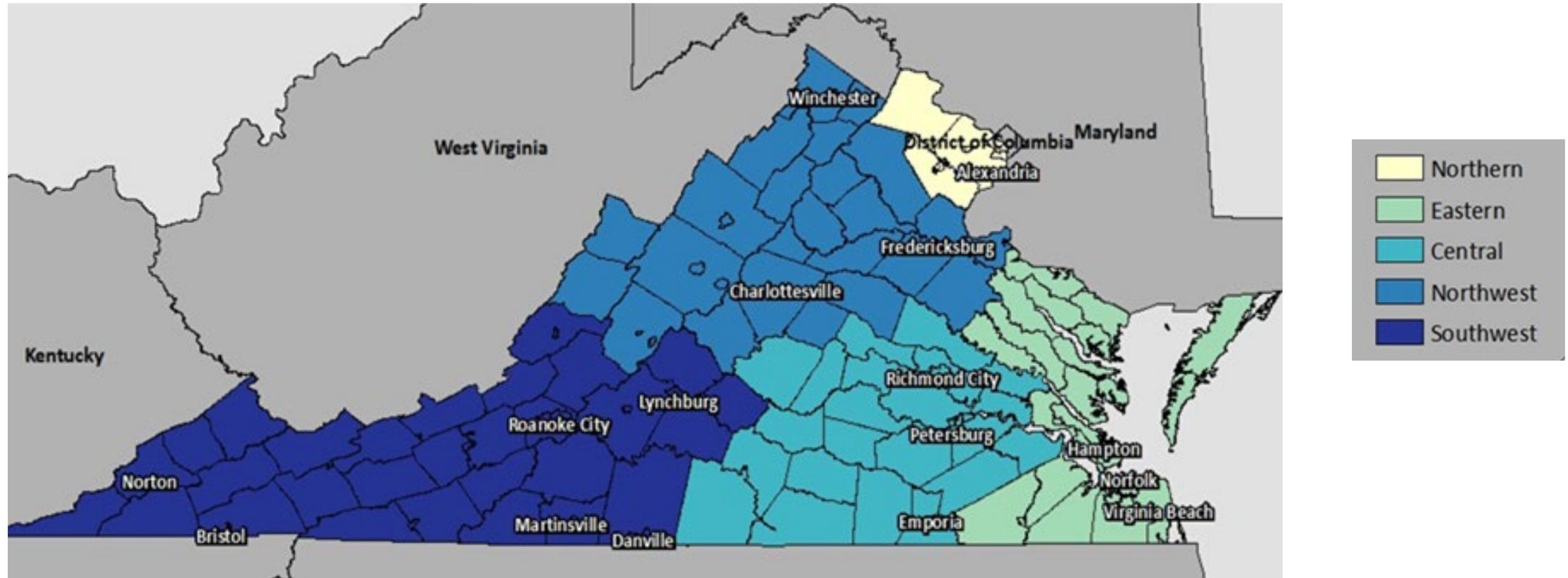
Director, HIV Care Services

**20** VA RWHAP B

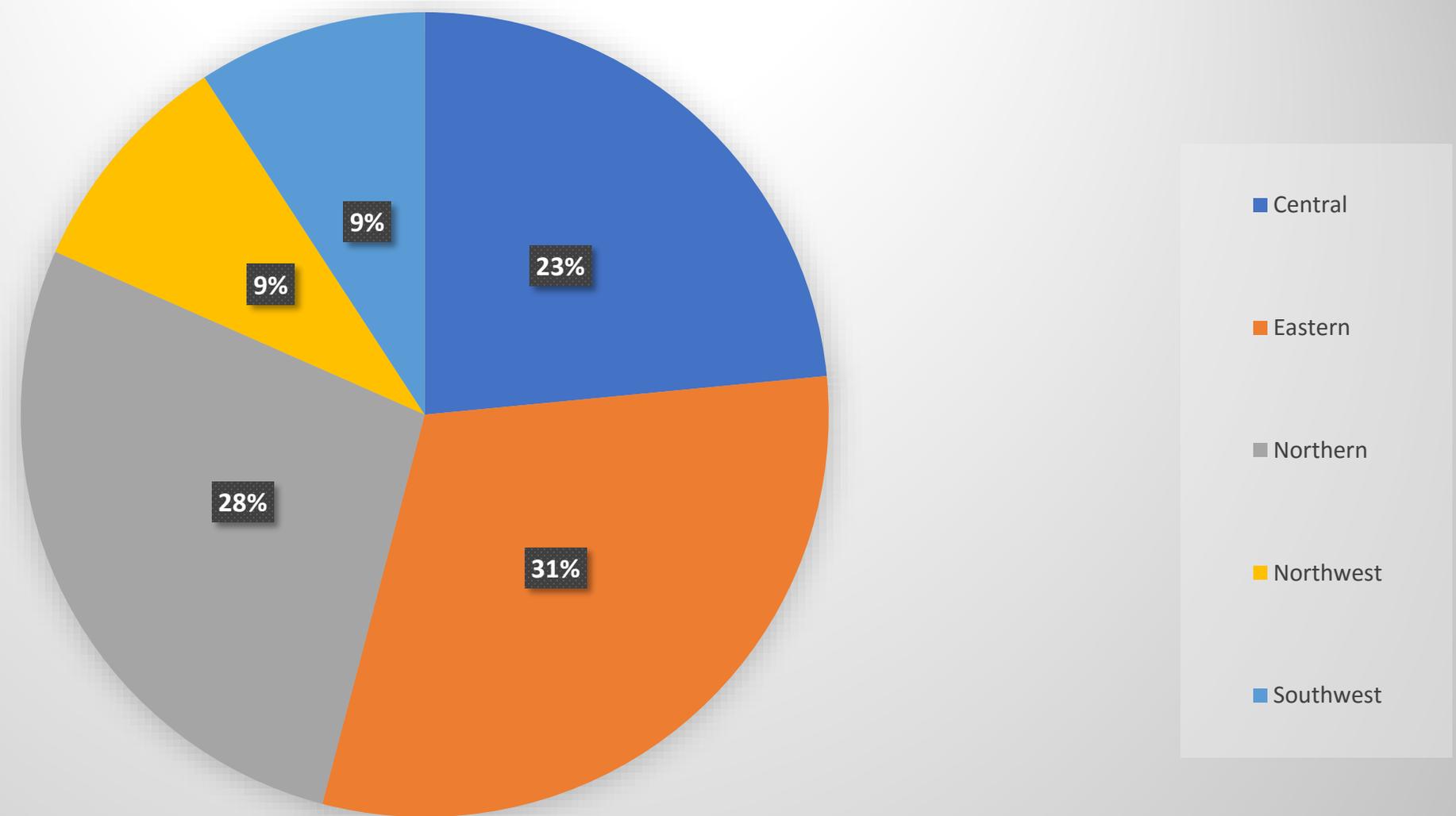
**22** Virginia Department of Health

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# Commonwealth of Virginia: Five Health Regions

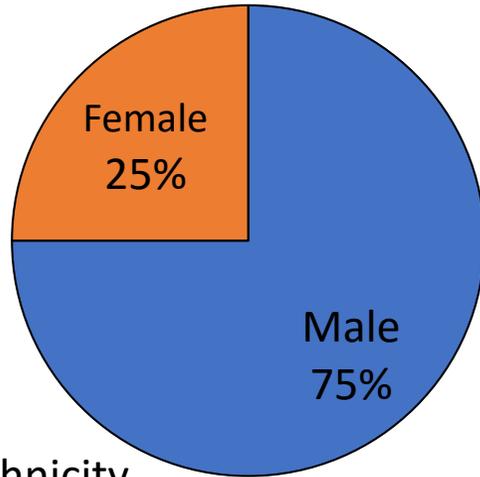


# Burden of Disease by Health Region as of December 31, 2021



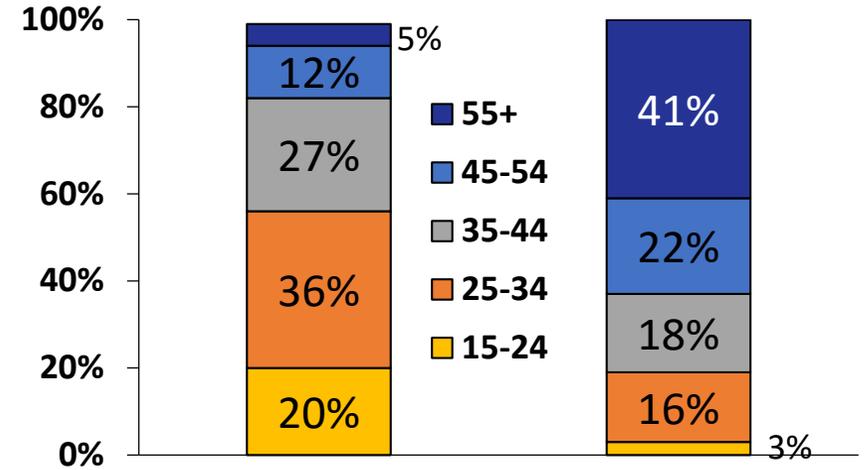
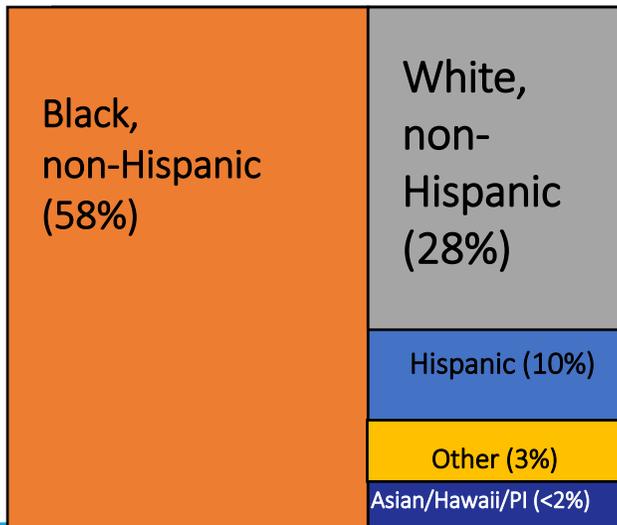
# Persons Living with HIV in Virginia as of December 31, 2021 (N=26,080)

Gender



87% aware of HIV status

Race/Ethnicity



Transmission Risk	% of PLWH
Men who have sex with men (MSM)	50%
No reported or identified risk (NIR/NRR)	21%
Heterosexual contact	19%
Injection drug use (IDU)	6%
MSM-IDU	3%
Other (mother-to-child and receipt of blood products)	1%

# Unmet Need in Virginia, 2020

## 26%

### Late Diagnoses

Number of people with late diagnosed HIV (first CD4 test result <200 cells/mL; CD4 percentage <14; or AIDS- defining condition ≤3 months after diagnosis) in the most recent calendar year (N=166)



**Denominator:** number of people in Virginia with HIV diagnosed in the most recent calendar year based on residence at time of diagnosis (N=630)

## 18%

### Unmet Need

Number of people living with diagnosed HIV infection **without** a CD4 test or VL test in the most recent calendar year (N=3,844)



**Denominator:** number of people living with diagnosed HIV in Virginia based on most recent known address who had an HIV diagnosis or any other HIV-related lab reported during the most recent 5-year period (N=21,183)

## 12%

### Virally Unsuppressed

Number of people living with diagnosed HIV infection who are in care and whose most recent viral load test was >200 copies/mL in the most recent calendar year (N=2,031)



**Denominator:** number of people living with diagnosed HIV infection in Virginia with a CD4 test or VL test in the most recent calendar year (N=17,339)

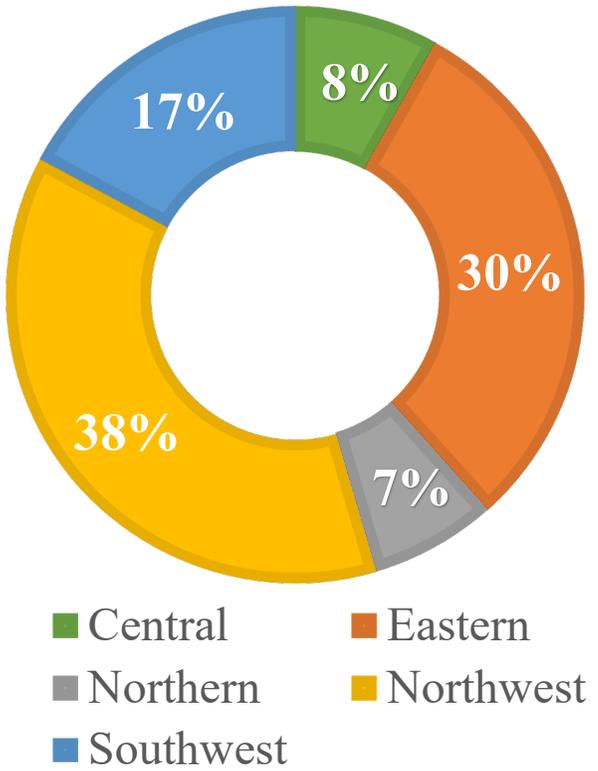
# Unmet Need in Virginia, 2020

Demographic	Late Diagnoses	Unmet Need	Virally Unsuppressed
Gender	-	-	-
Male	26%	19%	12%
Female	28%	16%	12%
Transgender	34%	19%	22%
Race	-	-	-
Black, non-Hispanic	26%	19%	14%
White, non-Hispanic	29%	17%	8%
Hispanic	28%	21%	9%
Age	-	-	-
13-24	8%	23%	20%
25-34	23%	25%	19%
35-44	39%	22%	13%
45-54	46%	17%	10%
55+	35%	13%	8%
Transmission Risk	-	-	-
MSM	22%	18%	11%
IDU	22%	16%	11%
MSM/IDU	25%	18%	13%
Heterosexual	43%	18%	14%

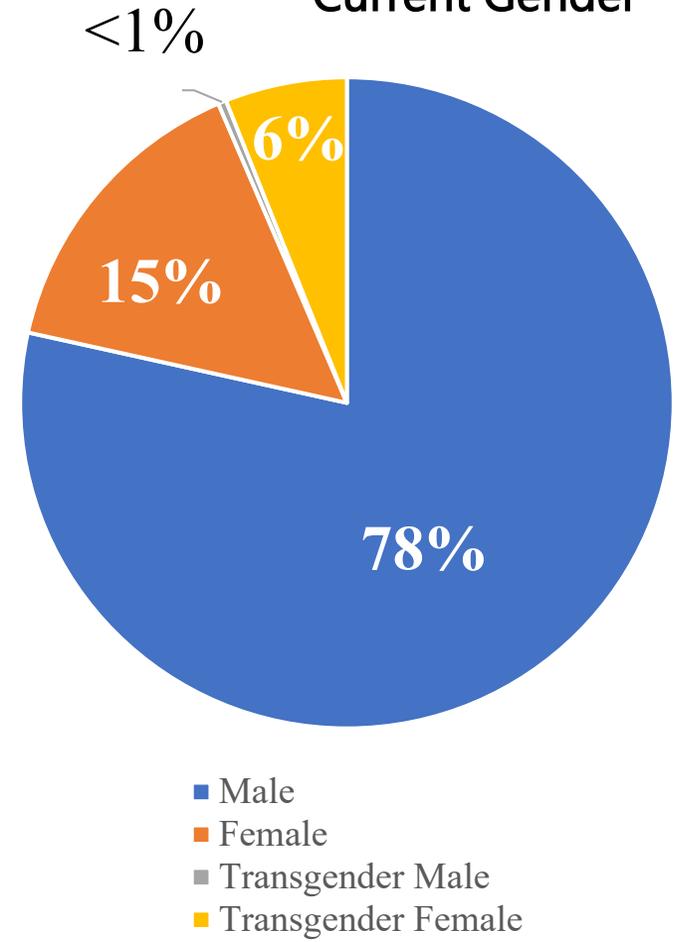
# Preview of another VA RWHAP B Presentation

## Rapid Start Demographic Data (7/1/2020 – 6/7/2022), N=269

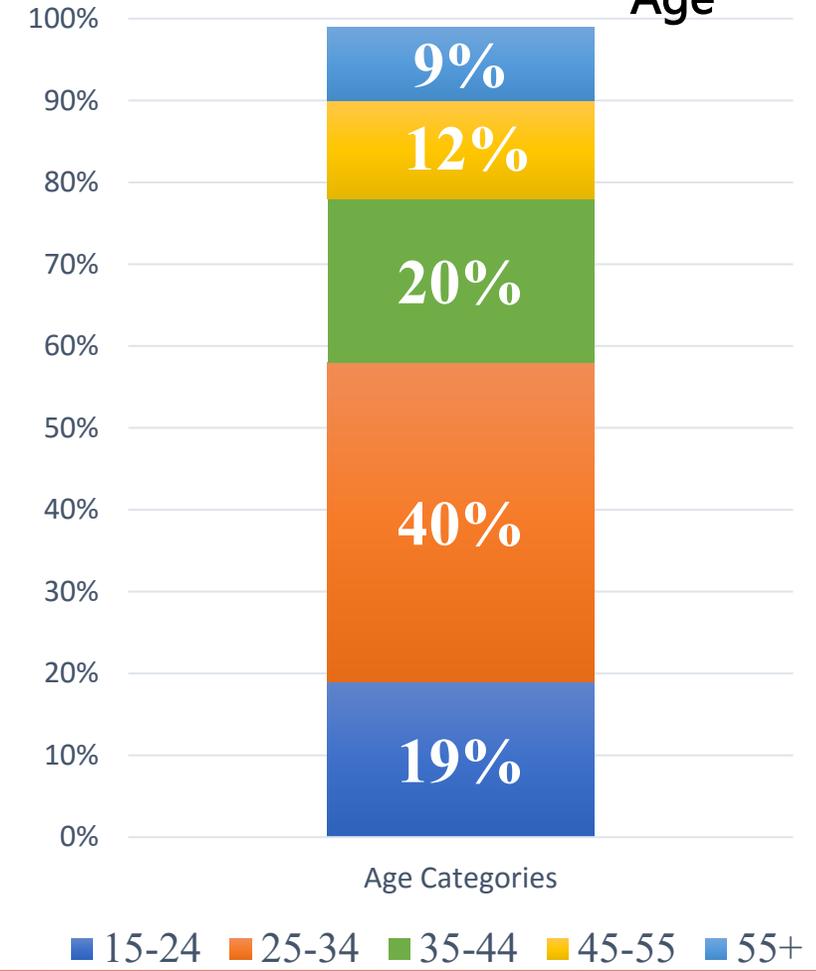
**Regional Distribution**



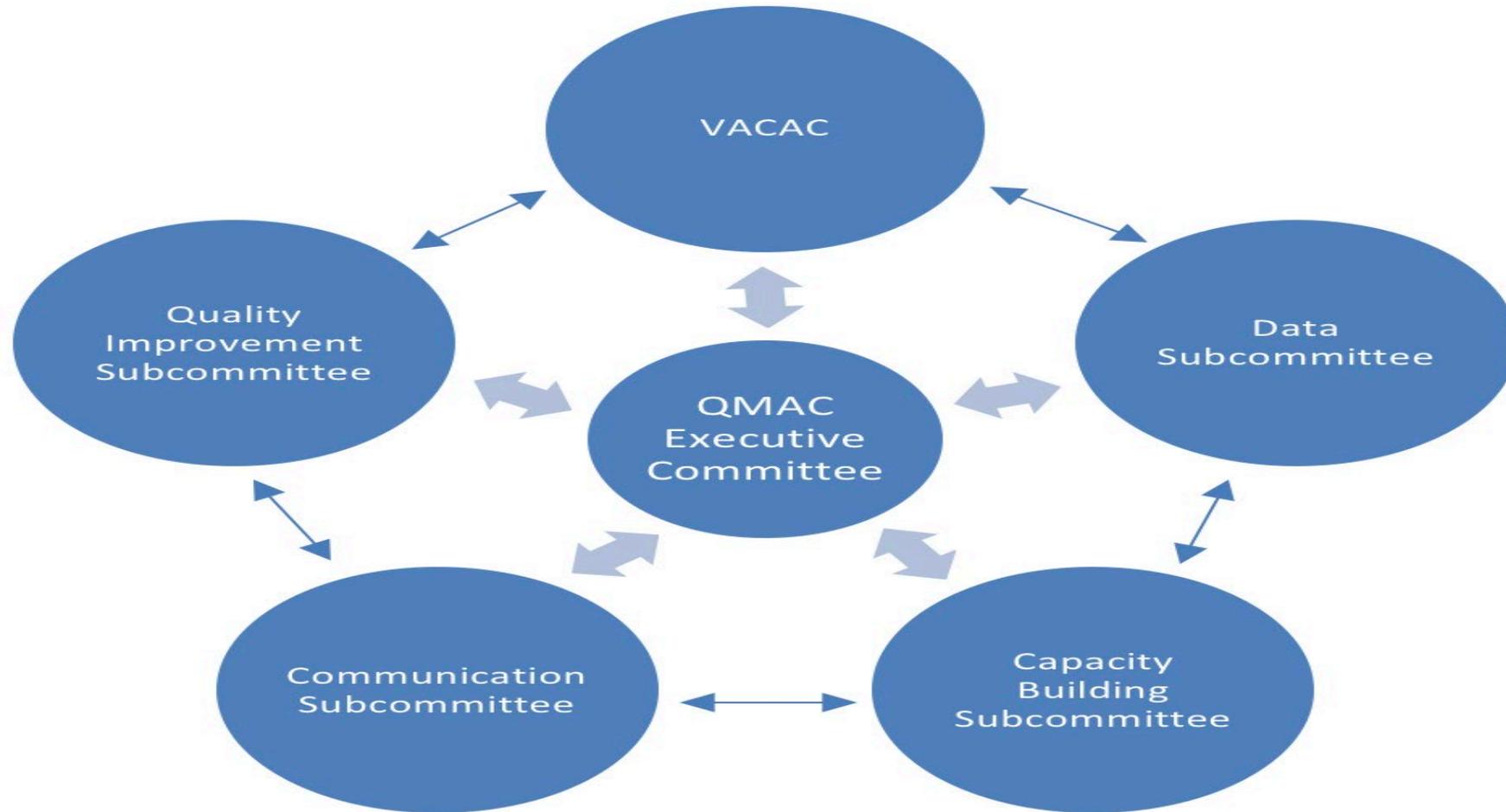
**Current Gender**



**Age**



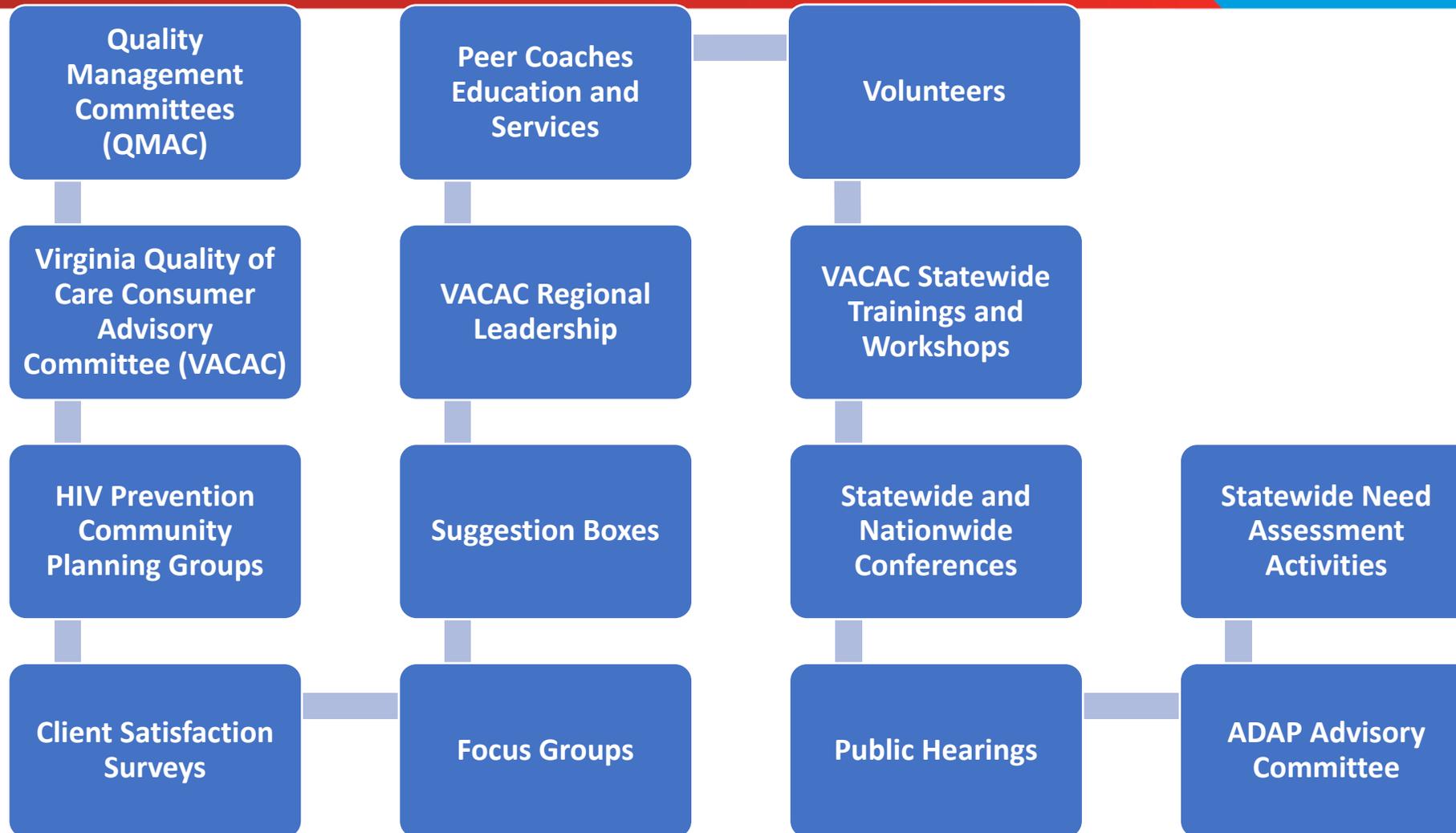
# Quality Management Advisory Committee Subcommittees



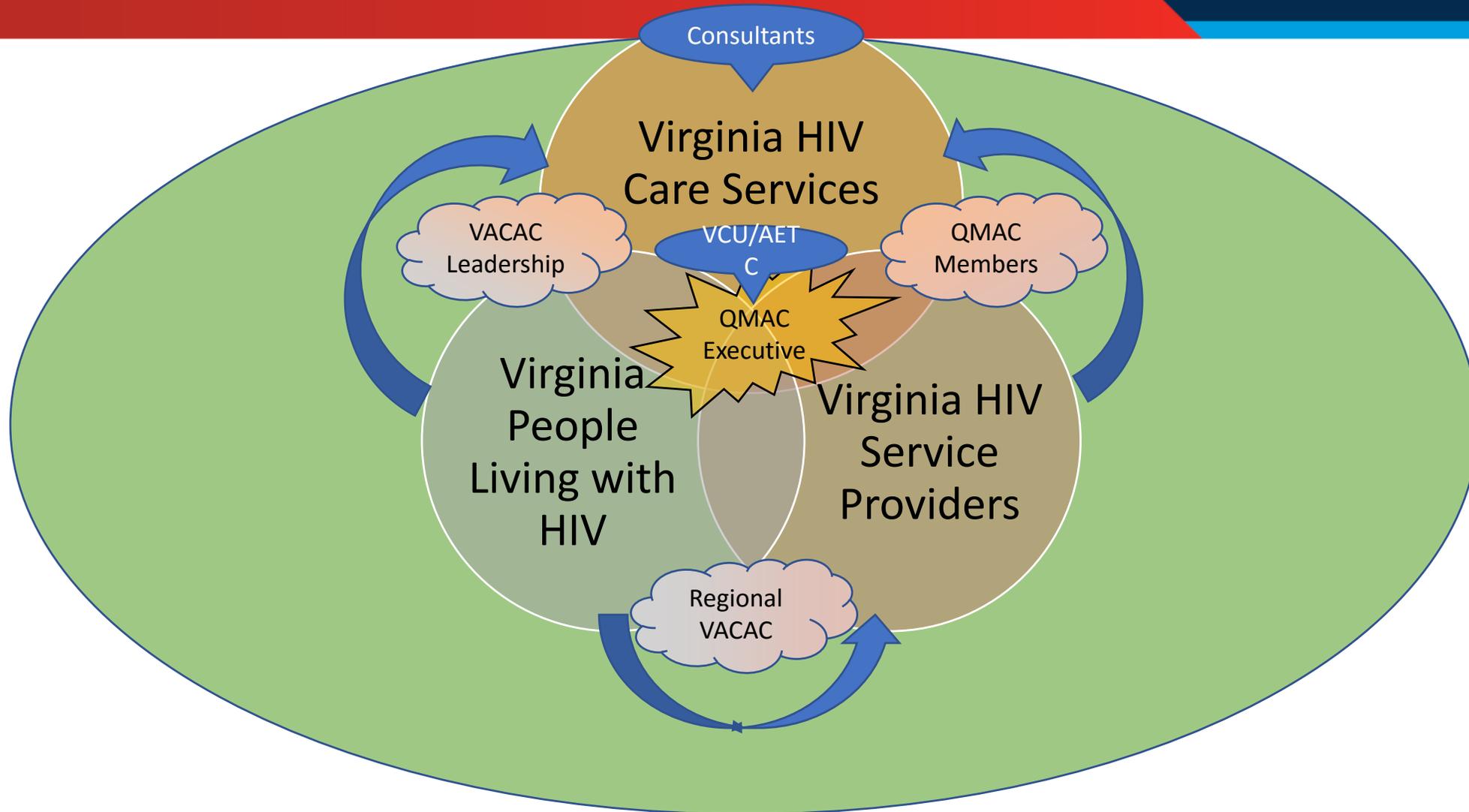
# Virginia's Consumer Advisory Committee Structure

- **Membership:** Unlimited
- **Executive Committee:** 27 members representing various HIV communities in Virginia
- **Regional representatives:** Five for each of the five regions
- **Meeting Structure:** quarterly meetings with specific educational topics for HIV provider & CAB engagement, HIV disease management, and other topics of interest. Has Committee structure and formal by-laws
- **Committee Co-Chairs:** Two consumer Co-Chairs

# Multiple Avenues for Consumer Engagement



# Virginia's HIV Environment



# VACAC ROCKS!

## VACAC Recruitment & Development



# Example of Tools for VACAC Reporting

## VACAC REGIONAL TEAM REPORT OUT

**Date:**

**Region:**

**Timeframe of the Action Plan:**      Month: \_\_\_\_\_ Year: \_\_\_\_\_

<b>Activities Completed &amp; Updates</b> <i>What have you been working on?</i>	
<b>Last Team Meeting</b> <i>Agenda topic? Who attended? What assignments?</i>	
<b>Membership</b> <i>New Members for VACAC? Regional Team Members Involvement?</i>	
<b>QMAC Subcommittee Participation</b> <i>Regional Team Members Involvement?</i>	
<b>Next meeting Date:</b>	
<b>Request or Comments:</b>	

# THANK YOU FROM VIRGINIA!!

If you have questions or would like more information, please feel free to contact any of us listed below:

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# City of Newark, New Jersey

Ending the HIV Epidemic

# REFRAMING THE FOCUS: Communities Ending the HIV Epidemic

HRSA 20-078: Ending the HIV Epidemic: A Plan for America – Ryan White HIV/AIDS Programs Parts A and B  
CDC PS19-1906: Strategic Partnerships and Planning to Support Ending the HIV Epidemic in the United States

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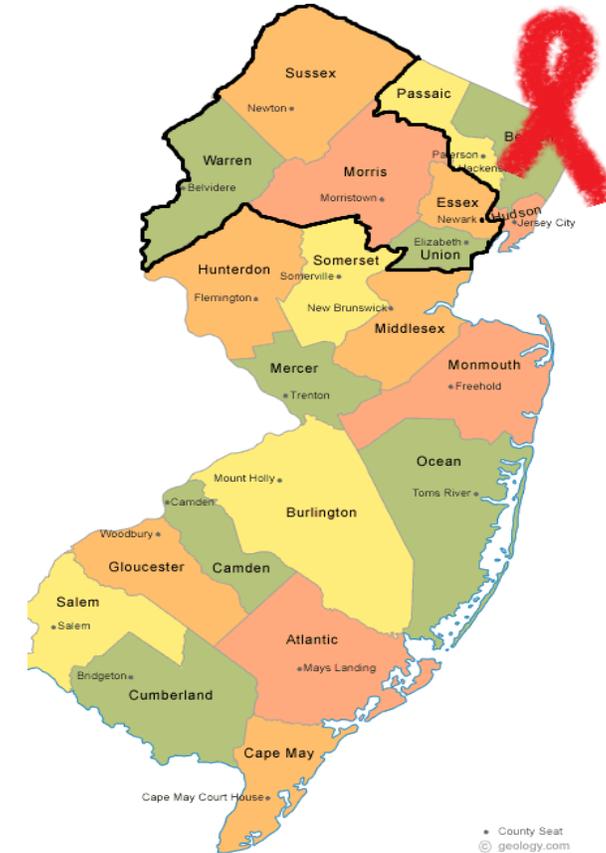
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# Program Overview

- The City of Newark is 1 of 57 priority jurisdictions in the Ending HIV Epidemic (EHE) initiative.
- Led by the City of Newark Department of Health and Community Wellness (DHCW), a recipient of Ryan White Part A funding for nearly 30 years.
- The Newark Eligible Metropolitan Area (NEMA) is comprised of 5 counties in northern New Jersey (Essex, Morris, Sussex, Union, and Warren).
- NEMA serves approximately 6,000 people living with HIV (PLWH) each year.
- 2019 - New Jersey Department of Health, Division of HIV, STD, and TB Services (DHSTS) received **Strategic Partnerships and Planning to Support Ending the HIV Epidemic in the United States (PS19-1906)** funding.
- 2020 - The City of Newark received **Ending the HIV Epidemic: A Plan for America – Ryan White HIV/AIDS Programs Parts A and B (HRSA 20-078)** funding.

# Newark, New Jersey – Jurisdictional Overview

- There are approximately 38,069 PLWH in the state of New Jersey.
- In 2020, NEMA accounted for approximately 36% of the state's HIV epidemic (13,790/38,069).
- 91% of NEMA's HIV epidemic is concentrated in the counties of Essex (69.6%) and Union (21.2%).
- Essex County is disproportionately affected by HIV with 9,630 PLWH – 25% of NJ's HIV epidemic, but only 9% of NJ's total population.
- The City of Newark is the epicenter of the epidemic with 41% of NEMA's PLWH.



# Essex County Epidemiological Snapshot

## Essex County (n = 9,630)

Demographic Composition	%	Mode of Transmission	%
Female	38%	Heterosexual Contact	44%
White	7%	MSM	37%
Black/AA	73%	PWID/IDU	17%
Hispanic/Latinx	19%	Persons in poverty ( ≤ 100% FPL)	71%
55+ years of age	46%	Uninsured	18%

Source: Newark EMA HIV Services Planning Council – 2021 Epidemiological Profile. <https://www.nemaplanningcouncil.org/community-reports/epidemiologic-profile>

# Community Engagement Process – Guiding Principles

- **Meaningful & Intentional Community Engagement**
- **Whole-of-Society Initiative**
- **Health in All Policies**
- **Disruptive Innovation**



# Community Engagement Process

- Community and stakeholder engagement activities began in November 2019.
- Planning meetings were coordinated in collaboration with the New Jersey Department of Health, Division of HIV, STD, and TB Services (DHSTS) and the Hudson County TGA.
- A situational analysis was conducted to identify jurisdictional strengths, weaknesses, and needs with respect to several key aspects of HIV prevention and care activities.



# Community Engagement Timeline 2019 - 2020

## November 2019

EHE planning activities begin with DHSTS, and Hudson and Essex stakeholders.

## March 2020

Jurisdiction hosts first community engagement meeting with over 75 participants.

## September 2020

Team approves community engagement surveys and community needs assessments (CNA).

## November 2020

Community surveys and CNA concludes.

## December 2019

Review results of situational analysis, draft EHE Plan and community engagement.

## March 2020 –



## October 2020

Community engagement surveys and CNA begins with key populations.

## DHSTS utilized local agencies to assist with community engagement and feedback

- DHSTS funded several Community Based Organizations (CBOs) in Essex and Hudson to administer community level surveys addressing SDOH and HIV care/prevention
- From survey feedback, drill-down focus groups were held to gain a deeper understanding of indicated needs
- Feedback from sessions, as well as input from 4 CBOs, were compiled to create community surveys
  - Survey addressed both HIV risk and related issues, as well as Social Determinants of Health
  - Surveys were housed by a third-party contractor on a virtual platform and administered to consumers in the community through CBOs
  - Survey was offered in multiple languages, as well as a read-aloud audio option
  - Each participant received a \$50 incentive card for completing the survey
- Virtual platform tracked participants to ensure lack of duplication

# Demographic Profile of Survey Respondents

A survey was conducted among 223 PLWH who were actively receiving HIV care.

Age Group	n (%)
25-34	35 (16%)
35-44	53 (24%)
45-54	52 (23%)
55+	73 (32%)

Gender	n (%)
Male	164 (74%)
Female	40 (18%)
Transgender	16 (7%)

Sexual Orientation	n (%)
Homosexual/Lesbian	111 (50%)
Bisexual	21 (9%)
Heterosexual	77 (35%)

Race	n (%)
Black/African-American	127 (57%)
Hispanic/Latinx	55 (25%)
White	20 (9%)

**CBOs utilized survey feedback to facilitate 11 drill-down focus groups to address what they felt were the most important gaps/issues.**

## **Provider deserts & Transportation**

In Essex, multiple provider deserts were identified; services are heavily concentrated in and directly surrounding Newark. Individuals residing outside of Newark indicate a strong need for transportation support to access services.

## **Access to food**

Majority of the participants utilize food pantries and bodegas for groceries. Supermarkets are not feasible to access without a car. Food that is available nearby is over-priced, low quality, and spoils quickly.

## **Provider sensitivity and knowledge of LGBTQ+ health**

Providers do not routinely inquire about sexual health. Discomfort at appointments from front-line staff. Suggested gender-affirming / confirming and sex positive trainings for healthcare providers and staff.

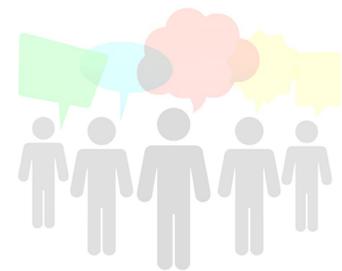
## **Childcare**

Although few of the participants had children, majority of cis-gender women with children find it difficult to maintain their health due to limited resources for childcare.

# Focus Group Highlights

## Participants reported:

- An array of living situations; they live with family and extended relatives, alone, with significant others, in shelters or couch surfing with friends.
- The stress of obtaining or maintaining housing trumps all other concerns.
- Their primary source of income were government benefits.
- Their wish for formal education, leadership skills, public speaking and computer training.
- They would only trust practitioners who would engage in honest dialogue on treatment options and innovations.
- Stress or trauma related to feeling or being identified as different by members of the community they currently live in.



# Listening Sessions

**Due to the COVID-19 pandemic, engagement sessions and planning continued virtually through 2020.**

- Early Intervention & Retention Collaboratives (EIRC)
  - Essex County
  - Union County
  - Morris, Sussex, and Warren Counties / MSW HIV Advisory Board
- Newark Eligible Metropolitan Area HIV Health Services Planning Council
- Community Involvement Activities Committee (CIA)
- NEMA Medical Case Management Certificate Ceremony
- New Jersey HIV Housing Collaborative



# Listening Session Highlights

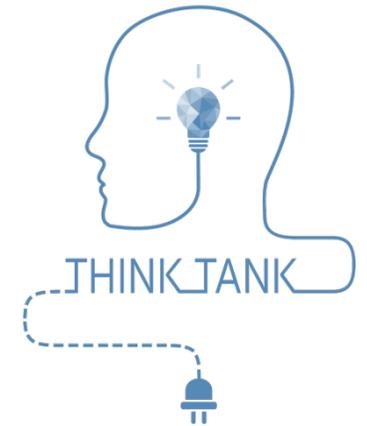
## Open-ended Questions

1. How do we ensure people living with HIV have equitable access to HIV treatment?
2. What can the Essex County community as a whole do to lessen the health disparities faced by its residents?
3. How can we build long-term working relationships with non-Ryan White providers and other nontraditional partners?

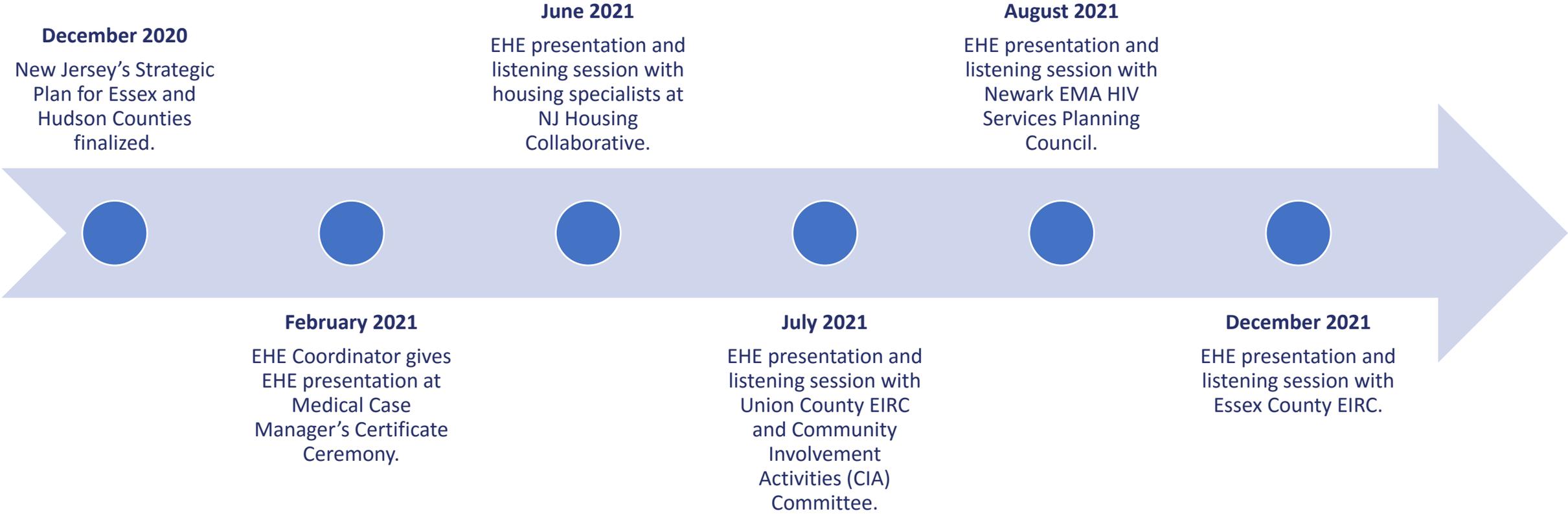
## Community Responses:

*“How do we ensure everyone living with HIV has access to HIV treatment?”*

- Improve ADAP/ADDP application process and wait time.
- More support after receiving a positive diagnosis to help get started on ARV’s and next steps.
- “Treatment on Demand” or other rapid initiation models.
- More mental health and social support outside of clinical setting.
- Have an HIV hotline to help PLWH navigate services or seek social support.



# Community Engagement Timeline 2020-2021



# From Engagement to Action

## Findings and themes identified through our EHE community engagement activities have:

- Shaped key EHE programs and activities
- Facilitated the combined plan for Essex and Hudson Counties to end the HIV epidemic by 2030, which outlines key objectives and the role of DHSTS and each jurisdiction
- Served as a resource guide when updating the jurisdictional EHE plan
- Guided programming, and the design of RFA's and RPF's for implementation funds
- Continued to inform novel and innovative approaches to ending the HIV epidemic.

## **Ending the HIV Epidemic:**

**New Jersey's Strategic  
Plan: Essex and Hudson  
Counties**

**2020-2030**

# Future Community Engagement - Goals & Activities

- Collaborate with community-based organizations to conduct additional listening sessions with:
  1. Gay/bisexual men, same-gender-loving men, and other MSM;
  2. Transgender community;
  3. Aging population;
  4. HIV Workforce; and
  5. Latinx/Hispanic population
- Collaborate with DHSTS on community engagement with priority populations through storytelling (AIDS Resource Foundation for Children and Hager Health)
  - Two primary prongs: Storytelling and community-level surveys
- Continue working on developing EHE website to educate and connect with community.
- Increase community mobilization by encouraging community-led work groups that focus on broader community issues affecting people living with and at risk for HIV.
- Develop a Community Advisory Board (CAB) from the participants to regularly weigh in and engage around EHE activities.



# THANK YOU!

CITY OF **NEWARK**  
Mayor Ras J. Baraka



Ending  
The  
HIV  
Epidemic

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**NJ Health**  
New Jersey Department of Health

# Miami-Dade County, Florida

Ryan White Parts A & B

# Community Engagement for Development of the 2022-2026 Integrated HIV Prevention and Care Plan

Successes, Challenges, and Lessons Learned

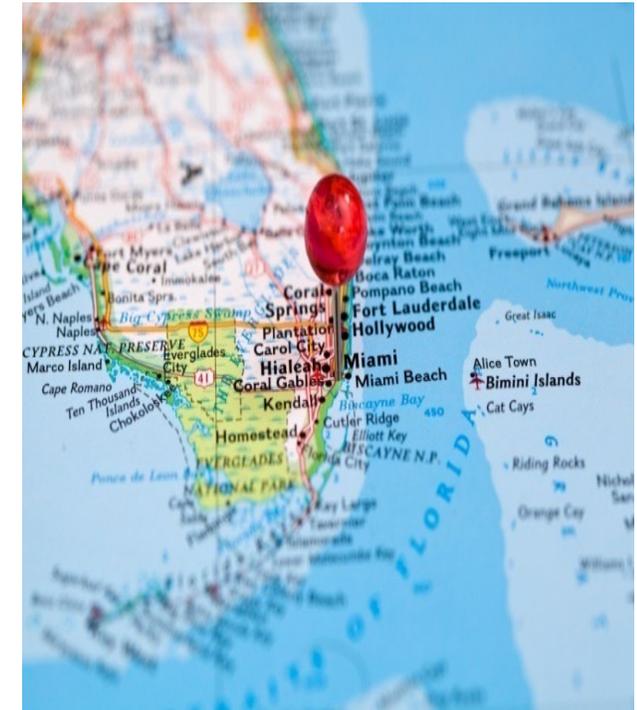
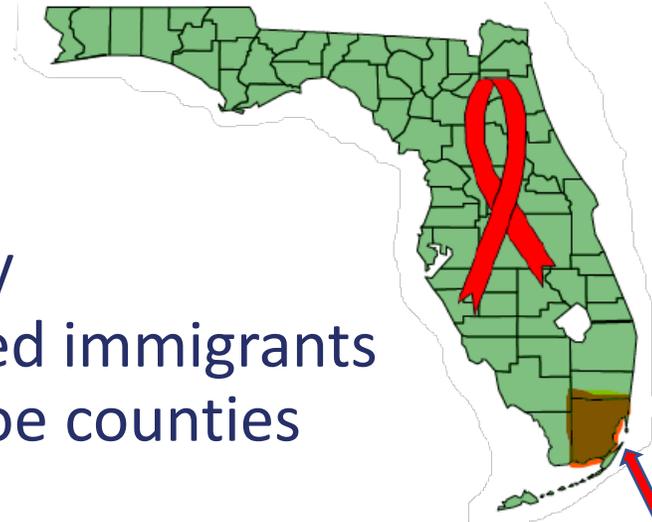
Miami-Dade County, Florida

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# Snapshot of the Miami-Dade County EMA

- **Miami-Dade County**
  - **2,864,600** population <sup>1</sup>
  - **2,431** total square miles
  - **16%** residents living in poverty
  - **24%** of Florida's undocumented immigrants live in Miami-Dade and Monroe counties combined
  - **Over 92%** of county residents and RWP clients are minorities

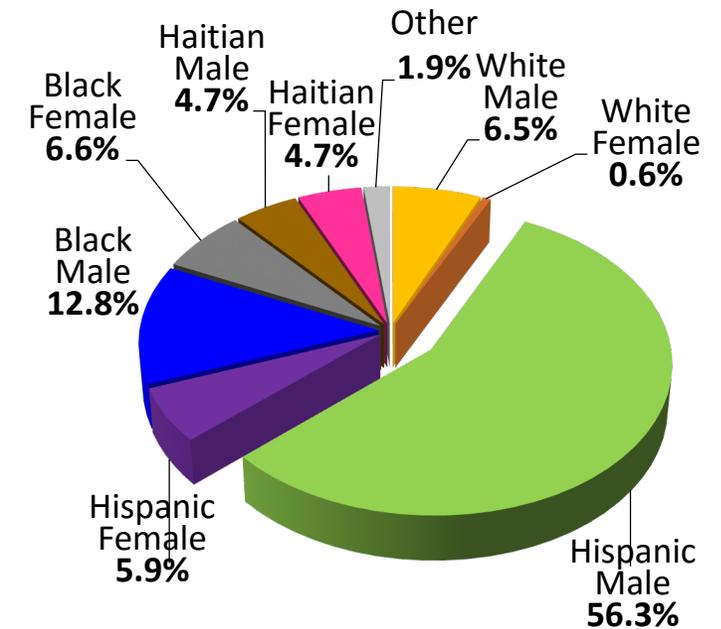


<sup>1</sup> 2020 FDOH data

# Snapshot of the Diversity of Ryan White Program (RWP) Clients

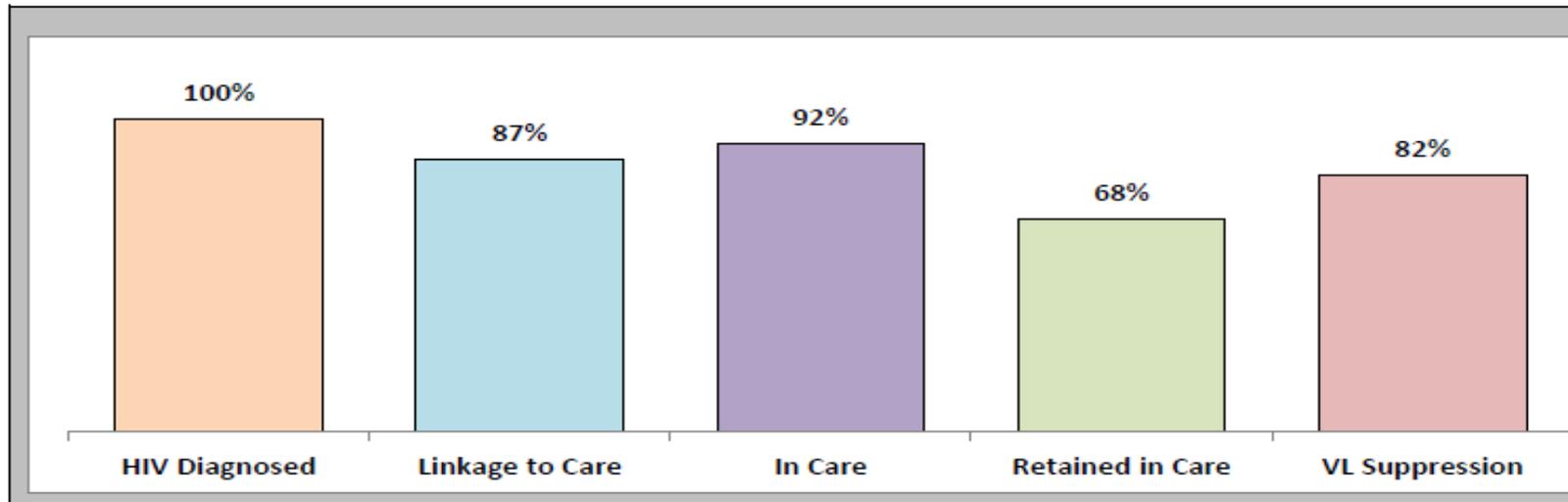
- **People with HIV**
  - **27,214** people with HIV (EMA prevalence) <sup>1</sup>
  - **8,418** people with HIV in care in the Ryan White Part A/Minority AIDS Initiative Program (RWP) (FY2021) <sup>2</sup>
    - **1,450** new clients
    - **93** transgender clients
    - **Majority** of households are below 135% of the Federal Poverty Level
    - **62%** of RWP clients prefer to speak Spanish or Haitian-Creole

**FY 2021 Ryan White Program  
Part A Clients**  
N=8,418



<sup>1</sup> 2020 FDOH data <sup>2</sup> 2021 RWP data

# Miami-Dade County RWHAP HIV Care Continuum – FY 2021



Continuum Stage	Numerator	Denominator	%	Data source*
HIV Diagnosed	8,418	8,418	100%	PE Miami, FY 2021
Linked to Care [for newly diagnosed]	314	360	87%	FDOH EIIHA, 2021
In Care	7,7741	8,418	92%	PE Miami, FY 2021
Retained in Care	5,686	8,418	68%	PE Miami, FY 2021
Viral Load (VL) Suppression	6,894	8,418	82%	PE Miami, FY 2021

\* Data Sources: PE Miami = Groupware Technologies LLC's Provide® Enterprise Miami data management system used by Parts A and B, Fiscal Year 2021;  
FDOH EIIHA = Florida Department of Health Early Identification of Individuals with HIV/AIDS data, 2021

# Community Engagement Challenges

## Connecting with a Fragmented Community

- **Goal:** Gather feedback from as many priority and emerging populations as possible, while addressing specific challenges:
  - **Stigma**
    - Racial-, ethnic-, sexual orientation-, and gender-based stigma exist in the EMA in addition to HIV-related stigma.
  - **Language Barriers**
    - English is not the first language of many respondents who either prefer to speak Haitian-Creole or Spanish.
  - **Cultural Differences**
    - The “Hispanic/Latinx” umbrella represents a broad range of countries and cultures, including Cubans - many new immigrants; Mexicans - predominantly farmworkers; El Salvadorans - large refugee community; and urbanized South Americans (Venezuelans, Colombians, Chileans) who have expatriated.



# Community Engagement Guiding Principles

Voices of the Community from Beginning to End

- **Intentional**

- Effective partnership between the Miami-Dade HIV/AIDS Partnership, RWP Recipient and subrecipients, Florida Department of Health in Miami-Dade County (FDOH-MDC), other stakeholders, and community groups.

- **Flexible and Tailored**

- Coordinated efforts to hold in-person, virtual, or phone meetings, as needed.



# Community Engagement Process

Targeted Engagement Groups Across a Diverse Service System

- **Listening Sessions**

- FDOH Workgroups
- RWP client groups (including priority and emerging populations)
- Non-RWP client groups and organizations
- Community Coalition Roundtable (Partnership Committee)

- **Surveys**

- Survey Monkey mirroring listening session questions
- Review of 2021 RWP Client Satisfaction Survey responses



# Community Engagement Lessons Learned

People with HIV Speak Out

Need to put “People”  
back into “People with  
HIV”!

***We’re dealing  
with a lot more  
than just HIV!***

It’s time to empower  
people with HIV!

Stigma is still  
with us!

***Why bother?***

Understand ACA  
Marketplace is complex  
for providers and clients  
to navigate.

Let’s see some  
messaging with people  
who look like us!

***Is PrEP for me?***

Don’t rush through appointments or  
get defensive if we express needs or  
feelings of isolation.

***Am I eligible for mental  
health counseling and  
support services like food  
bank?***



# Community Engagement Lessons Learned

Breaking Out of Silos and Facing Our Own Biases

- **Where do we go from here?**

- Address complexities of service delivery - promoting dignity and respect
- Address housing crisis
- Implement cultural sensitivity/humility training and monitor effectiveness
- Enhance processes that include mental health support protocols
- Ensure Integrated Planning results in Integrated Service Delivery



# Community Engagement for Development of the 2022-2026 Integrated HIV Prevention and Care Plan

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# Questions?

