
# Driven by Community: A NYC Directive to Improve Health Outcomes for People of Transgender Intersex Gender Non-Binary or Non-Conforming Experience


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# Disclosures


Presenters have no financial interest to disclose.

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# Acronyms, Odds and Ends



- **RWPA**: Ryan White Part A
- **EMA**: The NY EMA consists of the 5 boroughs of New York City, and Westchester, Putnam & Rockland counties
- **PWH**: People with HIV
- **TIGNBNC**: Transgender, Intersex, Gender Non-Binary or Non-Conforming
- **MSM**: Men who have sex with men
- **Needs Assessment, Integration of Care, Priority Setting & Research Allocation** are committees of the NY HIV Health & Human Services Planning Council. Bylaws that guide committee work can be found here.[1]
- **eSHARE** is the data collection system used by NY RWPA
- **Recipient**: RWPA Grant recipient. In the NY EMA, the NYC Department of Health & Mental Hygiene is the recipient.

1. https://nyhiv.org/wp-content/uploads/2019/12/Planning-Council-Bylaws-Approved-by-PC-12-21-17.pdf

# Mapping Our Process



Today, we will:

- Walk you through what the NYC portion of the EMA did to design and fund this service directive
- Discuss the timeline as it relates to the NYC Department of Health protocols and available resources
- Highlight key factors that contributed to the successful development of the service directive
- Outline key challenges that came up throughout the process

# Things to Consider



- Do you have access to accurate programmatic and surveillance data?
- Is there expertise/experience on the Planning Council with the TIGNBNC community?
- Are there champions who want to address inequitable outcomes for this priority population?
- Are there partner organizations that can help ensure that people of trans experience are in the room?
- Are there persons of trans experience in leadership positions at the organization?

# Our Timeline


**1st**

**Psycho-social Support Service Directive for People of Transgender, Intersex, Non-Binary and Non-Conforming (TIGNBNC) Experience**

*Name of subcommittee preceded the umbrella term of the service directive they created

# Needs Assessment



- The Needs Assessment Committee, per Council by-laws, is charged with selecting topics to investigate to contribute to the Planning Council's assessment of local needs for treatment and care services

- In  February of 2018, the committee interpreted this as a mandate to review priority populations such as young Black MSM, Black women and people of trans experience

- From March –July 2018 the committee received quantitative and qualitative presentations and facilitated trans inclusive community meetings that engaged providers of trans experience.

# Data Request on Trans Women in RWPA



- **Spring 2018**: The HIV Epidemiology Program and the Research and Evaluation unit in the Care and Treatment Program received a data request from the Needs Assessment Committee to run data on trans women in NYC and RWPA
  - Request was placed to report on the most recently available demographics and HIV care continuum outcomes data
  - Data request was completed in one month

# Transgender People With HIV (PWH) Are A National And Local Priority



National HIV/AIDS Strategy for the United States Updated to 2020 (December 2016)

- Indicator 11: Increase the percentage of transgender women in HIV medical care who are virally suppressed to at least 90%
- Uses Ryan White HIV/AIDS Program data to track this indicator
- In 2018, viral suppression was 82% among transgender PWH vs. 87% among all PWH in HIV care in RWPA nationally

2015 NY Ending the HIV Epidemic Blueprint

- Recommendation 19: Institute an integrated comprehensive approach to transgender health care and human rights

In 2018, 78% viral suppression among transgender PWH vs. 87% among cisgender male PWH and 85% among cisgender female PWH in HIV care in New York City

# How Is Transgender Status[1] Collected by NYC HIV/AIDS Surveillance?



Includes people identified as transgender by diagnosing provider, self-report, or medical chart review

- Requires accurate collection of both current gender identity and sex assigned at birth

Since 2005, the HIV surveillance registry has been able to collect both gender identity and sex assigned at birth

- Not all cases have accurate information on gender identity, thus the registry likely undercounts persons identified as transgender

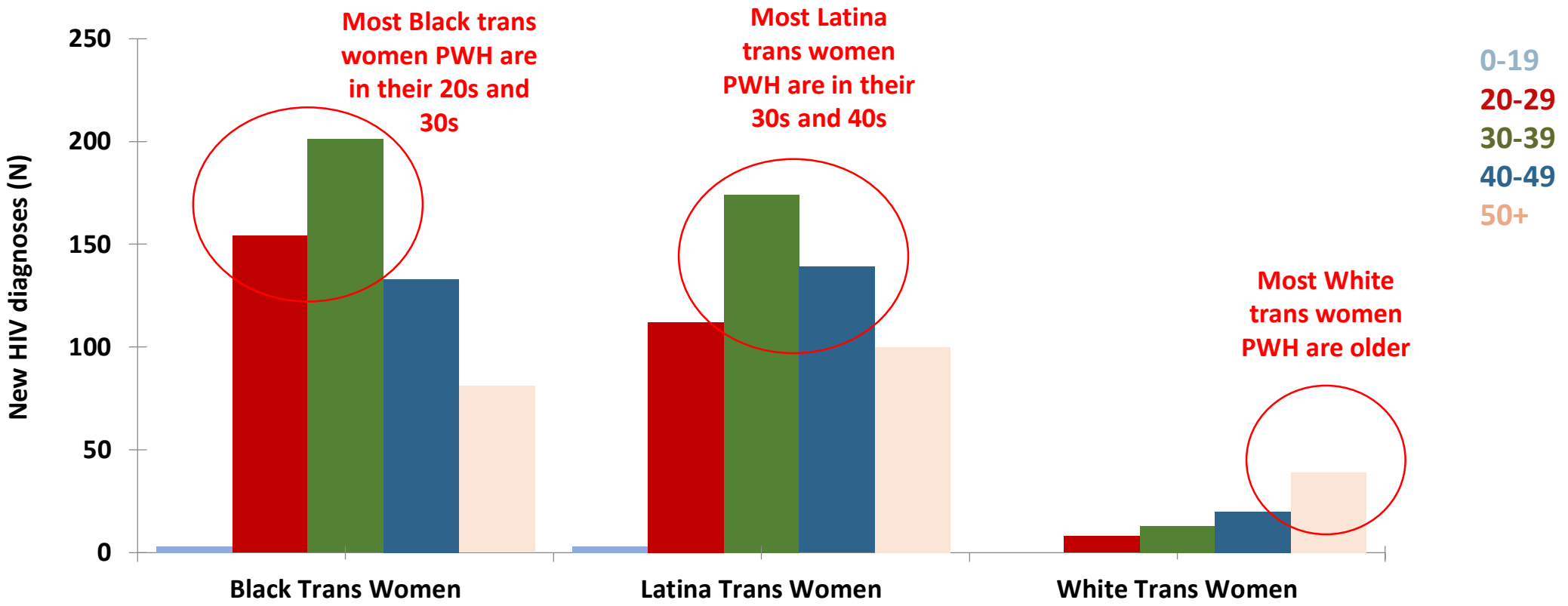
The total population of transgender people living in NYC is unknown

Analysis of Medicaid claims from 2013-2017, found over 6,000 transgender persons living in NYC and 28% were PWH[1]

[1] https://www1.nyc.gov/assets/doh/downloads/pdf/dires/improving-data-hiv-transgender-medicaid.pdf

# Transgender Women By Race/ Ethnicity And Age In NYC, 2016

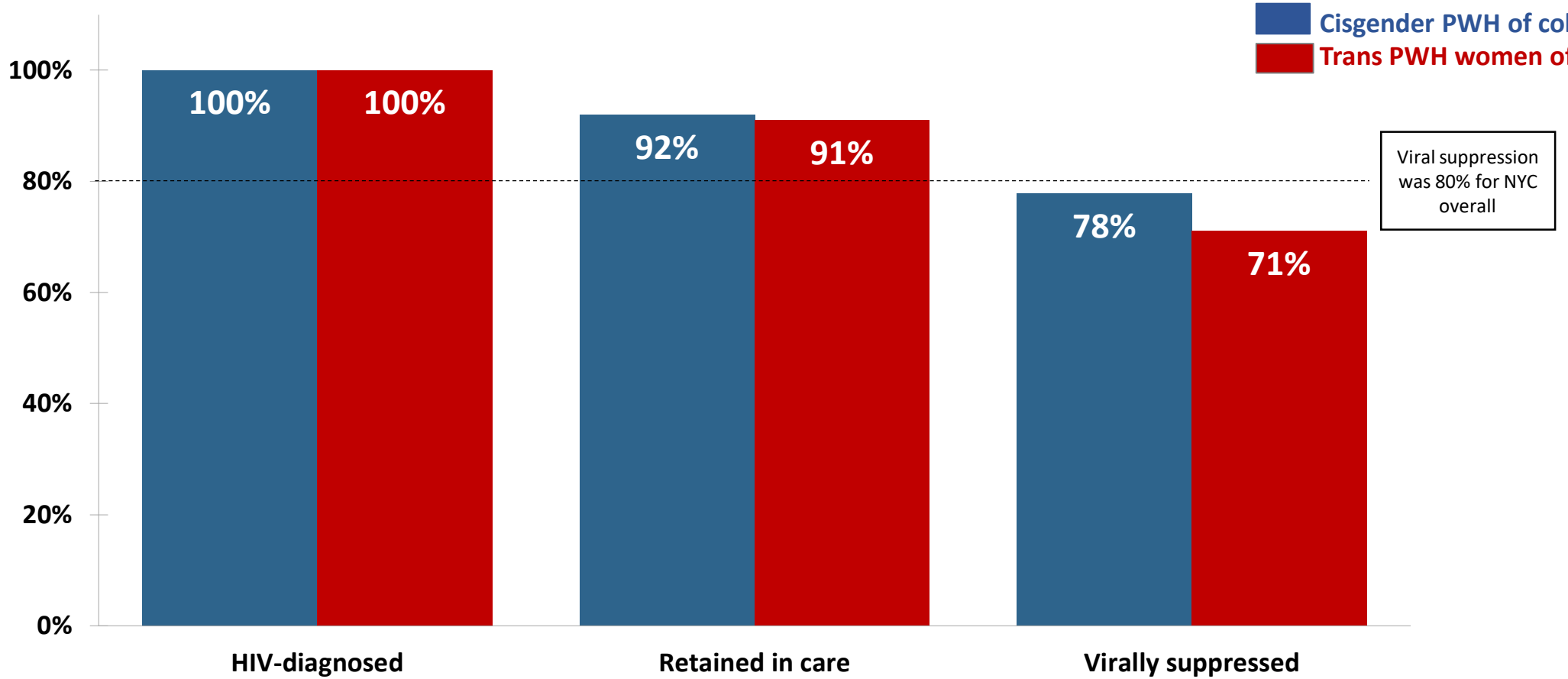





**~90% of transgender PWH are people of color. The majority of Black and Latina transgender women living with HIV are in their thirties while the majority of white transgender women are older.**

# HIV Care Continuum Among Cisgender PWH Of Color vs. Trans Women Of Color, 2016



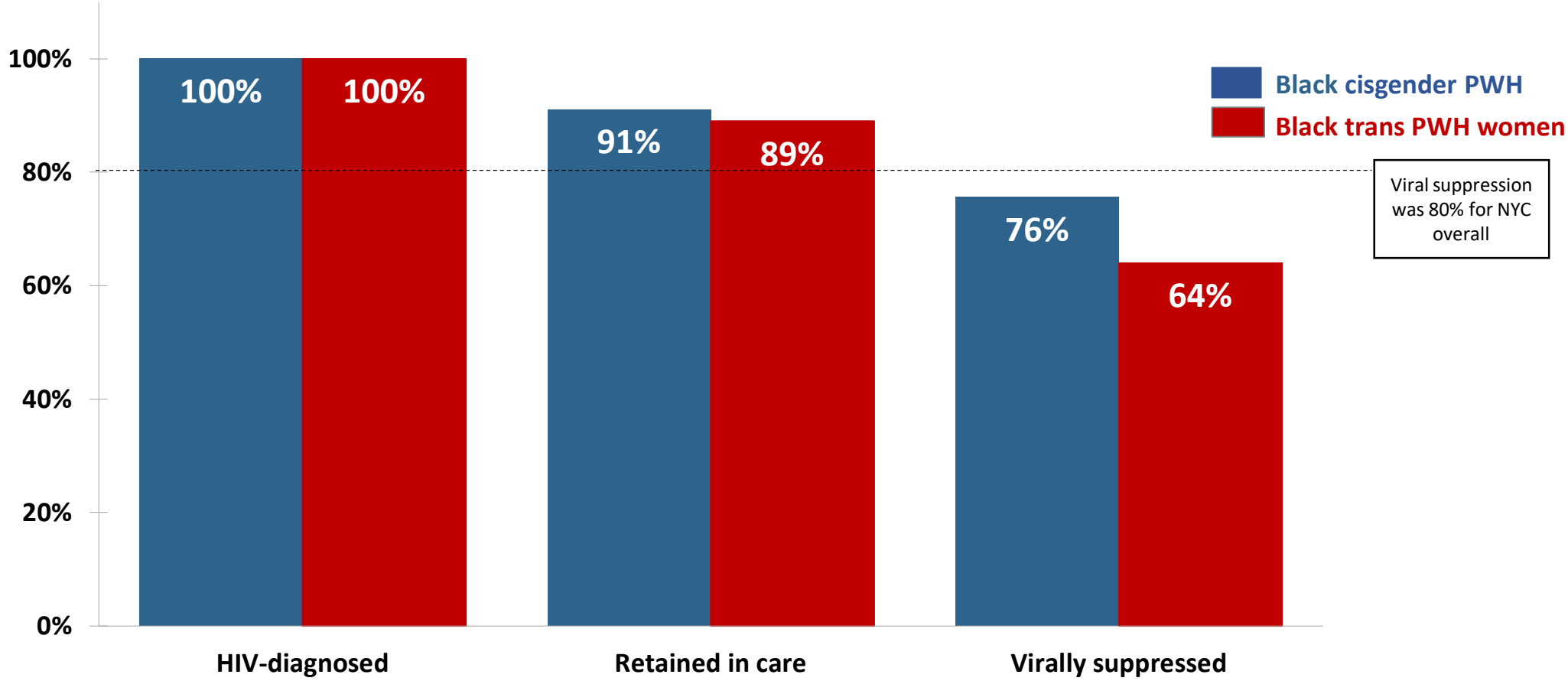



**78% of cisgender PWH of color in NYC in 2016 were virally suppressed compared to 71% among transgender women of color (Black or Latina).**

"Received care": PWH with ≥1 VL or CD4 count or CD4 percent reported in 2018; "Virally suppressed": calculated as PWH in care with a most recent viral load measurement in 2018 of <200 copies/mL

# HIV Care Continuum Among Black Cisgender PWH vs. Black Trans Women, 2016

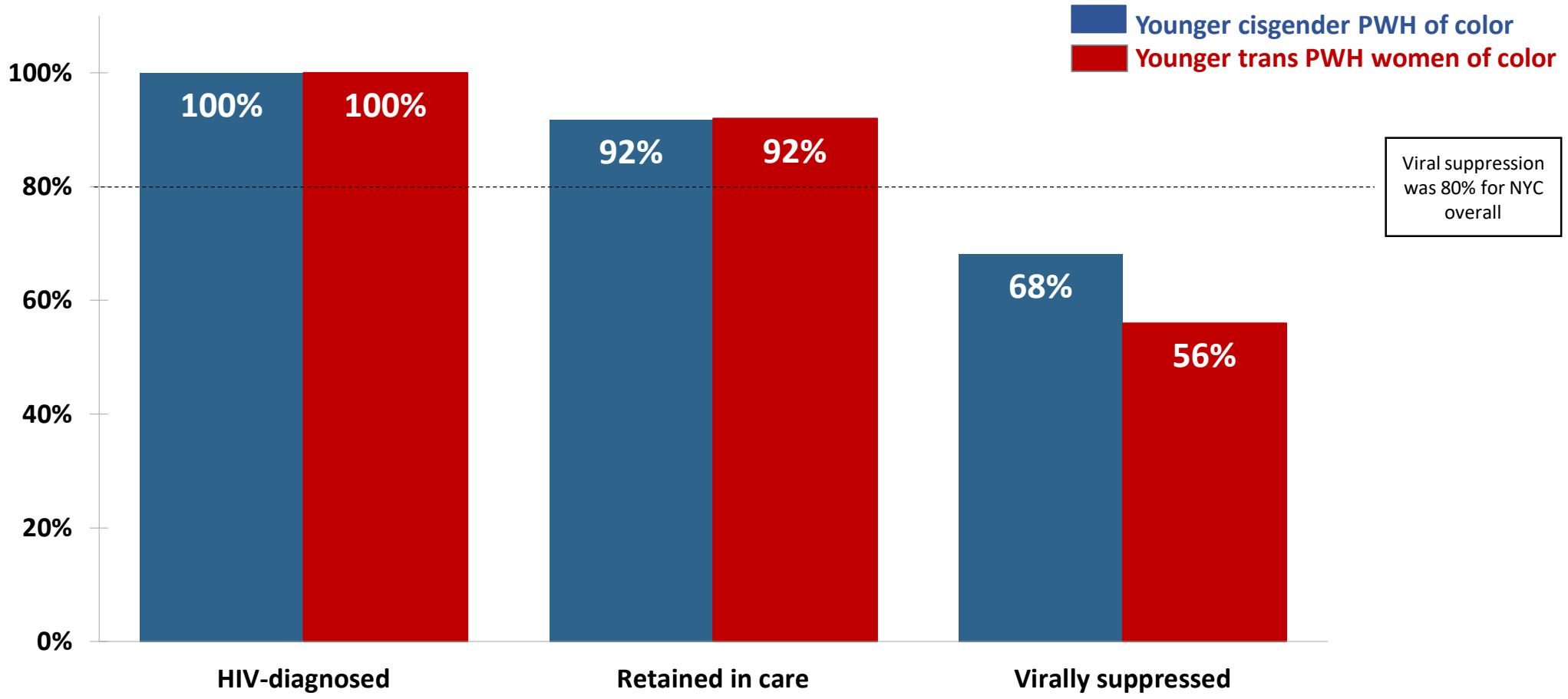





**76% of Black cisgender PWH in NYC in 2016 were virally suppressed compared to 64% among Black trans women.**

# HIV Care Continuum Among Younger Cisgender PWH vs. Younger Trans Women, 2016

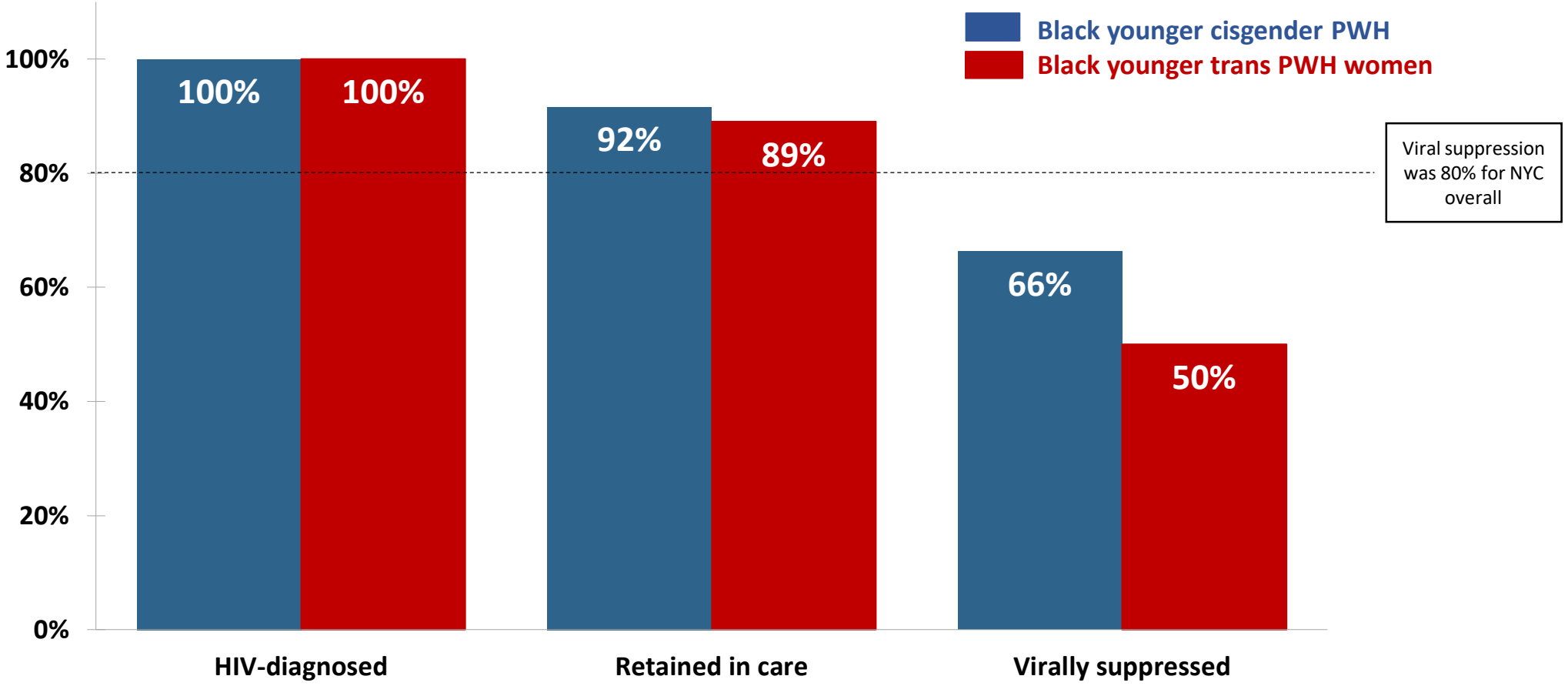





**68% of younger cisgender PWH of color in NYC in 2016 were virally suppressed compared to 56% among younger trans women of color (ages under 30).**

# HIV Care Continuum Among Black Younger Cis-gender PWH vs. Black Younger Trans Women, 2016

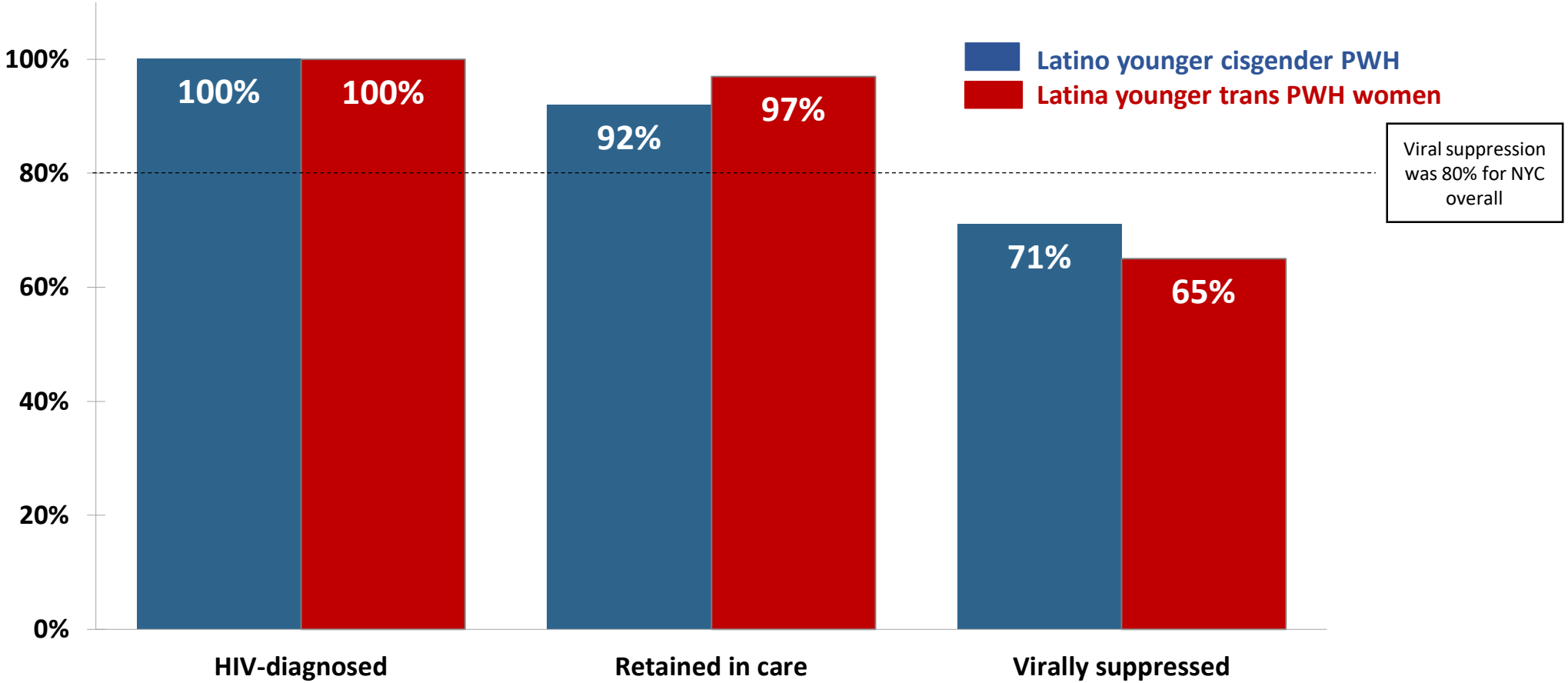





**66% of Black younger cisgender PWH in NYC in 2016 were virally suppressed compared to 50% among Black younger trans women (ages under 30).**

# HIV Care Continuum Among Latino Younger Cisgender PWH vs. Latina Younger Trans Women, 2016

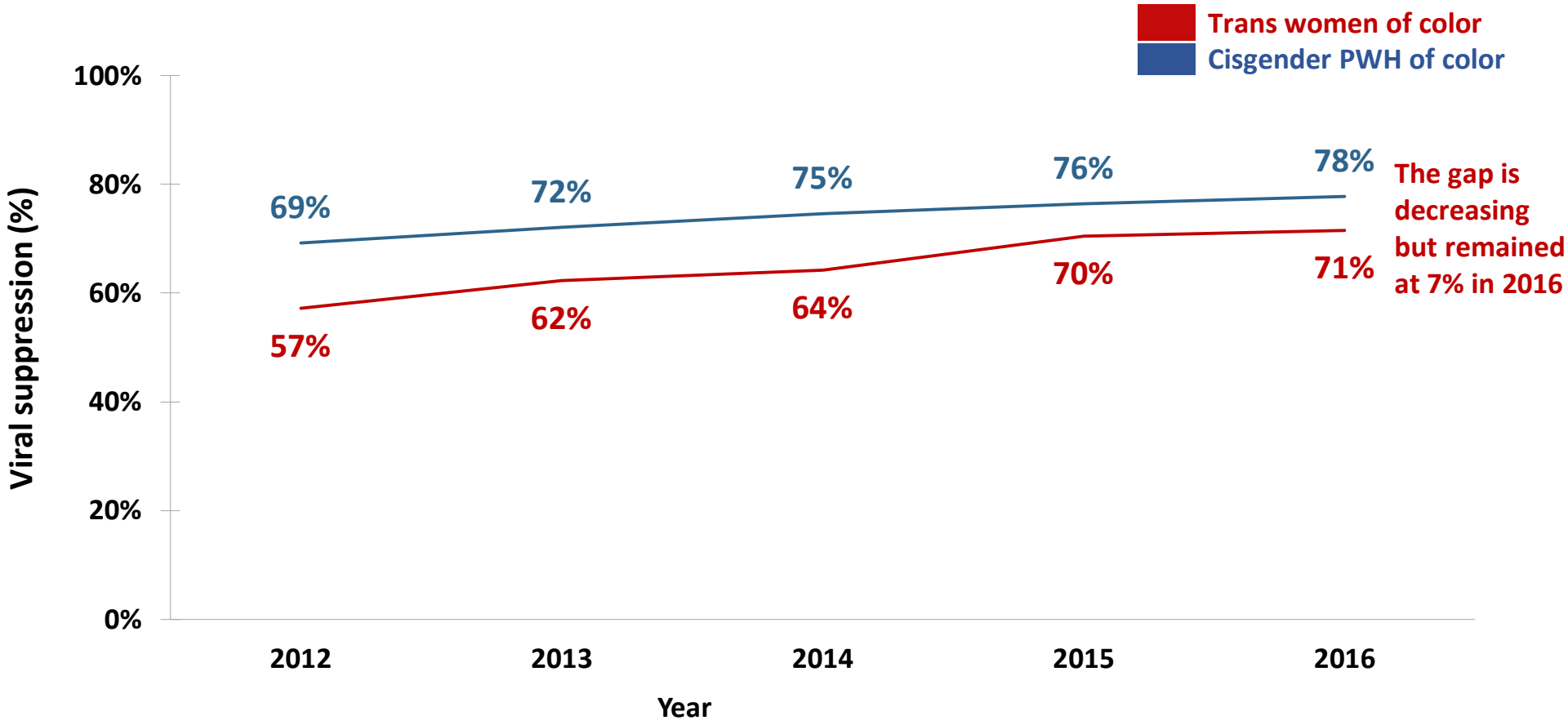





**71% of Latino younger cisgender PWH in NYC in 2016 were virally suppressed compared to 65% among Latina younger trans women (ages under 30).**

# Viral Suppression By Year In NYC Comparing Cisgender PWH Of Color To Transgender Women Of Color, 2012-2016

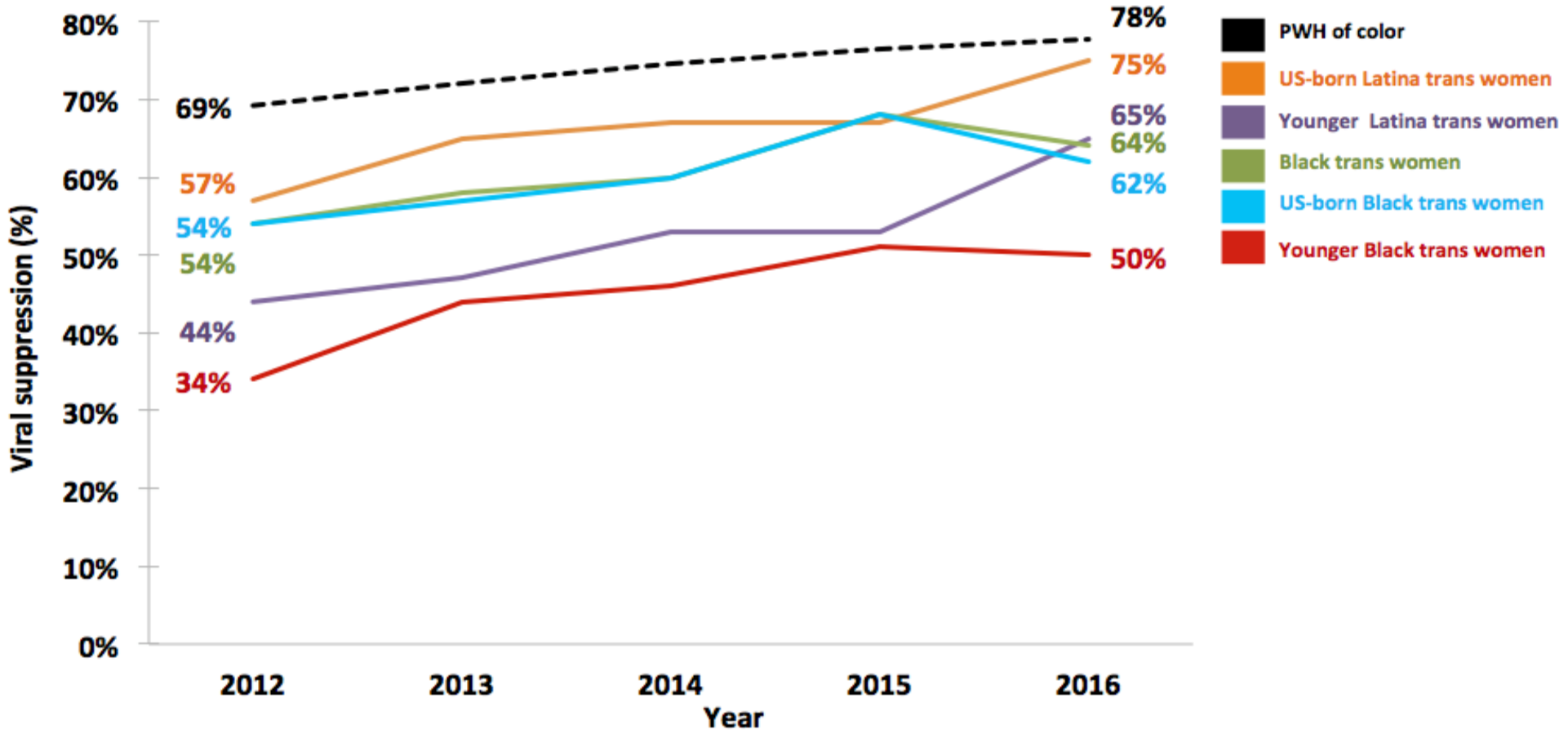





**Viral suppression among cisgender PWH of color and transgender women of color steadily increased in NYC between 2012 and 2016, but was higher among cisgender PWH of color overall.**

# Viral Suppression By Year In NYC Comparing Cisgender PWH Of Color To Transgender Subpopulations, 2012-2016



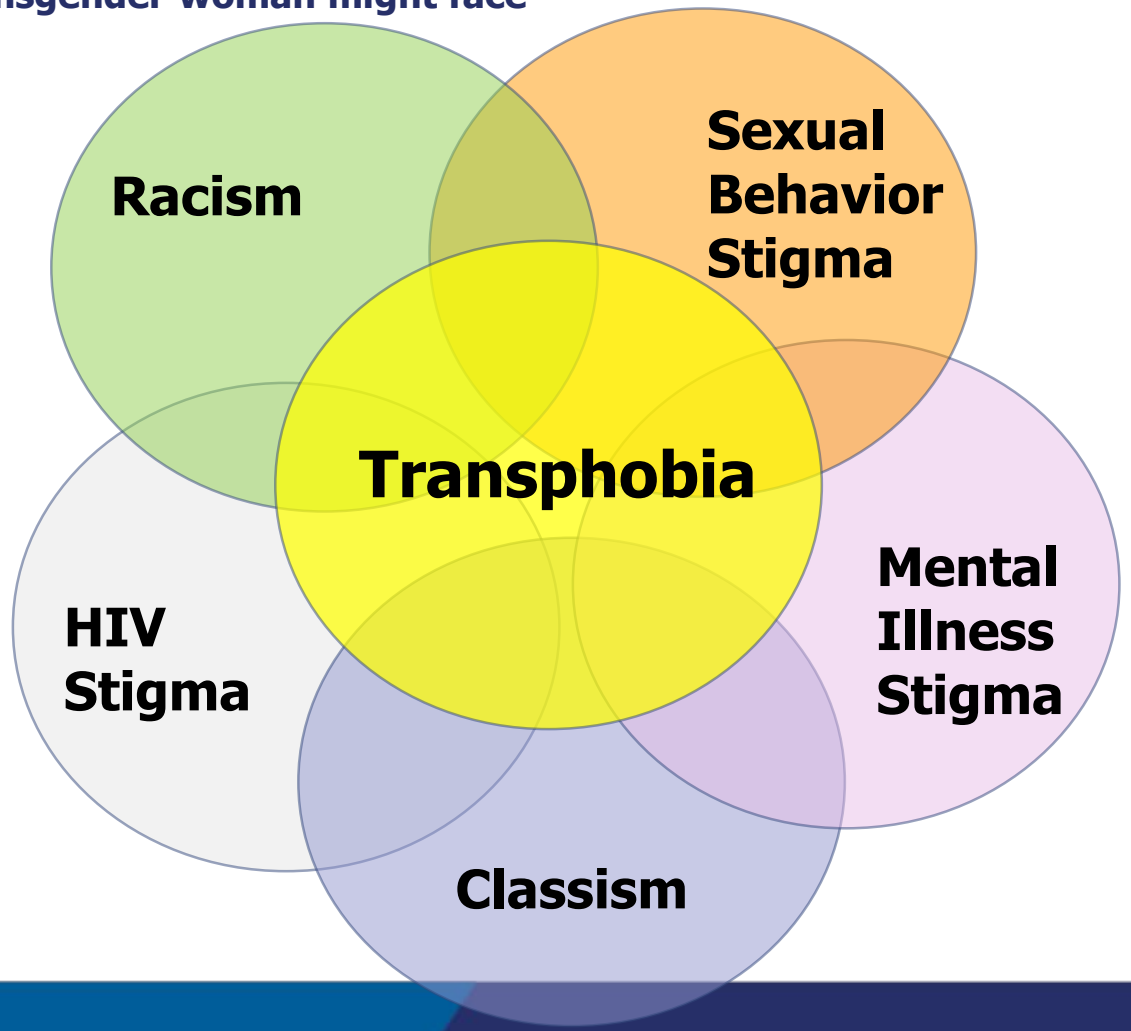



**Viral suppression among all transgender groups increased from 2012-2016, but was lowest for Black trans women and younger trans women (ages under 30).**

# Importance of Intersectionality



**The Venn diagram shows multiple stigmas a transgender woman might face**




Transgender women's health is often shaped by intersecting processes that are stigmatizing, complex and interdependent.

It's important to take intersectionality into account in analyses and programming as subpopulations of transgender women may be uniquely marginalized.

# NY EMA RWPA Data on Trans Women

Self reported screening data collected from e-SHARE assessments

# Trans Women in RWPA in the NY EMA



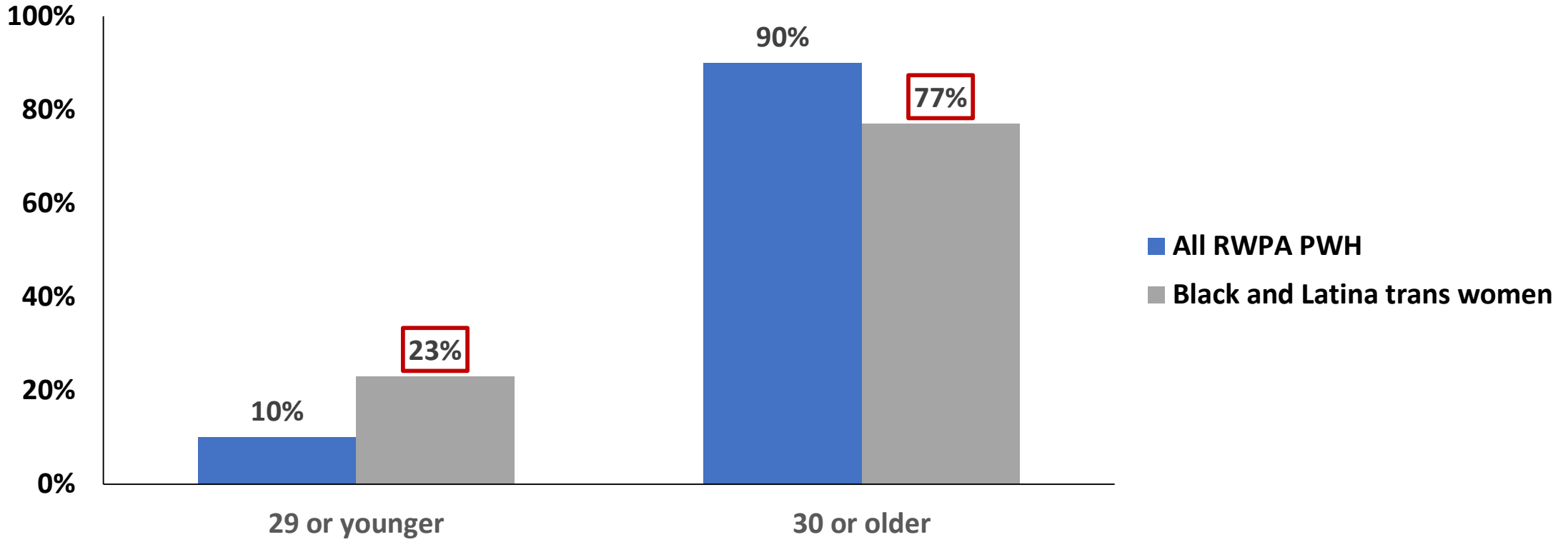
- **May 2018**: Presented on Trans Women of Color in the NY EMA
  - Presentation was primarily focused on Black and Latina trans women because more than 90% of trans clients in the NY EMA are Black and Latina women
- Presentation was based on PWH at the end of 2016, who received at least one RWPA service in 2016
- Trans woman defined as an individual whose gender was reported as trans woman or whose sex at birth was reported as male while gender was reported as female at any point in time, in our database

# Trans Women in RWPA in the NY EMA (cont.)



- In 2016, a total of **14,336** of PWH received RWPA services in the NY EMA
  - **452** (3%) were able to be ascertained from eSHARE as trans women
    - **412** (91%) of these trans women in RWPA were Black or Latina
      - **230** (56%) were Black
      - **182** (44%) were Latina

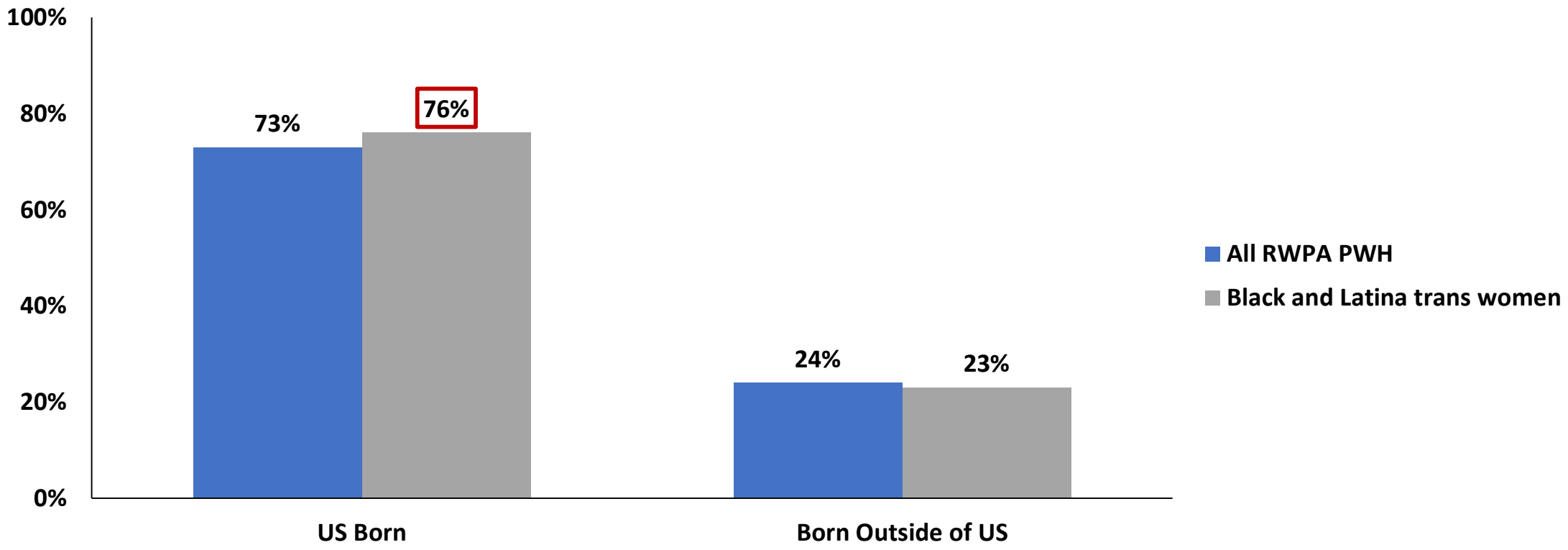
# NY EMA: All RWPA PWH vs. Black and Latina Trans Women by Age Group, 2016




**Compared to all RWPA PWH, a higher proportion of Black and Latina trans women were younger than 30.**

# NY EMA: All RWPA PWH vs. Black and Latina Trans Women by Country of Birth, 2016

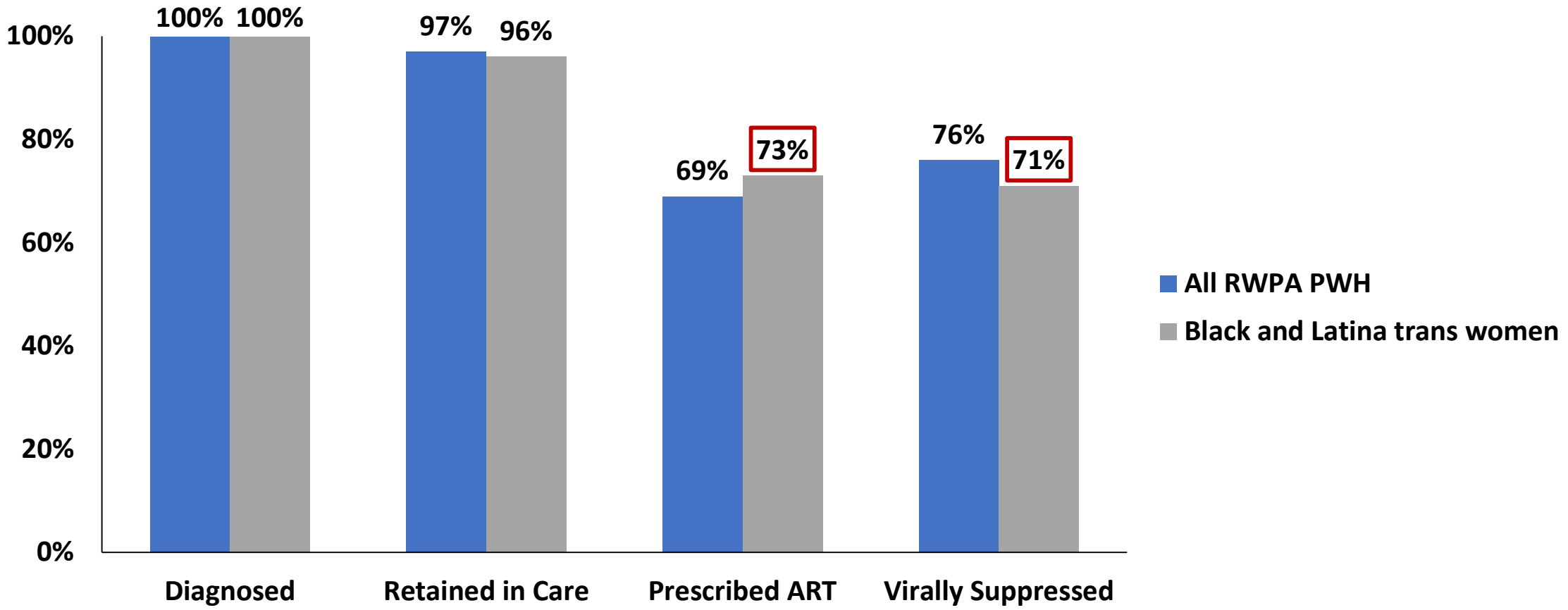





**Compared to all RWPA PWH, a slightly higher proportion of Black and Latina trans women were born in the US.**

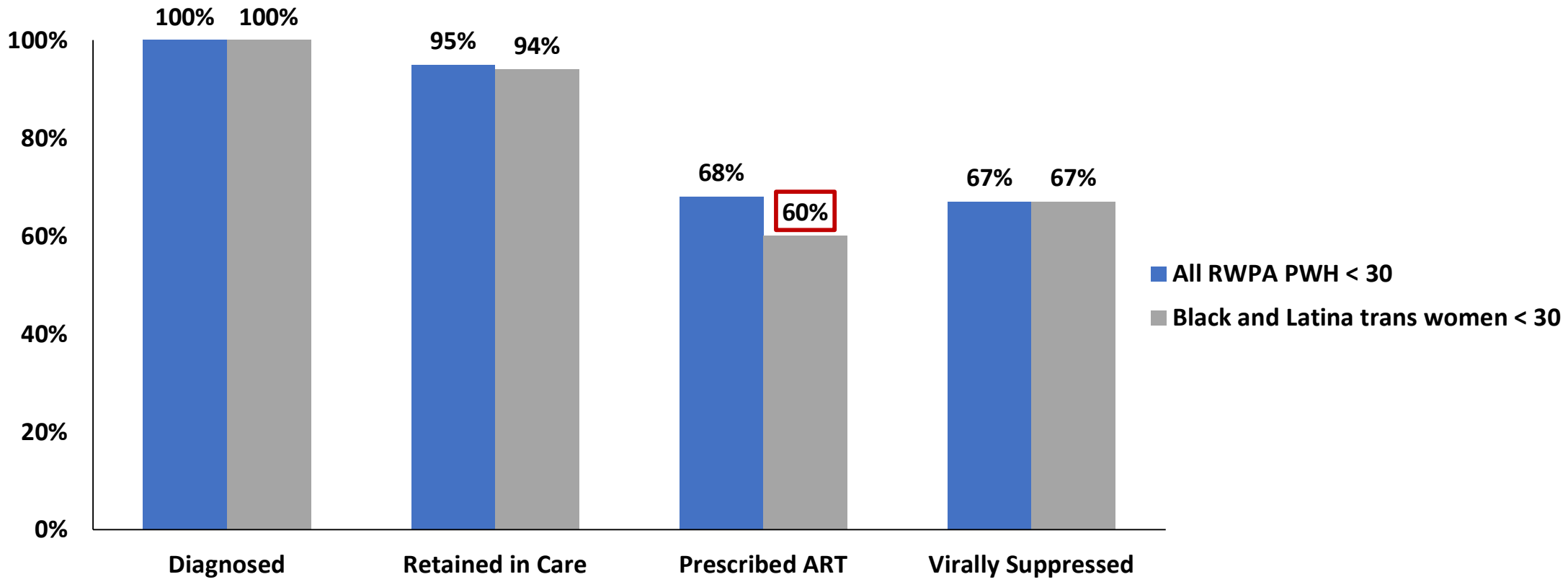
# NY EMA: All RWPA PWH vs. Black and Latina Trans Women, HIV Care Continuum Outcomes, 2016






**Compared to all RWPA PWH, a lower proportion of Black and Latina trans women were virally suppressed in 2016, despite a higher proportion of those trans women being prescribed ART.**

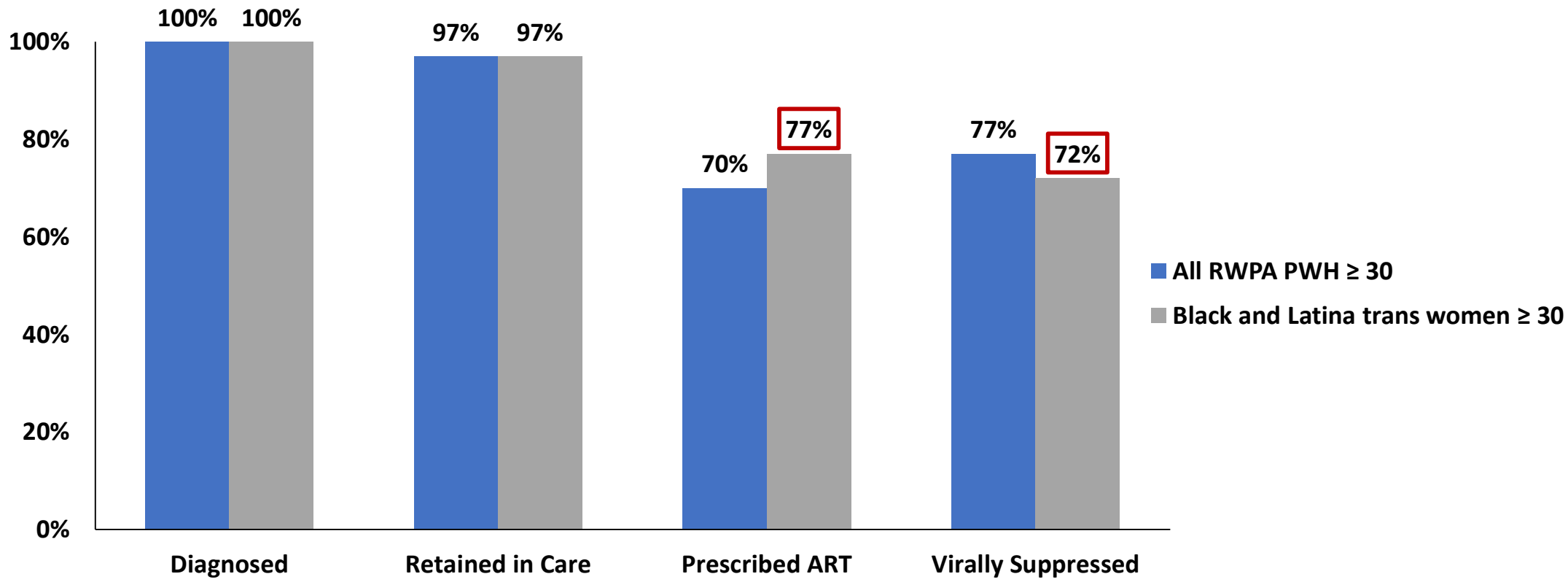
# NY EMA: All RWPA PWH vs. Black and Latina Trans Women, HIV Care Continuum Outcomes, < 30 years, 2016




**Compared to all RWPA PWH under the age of 30, a lower proportion of Black and Latina trans women under the age of 30 reported having an ART prescription.**

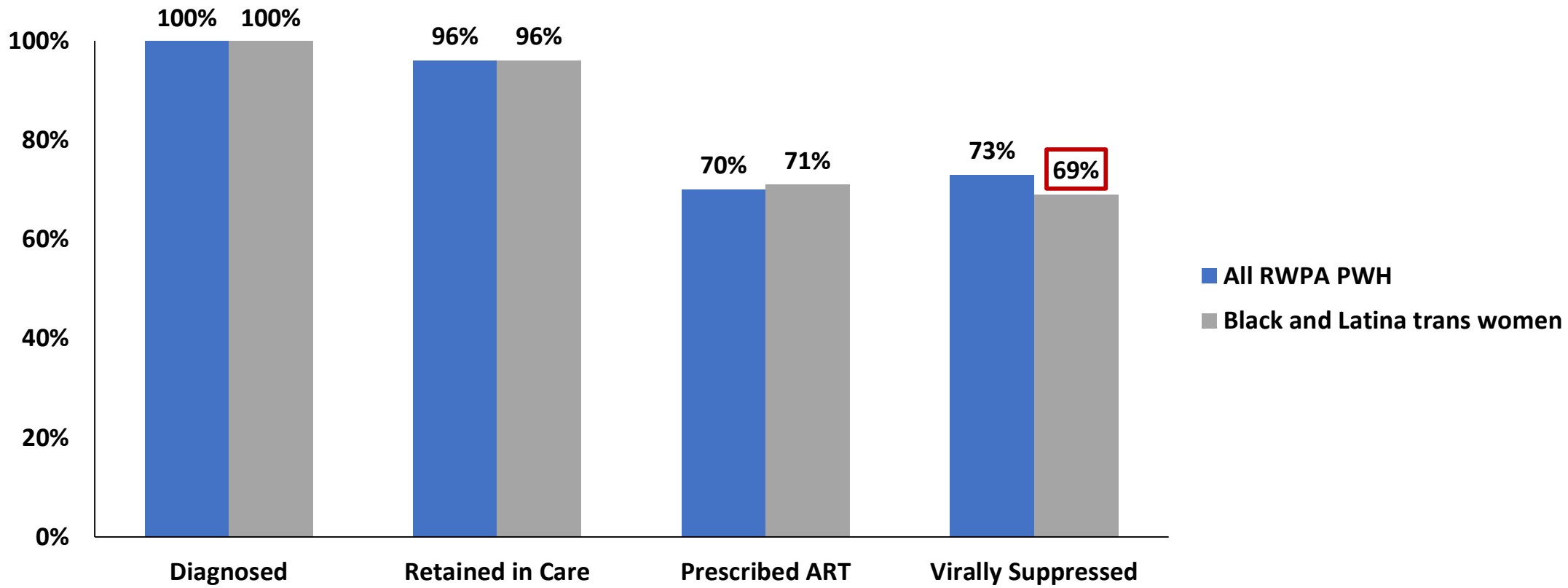
# NY EMA: All RWPA PWH vs. Black and Latina Trans Women, HIV Care Continuum Outcomes, ≥30 years, 2016





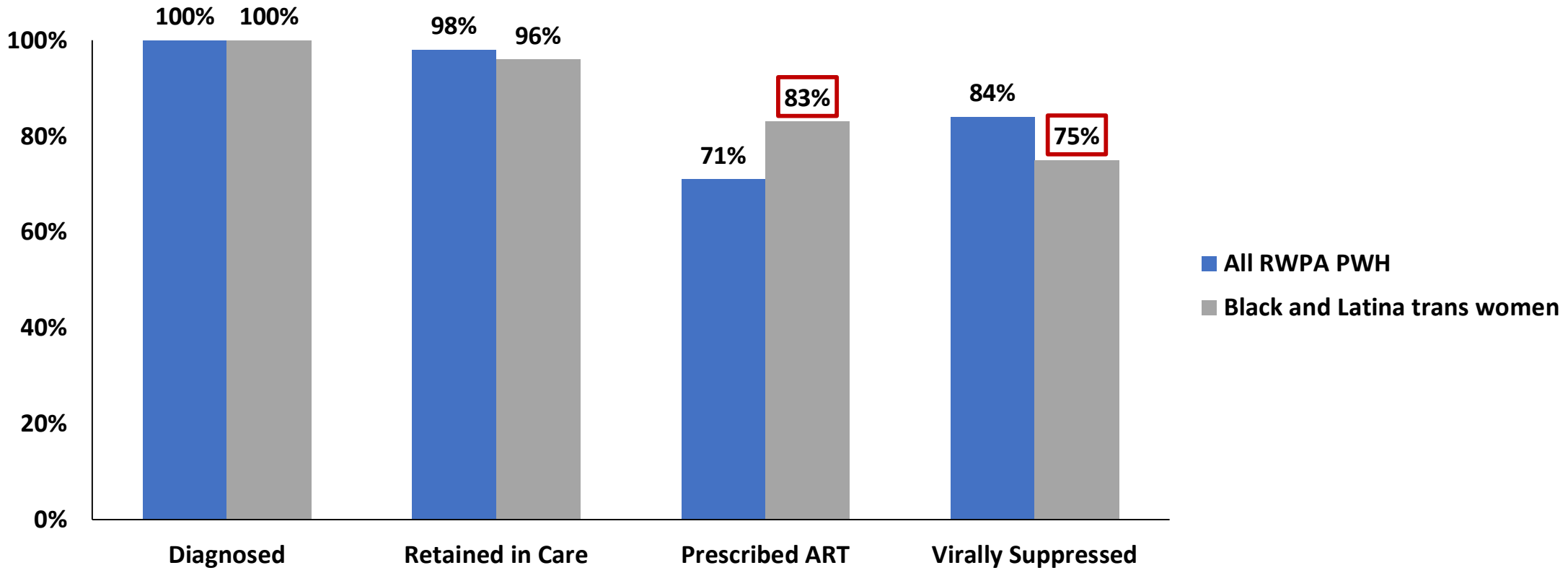

**Compared to all RW PWH aged 30 and older, a higher proportion of Black and Latina trans women 30 and older reported having an ART prescription, but a lower proportion were virally suppressed.**

# NY EMA: All RWPA PWH vs. Black and Latina Trans Women, HIV Care Continuum Outcomes, US Born, 2016




**Compared to all US-born RWPA PWH, a lower proportion of US-born Black and Latina trans women were virally suppressed.**

# NY EMA: All RWPA PWH vs. Black and Latina Trans Women, HIV Care Continuum Outcomes, Born Outside US, 2016




**Compared to all RWPA PWH born outside of the US, a higher proportion of Black and Latina trans women born outside of the US reported having an ART prescription, but a lower proportion were virally suppressed.**

# Resources to Inform Context



- Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People
- Transgender health and economic insecurity:A report from the 2015 LGBT Health and Human Services Needs Assessment Survey
- NYS AIDS Institute Ending the Epidemic Transgender and Gender Non-Conforming People Advisory Group
- Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People The World Professional Association for Transgender Health
- 2015 U.S. Transgender Survey
- Stepping Up Best Practices In Providing HIV Medical Care, Support Services, And Funding To Trans Communities
- AIDS United: Creating  a Transgender Affirming Organization

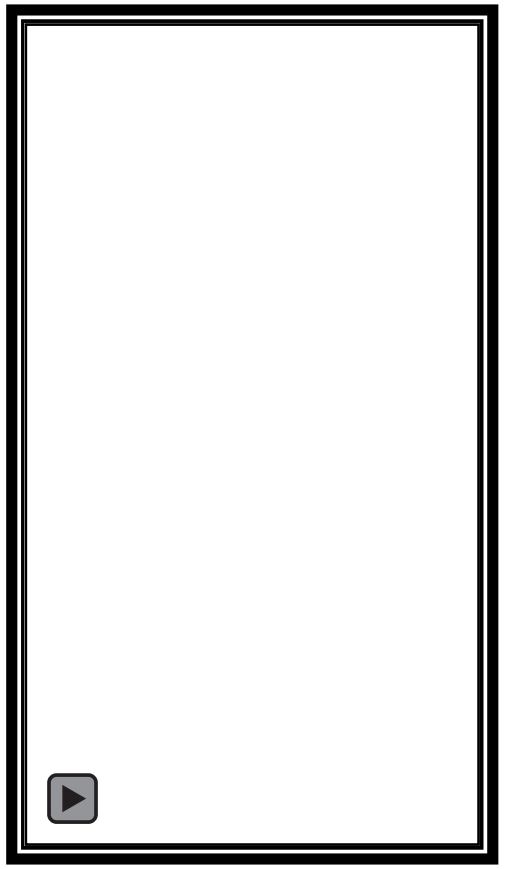
# Resources to Inform Context (cont.)



**Groups, Agencies & Coalitions**

- Callen Lorde Community Health Center
- Exponents
- New York State (NYS) TGNC Advisory Group
- NY Trans Advocacy Group
- The Audre Lorde Project
- AmidaCare

# Why this Work Matters



**This presentation originally included the following video: The Trans Community's Overlooked Struggle For Basic Healthcare**
**(https://www.youtube.com/watch?v=UPJE4XTy_h4)**
**BUT we were honored to receive a video submission from sub-committee member Pheonix Robinson which we are including in its stead.**

# Testimonials



The Needs Assessment Committee held a listening session for people of trans experience. The following summarize the experiences shared:

- People of TIGNBNC experience frequently noted that they do not feel welcome or comfortable accessing healthcare and support services throughout this process
- People of TIGNBNC experience are subject to pervasive and widespread discrimination and violence, even in the offices of service providers, where a lack of expertise, sensitivity and awareness frequently characterizes service delivery
- Barriers to engagement in and adherence to treatment among TIGNBNC persons have not been adequately identified, studied or addressed
- People of trans experience noted deficiencies in the quality of gender affirming care throughout NYC, including a lack of transparency about the availability of services, lack of representation of people of trans experience among service provider staff, and a lack of up-to-date and accurate information on how to deliver gender affirming care.

# Recommendations



1. Increase  the capacity of the NY HIV Planning Council to address the needs of people of TIGNBNC  experience seeking services provided by Ryan White Part A programs.
2. Increase and ensure the capacity of RWPA funded organizations to provide appropriate and relevant services to TIGNBNC
3. Evaluate current capacity of RWPA portfolio to improve health outcomes among TIGNBNC clients

# Recommendations (cont.)



4. Develop strategies, best practices and interventions that address stigma and discrimination against TIGNBNC clients in RWPA services
5. Assess and address barriers to care unique to the TIGNBNC experience

# Actualizing the Recommendations

# Integration of Care Committee



- Committee is required to update service guidance along a timeline that facilitates compliance with the city of New York's contracting guidelines
- Developing a new service directive would have interrupted and delayed the timeline
- To move the work forward, a subcommittee was formed
- People with lived experience on the Council were tapped for leadership
- The subcommittee's first meeting was held April 2019

# Process


- Created a subcommittee to address TIGNBNC-specific needs
- HIV Planning Council Members of Transgender experience serving as 2 of the 3 subcommittee Co-Chairs
- Developed a flyer and recruited among gender affirming networks
  - Subcommittee brought community into the room
- Open style forum to discuss anything related to their HIV/AIDS care in New York City
- Meetings held in a gender affirming space (Exponents)
- Focused on ensuring representative community voices were in full participation throughout process

# The Subcommittee

VIRTUAL 2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

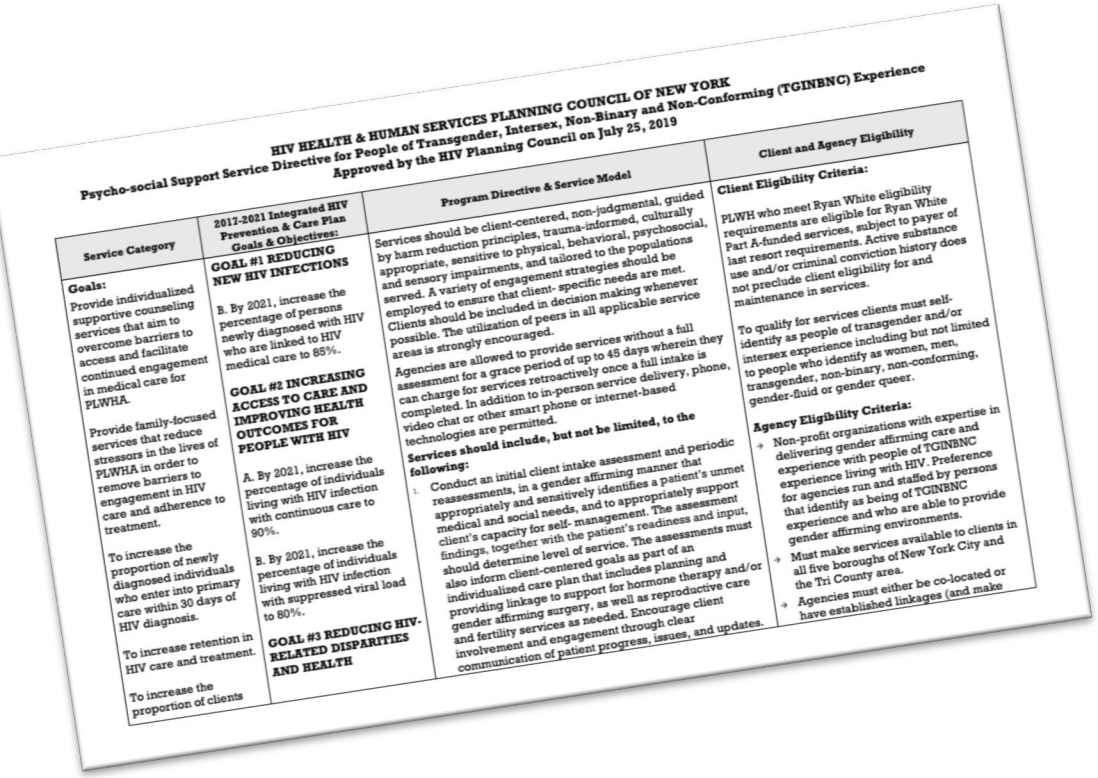
**The Set Up:**

- Care landscape in NYC: wrap around services through multiple funders
- Subcommittee orientation:
  - Intro to RWPA funding, including funding limitations
  - Review of the Needs Assessment committee's recommendations
- Discussion centered participant experience in accessing services
  - Highlighted gap between what is available and what is needed

**Highlights:**

- Housing
- End of Life Care
- Competency and Training
- Employment & Educational Support

# A First Ever…



**HIV HEALTH & HUMAN SERVICES PLANNING COUNCIL OF NEW YORK**
**Psycho-social Support Service Directive for People of Transgender, Intersex, Non-Binary and Non-Conforming (TGINBNC) Experience**
**Approved by the HIV Planning Council on July 25, 2019**

| Service Category | 2017-2021 Integrated HIV Prevention & Care Plan Goals & Objectives: | Program Directive & Service Model | Client and Agency Eligibility |
|---|---|---|---|
| **Goals:**<br>Provide individualized supportive counseling services that aim to overcome barriers to access and facilitate continued engagement in medical care for PLWHA.<br><br>Provide family-focused services that reduce stressors in the lives of PLWHA in order to remove barriers to engagement in HIV care and adherence to treatment.<br><br>To increase the proportion of newly diagnosed individuals who enter into primary care within 30 days of HIV diagnosis.<br><br>To increase retention in HIV care and treatment.<br><br>To increase the proportion of clients | **GOAL #1 REDUCING NEW HIV INFECTIONS**<br><br>B. By 2021, increase the percentage of persons newly diagnosed with HIV who are linked to HIV medical care to 85%.<br><br>**GOAL #2 INCREASING ACCESS TO CARE AND IMPROVING HEALTH OUTCOMES FOR PEOPLE WITH HIV**<br><br>A. By 2021, increase the percentage of individuals living with HIV infection with continuous care to 90%.<br><br>B. By 2021, increase the percentage of individuals living with HIV infection with suppressed viral load to 80%.<br><br>**GOAL #3 REDUCING HIV-RELATED DISPARITIES AND HEALTH** | Services should be client-centered, non-judgmental, guided by harm reduction principles, trauma-informed, culturally appropriate, sensitive to physical, behavioral, psychosocial, and sensory impairments, and tailored to the populations served. A variety of engagement strategies should be employed to ensure that client- specific needs are met. Clients should be included in decision making whenever possible. The utilization of peers in all applicable service areas is strongly encouraged.<br>Agencies are allowed to provide services without a full assessment for a grace period of up to 45 days wherein they can charge for services retroactively once a full intake is completed. In addition to in-person service delivery, phone, video chat or other smart phone or internet-based technologies are permitted.<br>**Services should include, but not be limited, to the following:**<br>1. Conduct an initial client intake assessment and periodic reassessments, in a gender affirming manner that appropriately and sensitively identifies a patient's unmet medical and social needs, and to appropriately support client's capacity for self- management. The assessment findings, together with the patient's readiness and input, should determine level of service. The assessments must also inform client-centered goals as part of an individualized care plan that includes planning and providing linkage to support for hormone therapy and/or gender affirming surgery, as well as reproductive care and fertility services as needed. Encourage client involvement and engagement through clear communication of patient progress, issues, and updates. | **Client Eligibility Criteria:**<br>PLWH who meet Ryan White eligibility requirements are eligible for Ryan White Part A-funded services, subject to payer of last resort requirements. Active substance use and/or criminal conviction history does not preclude client eligibility for and maintenance in services.<br><br>To qualify for services clients must self-identify as people of transgender and/or intersex experience including but not limited to people who identify as women, men, transgender, non-binary, non-conforming, gender-fluid or gender queer.<br><br>**Agency Eligibility Criteria:**<br>→ Non-profit organizations with expertise in delivering gender affirming care and experience with people of TGINBNC experience living with HIV. Preference for agencies run and staffed by persons that identify as being of TGINBNC experience and who are able to provide gender affirming environments.<br>→ Must make services available to clients in all five boroughs of New York City and the Tri County area.<br>→ Agencies must either be co-located or have established linkages (and make |

- Staff liaison developed a draft directive based on committee conversation
- Subcommittee conducted line by line editing of the draft
- Produced 1st NYC service directive to address the needs of a specific priority population, and TIGNBNC people specifically
- Linked services, acknowledging the vital links between housing, employment and legal assistance
- Created specific expectations for organizations to meet when serving the TIGNBNC community

# NY Ryan White Part A Portfolio



Across the portfolio, the master directive requires that services be:

- Client-centered, non-judgmental, guided by harm reduction principles, trauma informed, culturally and age-appropriate, sensitive to physical and sensory impairments, and tailored to the population served
- Provided in a user-friendly manner maximizing access and promoting total health, i.e., hours of operation should be appropriate to the population served, and the facility should be accessible by public transportation and to the physically impaired

# NY Ryan White Part A Portfolio (cont.)



Across the portfolio (cont.)

- Must refer clients, as appropriate, to entitlements and benefits specialists with experience within the health care system
- As unmet medical and social service needs are identified, referrals and linkages must be made to those services
- Concerted outreach efforts should be made to schedule, re-confirm, and follow-up on missed appointments for individuals whose circumstances present added barriers to remaining in care such as youth, the homeless and unstably housed, mentally ill individuals, and substance users

# Highlights



- Directive written as a Psycho-Social Support service to offer group and individual counseling as a core service that complements and provides support for accessing referral services
- Wrap-around services made available through referrals with accompaniment to support navigation and improve utilization
    - Expanded recommended referral services to address drivers of inequitable health outcomes
- Recommended cultural humility training for entire agency – not only persons who deliver direct services*
- Developed organizational standards for delivering services to the TIGNBNC community

*Ryan White Part A can only require trainings for staff funded by the grant

# Highlights (cont.)



- Direct navigational support to access gender affirming care, including planning and providing linkages to support for hormone therapy and/or gender affirming care.
  - Direct navigational support for reproductive care and fertility services
- Mandate to:
  - Coordinate all levels of medical and behavioral health, as needed
  - Develop a publicly available directory of gender affirming primary, HIV care and mental health providers
  - Offer telehealth support for medication adherence
  - Promote self management and life skills

# Highlights (cont.)



- Provide linkage/referrals to clients for programs and services that facilitate client stabilization, including but not limited to
  - credit repair
  - financial literacy
  - estate planning
  - end of life planning
  - job readiness
  - housing readiness
  - housing starter kits
  - basic and continuing educational opportunities

# Highlights (cont.)



- Develop/adapt a publicly available curriculum toward implementing broad based education, prevention, intervention and remediation programming to address and dismantle stigma and discrimination such as intimate partner violence, hate based crimes and state/institutional violence.
- Develop and maintain a publicly available resource guide to support these processes among providers and individuals

# Highlights (cont.)



- Agencies will identify barriers to accessing services to inform strategies toward the improvement of gender affirming care throughout their referral networks.
- Preferential language supports contracting with agencies run and staffed by persons that identify as being of TIGNBNC experience who can best provide gender affirming environments.

# Priority Setting & Resource Allocation



The Priority Setting & Resource Allocation committee is responsible for allocating funding for all services. The committee received funding proposals from the Recipient toward the implementation of a pilot TIGNBNC Psycho-Social Support program. The proposals considered the following data:

- Surveillance and Ryan White Part A data
- Number of transgender PWH in NYC
- Age, race, ethnicity and transmission risk
  - Rate of new HIV infections
- Community density by borough across NYC

A pilot program allows the recipient to scale up and strengthen the model before rolling out multiple programs.

The Recipient will build work with contracted agencies to build capacity to deliver services in a gender affirming manner across the portfolio.

# Priority Setting & Resource Allocation (cont.)



Two pilots were proposed:

| Scenario 1: Job Position | Salary ranges (AVG$) | Actual Salary Ranges (via Glassdoor) |
|---|---|---|
| 1 Program Director (0.5 FTE) | 32,500-35,000 | 65,000-70,000 |
| 1 Clinical Support for Staff (0.15FTE) | 10,000-20,000 | 65,000-130,000 |
| 2 Case Manager(s) | 45,000-60,000 | 45,000-60,000 |
| 1 Peer Navigator | 35,000-45,000 | 35,000-45,000 |
| Total Staffing Cost (1 program) | $167,500 - $220,000 | |
| TOTAL PROGRAM COST (Personnel + 25% Fringe Benefits + 11% OTPS + 10% Admin) | $255,646 – $335,775 | |

Staffing would allow for caseload of 50 – 60 clients per program

# Priority Setting & Resource Allocation (cont.)



| Scenario 2: Job Position | Salary ranges (AVG$) | Actual Salary Ranges (via Glassdoor) |
|---|---|---|
| 1 Program Director (0.5 FTE) | 32,500-35,000 | 65,000-70,000 |
| 1 Clinical Support for Staff (0.15FTE) | 10,000-20,000 | 65,000-130,000 |
| 3 Case Manager(s) | 45,000-60,000 | 45,000-60,000 |
| 1 Peer Navigator | 35,000-45,000 | 35,000-45,000 |
| Total Staffing Cost (1 program) | $212,500 - $280,000 | |
| TOTAL PROGRAM COST (Personnel + 25% Fringe Benefits + 11% OTPS + 10% Admin) | $324,327 - $423,500 | |

Staffing would allow for total case-load of 75–90 clients per program

# Priority Setting & Resource Allocation (cont.)



Funding determination:

- Psycho-Social Support for TIGNBNC:
  - $50,000 for resource directory and training curriculum (updates in future years at $10K)
  - Request for proposals for the resource directory will be conducted during the 2020 fiscal year in anticipation of programming in 2021
  - Program services have been funded in FY 2021 at $423,500, half of the recommended allocation
    - Accommodates the mid year roll out of two programs using staffing and program estimates from scenario 2

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# Thank you!


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