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HIV CARE & TREATMENT

# Community Planning in Response to the Needs of Older People with HIV

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- Graham Harriman, Sarah Kozlowski, and Scott Spiegler have no relevant financial or non-financial interests to disclose.
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# Learning Outcomes:



- Share epidemiological data describing Older People with HIV (OPLWH) in NYC
- Describe the challenges and opportunities for wellness and prevention among OPLWH in NYC
- Describe the gaps in service provision for OPLWH in NYC
- Contribute to the national development of best practices in the delivery of care and support services to meet specific needs of OPLWH
- Apply lessons learned in New York City to other jurisdictions

## Aging with HIV in NYC

# HIV/AIDS Among People 50 and Older (OPLWH) in NYC, 2018\*



- **57.7%** of People Living with HIV in NYC are  $\geq$  50 years of age (N=73,524)
- Among this population in 2018, there were:
  - 382 new HIV diagnoses
    - 121 of new HIV diagnoses concurrent with an AIDS diagnosis
  - 453 new AIDS diagnoses
  - 1,332 deaths
    - 18.3 deaths per 1,000 older adults with HIV\*\*

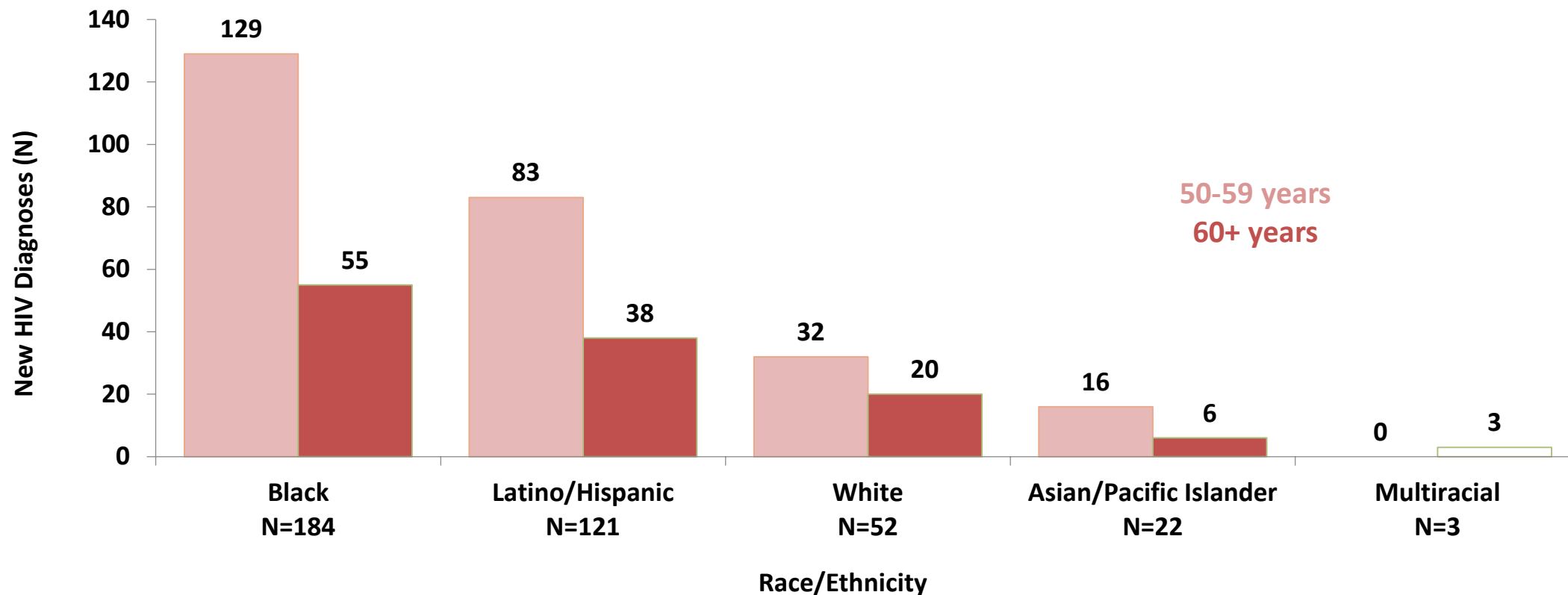
\*Data as of 12/31/2018; see <https://www1.nyc.gov/assets/doh/downloads/pdf/dires/hiv-aids-in-youth-and-older-adults.pdf>

\*\*As reported to the New York City Department of Health and Mental Hygiene by March 31, 2017

# Number of New HIV Diagnoses Among Persons Aged 50+ by Race/Ethnicity in NYC, 2018

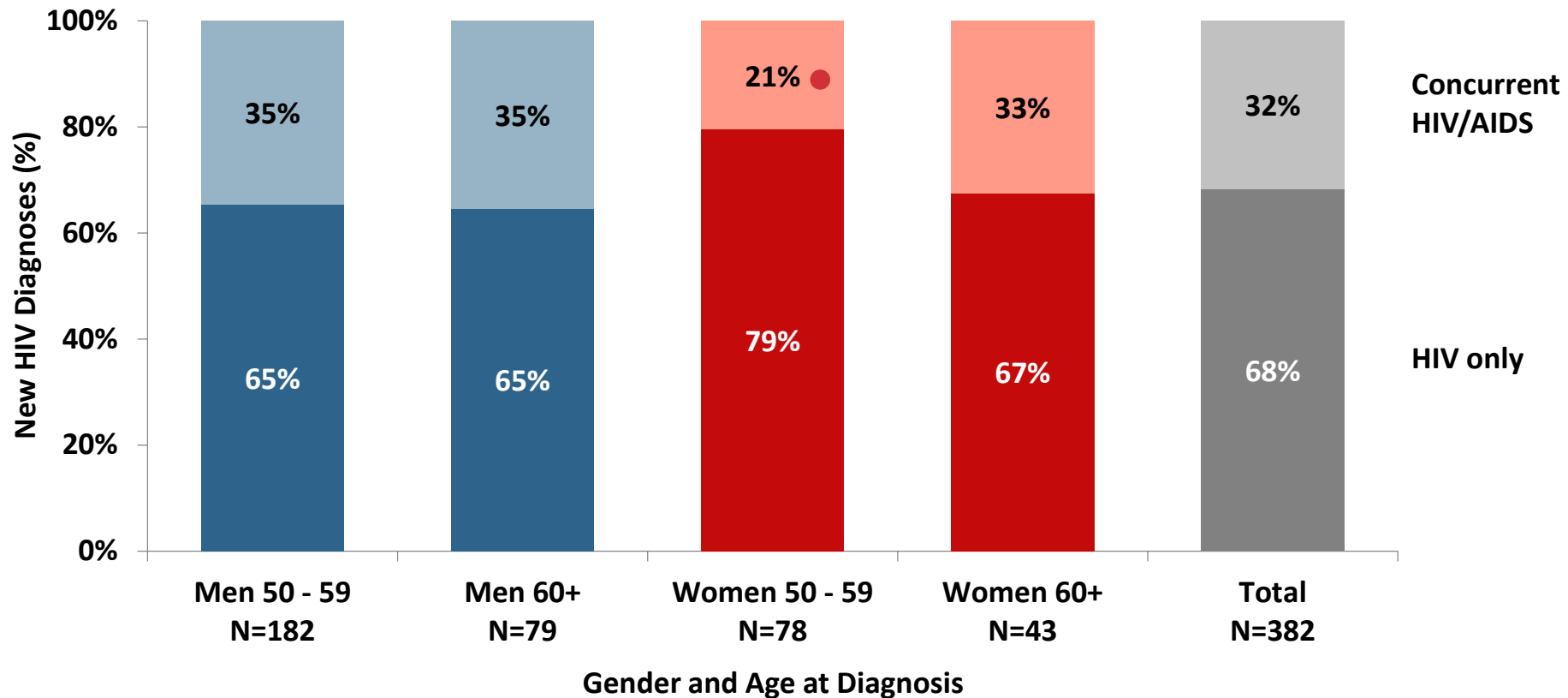


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**In 2018, Black people 50 years and over had more new HIV diagnoses than any other race/ethnicity. Across nearly all race/ethnicities, more newly diagnosed people were in the 50-59 age group than 60+.**

# Percentage of New HIV Diagnoses Concurrent with an AIDS Diagnosis\* Among Persons 50 and Older by Gender and Age in NYC, 2018

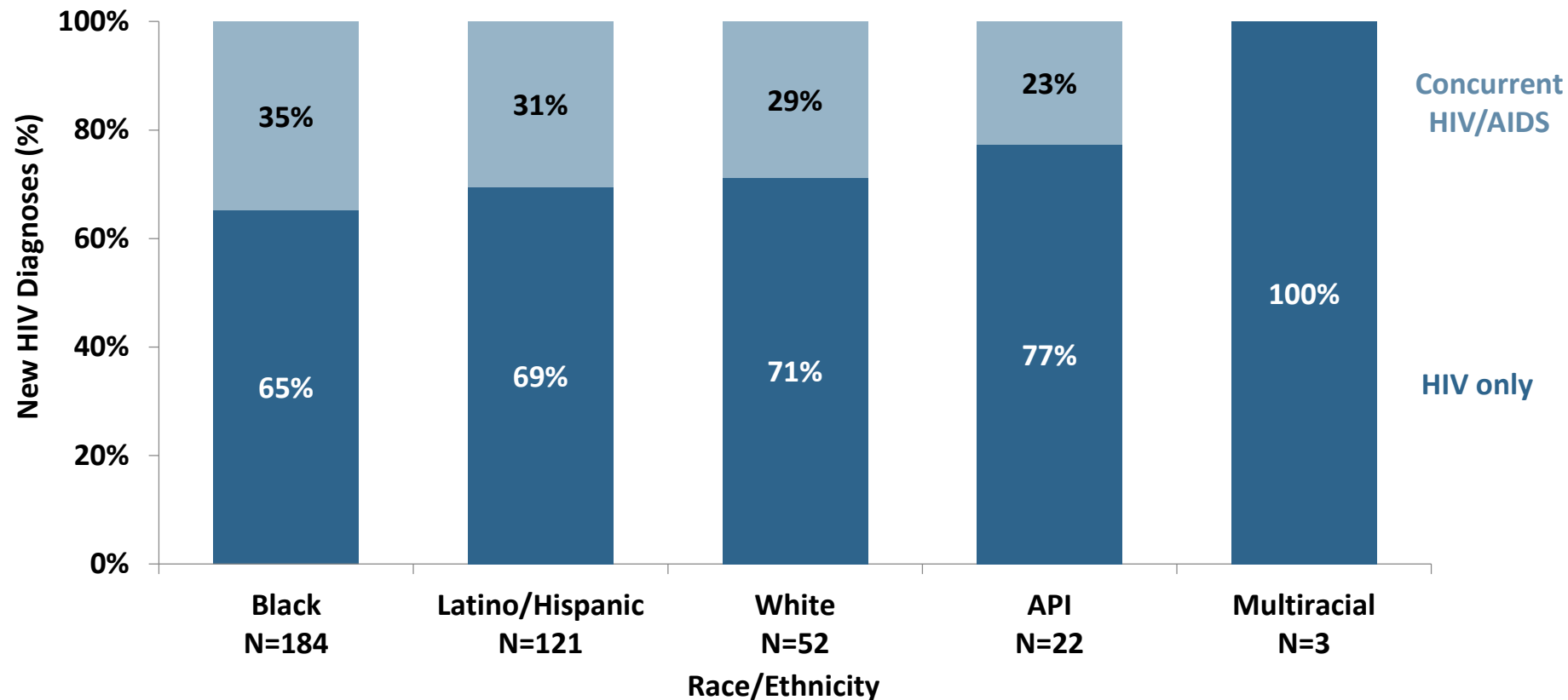


**Men 50 to 59 years and 60+ years had a higher proportion of concurrent HIV/AIDS diagnoses than women in the same age group.**

\*AIDS diagnosis within 31 days of HIV diagnosis.

Men includes transgender men and women includes transgender women. As reported to the New York City Department of Health and Mental Hygiene by March 31, 2019.

# Percentage of New HIV Diagnoses Concurrent with an AIDS Diagnosis\* Among Persons 50 and Older by Race/Ethnicity in NYC, 2018



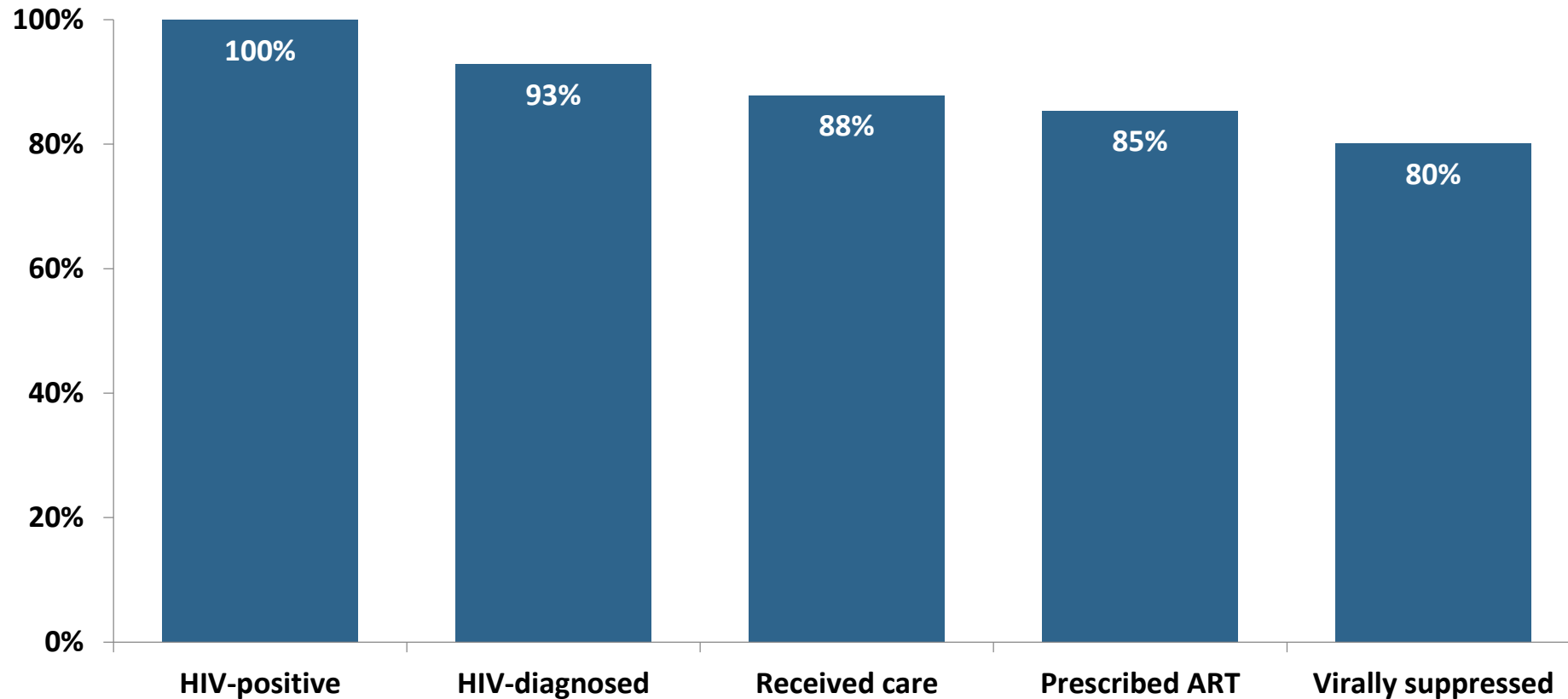
The proportion of concurrent HIV/AIDS diagnoses was higher among Black people (35%) and Latino/Hispanic people (31%) ages 50+ years than among White people (29%) and API people (23%).

\*AIDS diagnosis within 31 days of HIV diagnosis

API=Asian/Pacific Islander. In 2018, there were no Native Americans ages 50 and older diagnosed with HIV. As reported to the New York City Department of Health and Mental Hygiene by March 31, 2019.



# Proportion of PLWH Aged 50 and Older Engaged in Selected Stages of the HIV Care Continuum in NYC, 2018

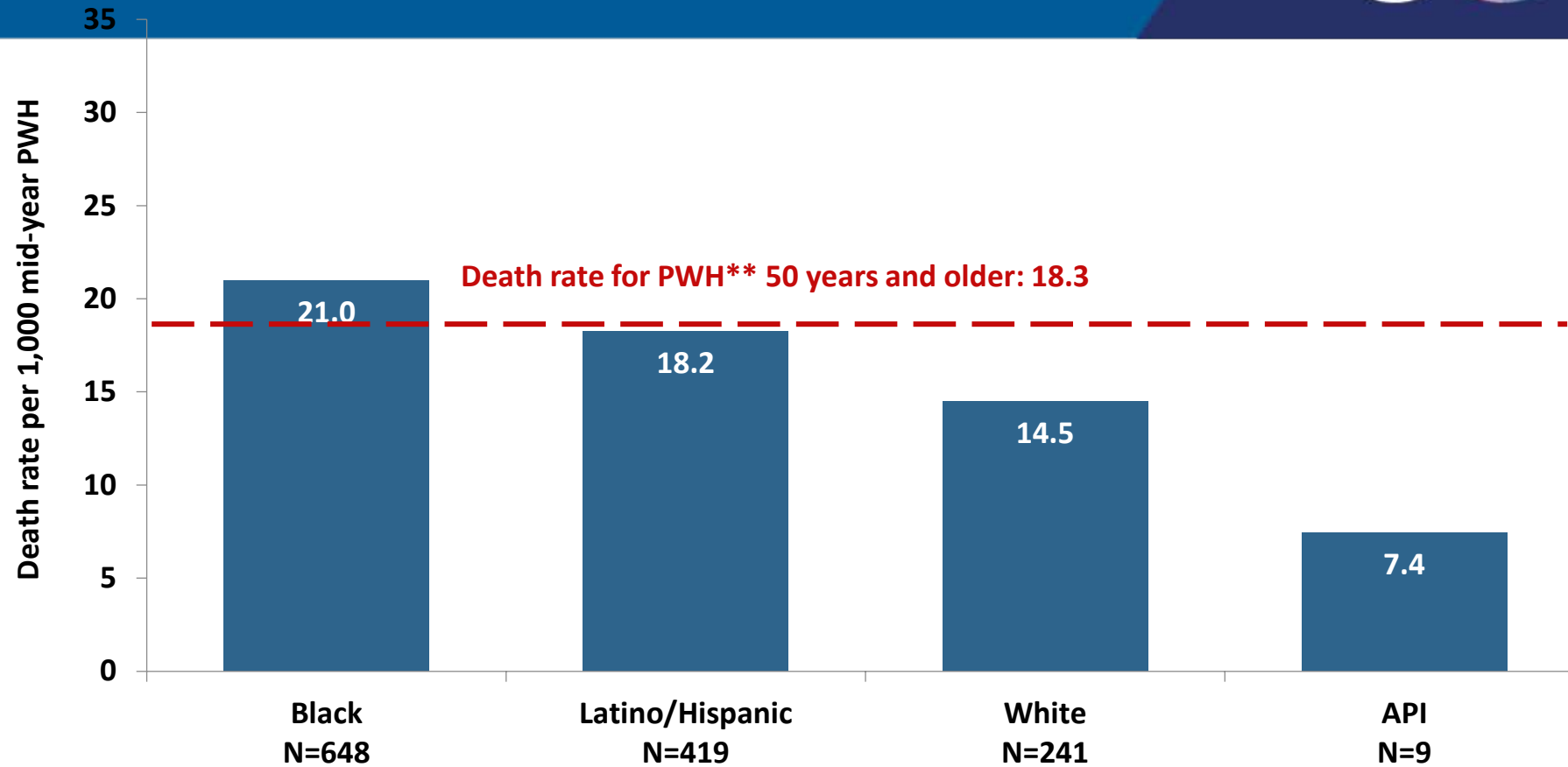


**Of the approximately 50,000 people ages 50 years and over with HIV and living in NYC in 2018, 80% had a suppressed viral load\*.**

\*Some people who had a suppressed viral load included people who may not have been in care or prescribed ART in 2018.

As reported to the New York City Department of Health and Mental Hygiene by March 31, 2019. For definitions of the stages of the continuum of care, see Appendix 2.

# Death Rates\* Among Persons 50 and Older by Race/Ethnicity in NYC, 2018



**Death rates among Black PWH ages 50 years and older were higher than the rates for PWH 50 years and older of other race/ethnicities.**

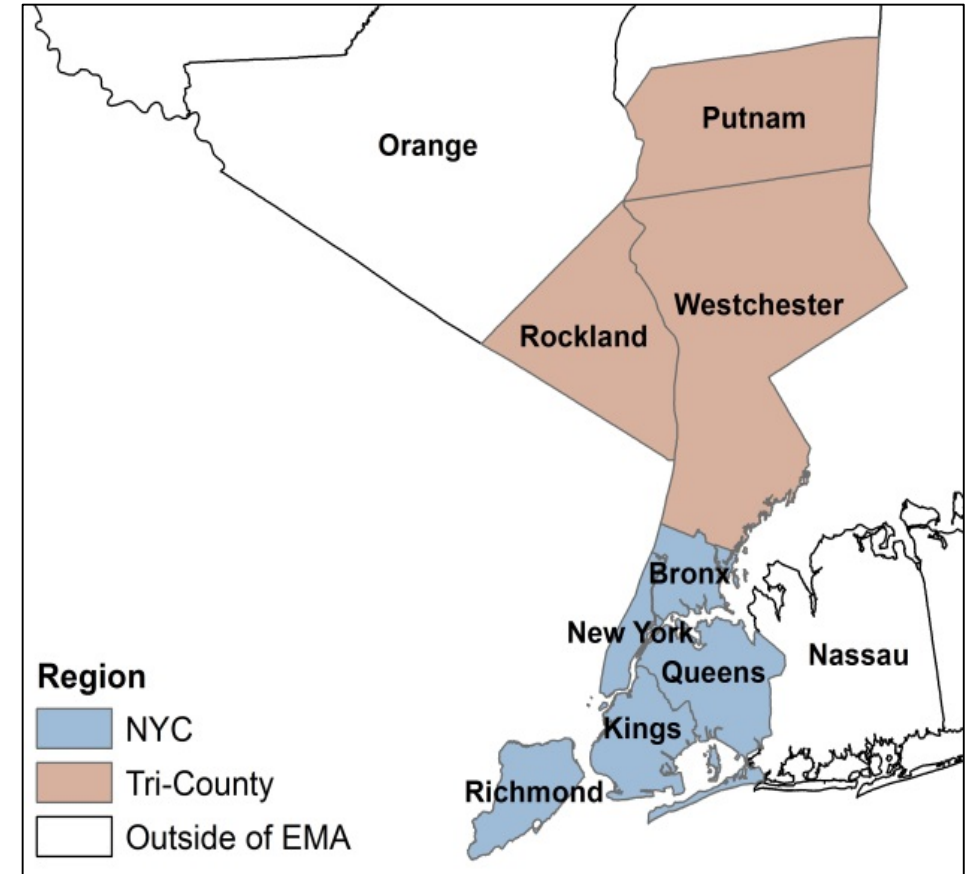
\*Crude death rates. Death data for 2018 are incomplete. \*\*PWH=People with HIV  
API=Asian/Pacific Islander As reported to the New York City Department of Health and Mental Hygiene by March 31, 2019.

# Overview: NY EMA Ryan White Part A (RWPA)



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- Part A: emergency assistance to areas hardest hit by epidemic
  - New York City Department of Health and Mental Hygiene (DOHMH) is the grantee for Ryan White Part A (RWPA) in the New York Eligible Metropolitan Area, or 'EMA' (NYC and Tri-County area)
    - Clients: >12,000 HIV-positive individuals served in grant year 2018
- DOHMH contracts with ~90 service delivery agencies
- The local program covers ~14 service categories, the largest programs include Medical Case Management, Housing, Harm Reduction, Food and Nutrition Services, and support for the NYS ADAP program



# OPLWH Demographics: New York EMA, 2018



Demographics	<i>Less than 50 years</i>	<i>50 years and older (OPLWH)</i>
<b>Total</b>	<b>5,850 (47.2%)</b>	<b>6,544 (52.8%)</b>
<b><i>Race/Ethnicity</i></b>		
Black	2,897 (49.5%)	3,505 (53.6%)
Hispanic	2,254 (38.5%)	2,297 (35.1%)
White	440 (7.5%)	579 (8.9%)
Asian/Pacific Islander	128 (2.2%)	49 (<1%)
Other/Unknown <sup>2</sup>	131 (2.3%)	114 (1.7%)
<b><i>Current Gender Identity</i></b>		
Man	3,993 (68.3%)	4,161 (63.6%)
Woman	1,449 (24.8%)	2,252 (34.4%)
TGNCNB <sup>3</sup>	394 (6.7%)	126 (1.9%)
Not Sure/Questioning	14 (<1%)	5 (<1%)

**12,394 total** active HIV+ clients in NYC Ryan White Part A Services<sup>1</sup>

<sup>1</sup>Clients must have had an open enrollment from 3/1/2018-2/28/2019 and received at least one service in a Ryan White Part A program in NYC during this time period.

<sup>2</sup>Other/Unknown includes clients who identified as other, mixed race, unknown, or declined to answer.

<sup>3</sup>TGNCNB represent clients who identified as transgender, gender nonconforming, and non binary.

# OPLWH Demographics: New York EMA, 2018 (cont'd)



Demographics (continued)	<i>Less than 50 years</i>	<i>50 years and older (OPLWH)</i>
<b>Total</b>	<b>5,850 (47.2%)</b>	<b>6,544 (52.8%)</b>
<b><i>Insurance Status</i></b>		
Uninsured	1,249 (21.4%)	593 (9.1%)
Insured – Public	4,332 (74.1%)	5,780 (88.3%)
Insured – Private	222 (3.8%)	138 (2.1%)
Other/Unknown	55 (<1%)	49 (<1%)
<b><i>Housing Status</i></b>		
Homeless	999 (17.1%)	890 (13.6%)
<b><i>Federal Poverty Level</i></b>		
<100% Federal Poverty Level	4,847 (82.9%)	5,297 (80.4%)
≥100% Federal Poverty Level	988 (16.9%)	1,236 (18.9%)
Unknown	15 (<1%)	11 (<1%)

**12,394 total** active HIV+ clients in NYC Ryan White Part A Services\*

\*Clients must have had an open enrollment from 3/1/2018-2/28/2019 and have received at least one service in a Ryan White Part A program in NYC during this time period.

## A Survey of HIV Care Providers

## **Goal:**

**To better understand the healthcare needs of OPLWH from the provider perspective**

## **Objectives:**

1. To assess the supports currently in place for OPLWH
2. To gather provider opinions on the availability or services for OPLWH
3. To lay the foundation for a community forum on HIV and Aging in NYC

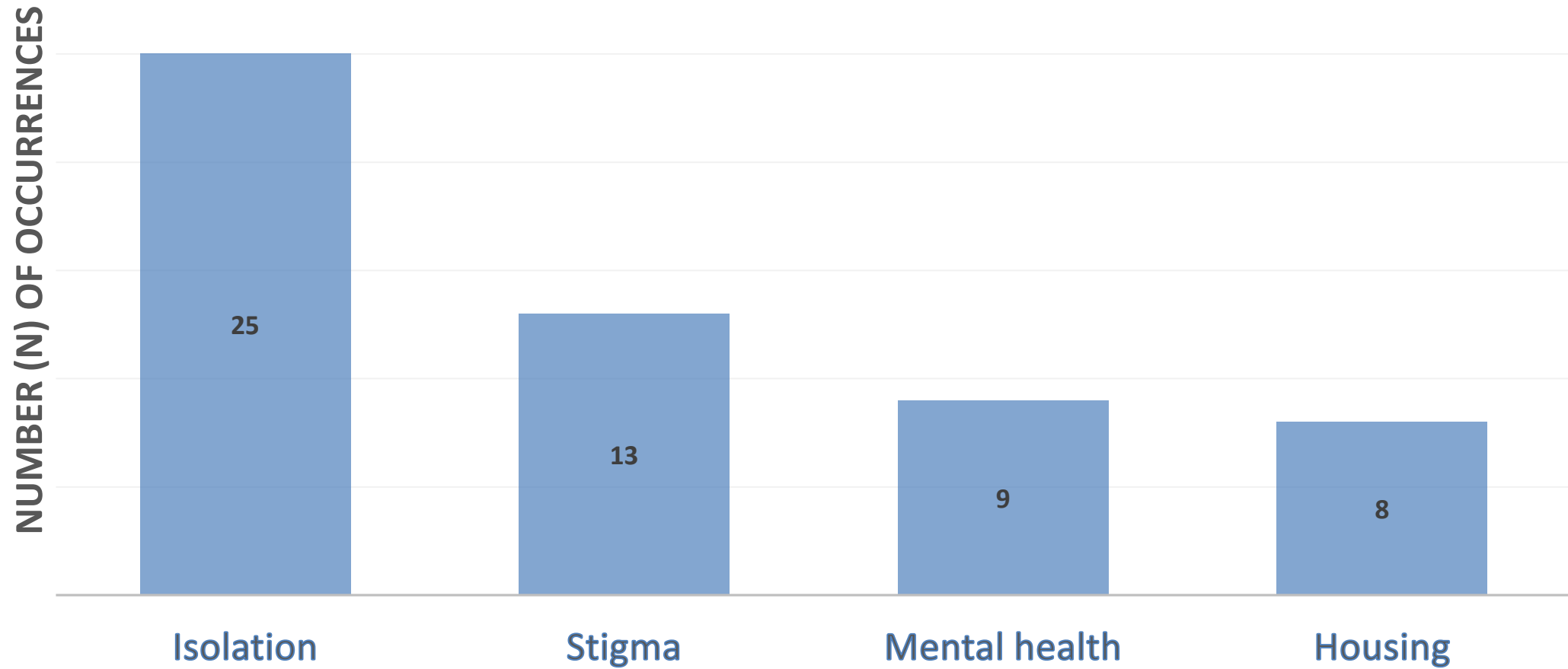
# Survey Methods



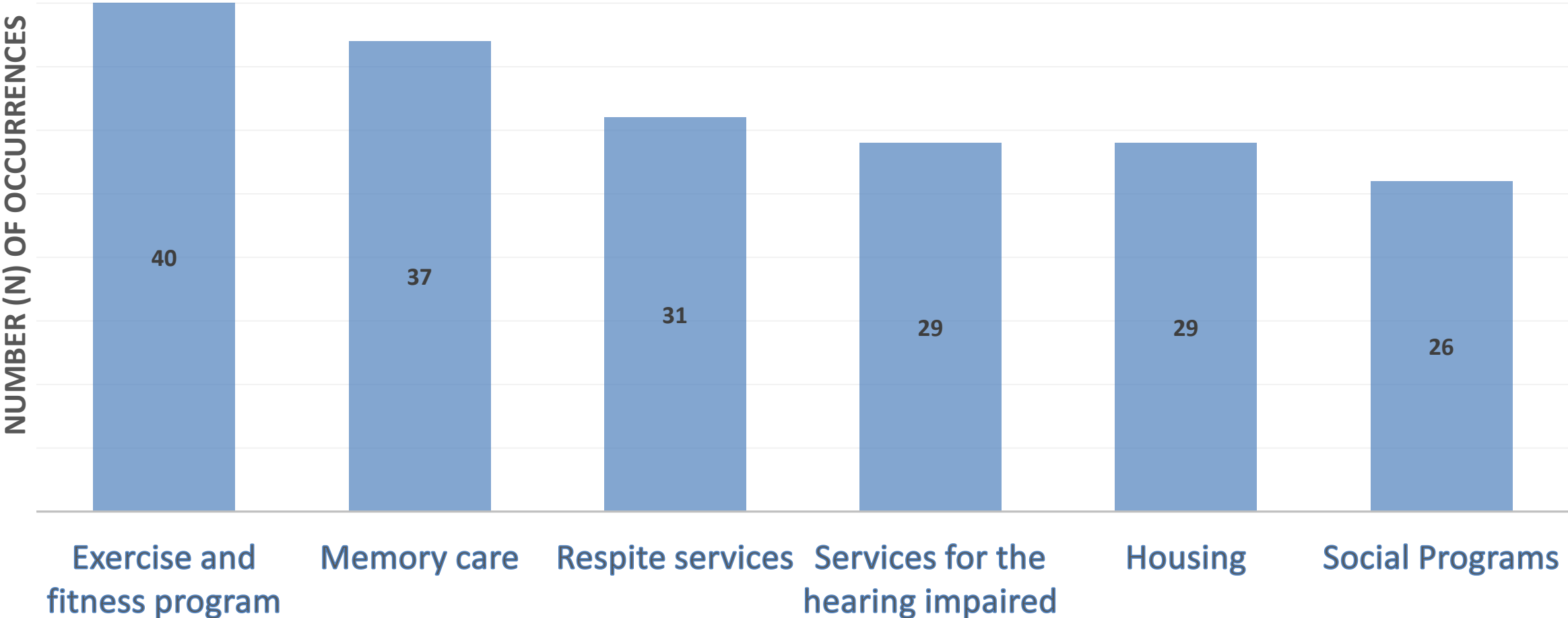
- The survey was open from 10/25/17 to 11/20/17
- 234 providers participated
  - 70 complete responses were gathered
- Respondents included representatives from hospitals, clinics, and CBOs
- **Questions explored:**
  - Resources currently available to OPLWH
  - Barriers and challenges commonly faced by OPLWH
  - Areas of unmet service need
  - Common resources and referrals provided to OPLWH



# Survey Results: Greatest Barriers/Challenges OPLWH in NYC Face *(Open Response Question)*



# Survey Results: Unmet and Somewhat Met Service Needs *(responses from list provided)*



## **A Community Forum about Addressing the Needs of OPLWH in NYC**

# Attendee-Identified Themes from Community Forum



1. Need for more consumer input
2. HIV competency in geriatric settings
3. Aging competency in HIV care settings
4. Evidence-based practices in care and treatment
5. Risk of social isolation
6. Social determinants of health
7. Integration of care



# Main Takeaways: Provider Survey and Community Forum



- ◉ Increase prevention resources
  - Need for testing and sexual health services
- ◉ Address provider needs
  - Clinical tool to address needs of the whole individual
  - Guidance on how to address non-medical issues
- ◉ Identify unmet need
  - More research needed on consumer-identified needs
    - What works in the system?
    - What is missing?
  - Use qualitative and quantitative data to influence future programming
- ◉ Address social isolation

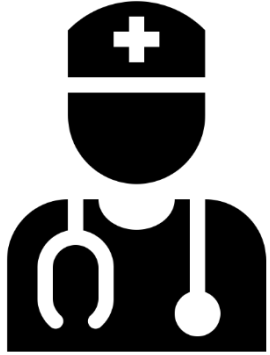
## The NYC HIV & Aging Focus Group Project

# Project Aim

To learn about the **strengths**, **unmet needs**, and **barriers** experienced by NYC's OPLWH



# Methods: Topic Domains



**Medical Care**

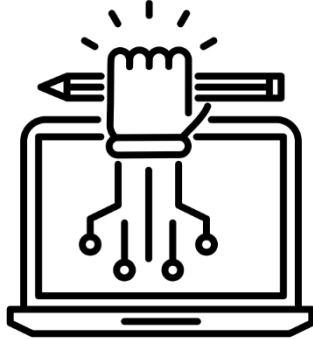


**Mental Health Care**



**Social Support**

**Educational Resources**



**Other Needs**

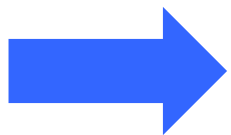
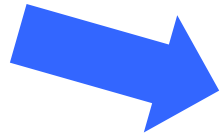




# Methods: Participant Eligibility



- Eligibility Criteria



Live in the  
5  
boroughs

Are you **50** or older?

Are you living with **HIV**?

Have you been diagnosed for **10** or more years?

The New York City Health Department is hosting focus groups throughout NYC this fall to hear about people's experiences living with HIV as they get older.

Participants will receive a **\$50 gift card** and a **round-trip MetroCard** for their time. Snacks and beverages will be provided.

*Si prefieres grupos en español, también los tenemos disponibles.*

We want to hear about your experiences! Please call Sarah at 347-396-7672 or Scott at 917-751-4818 to find out if you're eligible to participate.

Are you **40** or older?

Are you living with **HIV**?

Do you identify as **transgender** or **gender non-conforming**?

The New York City Health Department is hosting a focus group for **transgender and gender non-conforming individuals** in NYC this fall to hear about their experiences living with HIV as they get older.

Participants will receive a **\$50 gift card** and a **round-trip MetroCard** for their time. Snacks and beverages will be provided.

We want to hear about your experience! Please call Sarah at 347-396-7672 or Scott at 917-751-4818 to find out if you're eligible to participate.

# Findings: Participants Characteristics



7 focus groups, **62 total participants**

	Cisgender men who have sex with men (MSM)	Cisgender men who have sex with women (MSW)	Cisgender women	Transgender & gender non-conforming (TGNC)
English	11	9	11	13
Spanish	10	2	6	N/A

# Findings: Participants Characteristics



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## General Demographics

	1 <sup>st</sup> Most Represented Group	2 <sup>nd</sup> Most Represented Group
<b>Borough of Residence</b>	Bronx	Brooklyn
<b>Age</b>	60-69	50-59
<b>Race/Ethnicity</b>	Black	Latino/Latina

Average Number of Years Diagnosed:

**24**

# Methods: Qualitative Analysis Approach



- ResearchTalk team developed the Sort and Sift, Think and Shift Qualitative Inquiry Approach.
  - This multidisciplinary approach combines threads from Grounded Theory, Phenomenology, Narrative Research and Qualitative Case Study to build an inductive and iterative approach to all phases of qualitative research projects.
- The analysis plan utilized ResearchTalk's co-analysis approach.
  - The approach builds on the strength of content experts and qualitative methods experts to process data as a team.
    - Two NYC staff members and two ResearchTalk qualitative data analysts used iterative phases of analysis.

# Methods: Qualitative Analysis Approach (cont'd)



- ◉ Analysis moved between “diving in” and “stepping back” phases of data analysis.
  - Team members engaged data and then reflected on lessons learned to shape next steps and outline findings (Maietta, 2006; Fryer, 2015).
  - “Diving in”: team members independently read two focus group transcripts. For each transcript, one team member from NYC and one from ResearchTalk processed the focus group file. Team members identified powerful quotations and developed holistic summaries of the data documents.
- ◉ The team reviewed these quotations and document reflections to develop a list of core topics to monitor through analysis. This list featured:
  - Deductive topics dictated by the focus group guide, like ‘clinical health navigation,’ and
  - Inductive topics, including ‘a life with HIV’ and an in-vivo category, “I’m comfortable in my own space.”

# Methods: Qualitative Analysis Approach (cont'd)



- ◉ Topic Monitoring: The team worked in pairs with one member of each organization monitoring each focus group for the core topics.
  - The team gathered to analyze quotations for each topic. Data segments were printed on index cards, then sorted by topic to understand their meaning and applicability to the project.
  - The team regularly did consensus checks of coding and the conversations emerging from their work.
- ◉ “Stepping back” to reflect on overall patterns
  - Bridged together findings
  - Framed a story of how people living with HIV move through a two-part evolution that represents their journey living with HIV

# Deductive Topic Findings



Prior to transcription and analysis, the NYC team outlined the following initial set of findings. These findings were supported after a deeper analytic treatment of the data.

- ◉ *Medication Adherence*

- *“The medicine is **so much easier to take** now than it was when I was originally diagnosed...”*

- Advances and development in HIV medication have made it easier to take medication consistently and according to prescribing protocols.

- ◉ *Mental Health Care*

- *“Well, black people, or minorities, are really beginning to realize that it’s **not only for white people.**”*

- Mental Health resources are limited despite increased need. This is especially true in minority communities

# Deductive Topic Findings (cont'd)



- ◉ *Social Support*

- *“I go to therapy at my job to solve my problems and I still try to see the therapist but there are **not many therapists who speak Spanish and understand our culture.**”*

- Participants in Spanish-speaking focus groups identified a need for additional support services/programs.

- ◉ *Access to Resources*

- *“... everything right now is about **doing your own research and doing your own footwork. Everything is not going to be handed out to you, or given to you. I had to find out a lot of things on my own. I had to talk to people.**”*

- Inconsistent knowledge of and access to resources revealed a need for consolidation of resources to support accessibility and utilization across the care continuum.



## A Two-Part Journey

- ◉ Part 1: ***The Person*** presents a life with HIV as a journey in which participants first work to understand life with the disease and then adapt to life with HIV and for some, move to advocate for others living with HIV.
- ◉ Part 2: ***The System*** details how participants navigate both the healthcare and housing systems by first working to understand the systems, adapting to the systems and for some, advocating to guide others through these systems.

# PART 1 – The Person: Personal Evolution



Understanding life  
with the disease

Adapting to life with HIV

> with support

> with spirituality

Advocating for others

- Participant stories reveal efforts to understand life with the disease, which translated to an acceptance characterized by efforts to adapt moving forward.
  - This process was often facilitated by support from formal and informal channels and spirituality.
- It was common for participants to describe a pathway that led them to advocate for other PLWH, especially for younger generations and those newly diagnosed.
- “The mental health part of it is you have to make a determination that you want to live, that you want to go on with your life. But you’ve got to do something. You’ve got to have some type of purpose.”

# PART 1 – The Person: Personal Evolution (cont'd)



**Understanding life  
with the disease**

**Adapting to life with HIV**

- > with support
- > with spirituality

**Advocating for others**

- ◉ “After [threatening suicide] I just went on a journey of finding out what is this HIV thing, like what is this? What is invading my body? What's making me feel this way? How can I get better? So I went to all these different trainings...and then I started going to other places and I was like wow, this is what's going on with my body? And talking to other people who's in the same boat, but even longer with this, with the HIV.”
- ◉ “As we are older, not just living with HIV. HIV living with us. To continue to take care of yourself and know your body and know the symptoms that go on in your body at the same time and as you recognize your symptoms you can address it and take care of it and be aware of it.”

# PART 1 – The Person: Personal Evolution (cont'd)

Understanding life  
with the disease

Adapting to life with HIV

- > with support
- > with spirituality

Advocating for others

- “I also found out that if I don't really speak about it, I really can't get help...when the time comes that I might need help, like connecting and networking and things of that nature.”

## With Support

- “Like I always tell my clients, have a good support team because if you don't have a support team, you're gonna be lost. You're going to be lost. Especially, at least, tell one person in your family what's going on with your bod- with you.”

## With Spirituality

- “I just want to say. Ever since my life turned out to be the best of everything, I say to my higher power, I thank Him because He gave me an opportunity to see better things in life. To see a different way of life. To see a different way of me.”

# PART 1 – The Person: Personal Evolution (cont'd)



Understanding life  
with the disease

Adapting to life with HIV

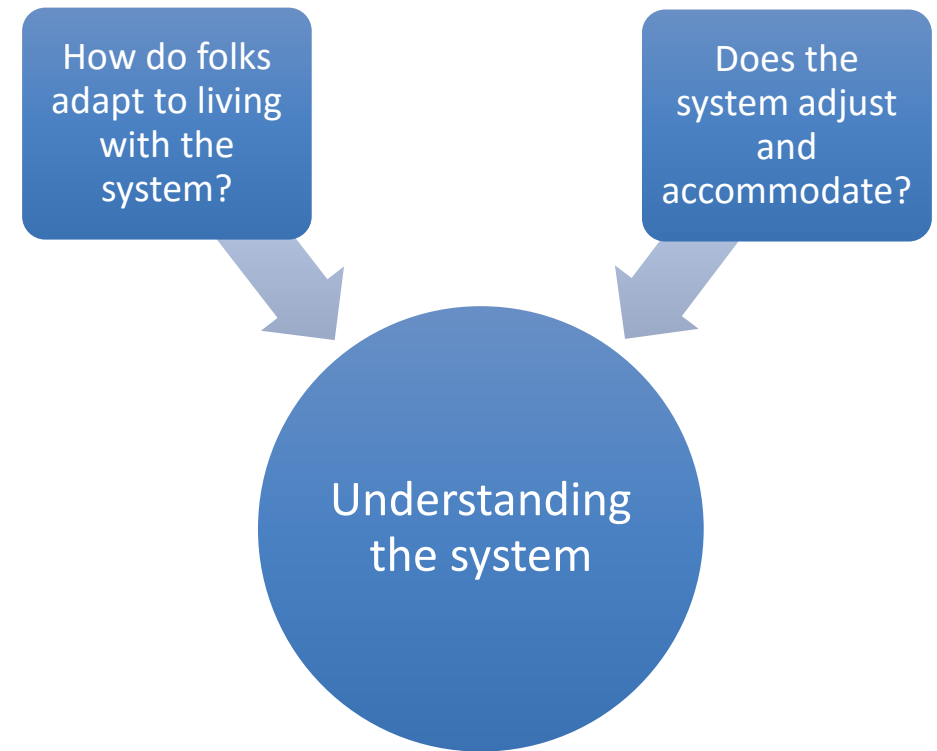
- > with support
- > with spirituality

Advocating for others

- “We're gonna do this together. And I get, I work with transwomen, transmen and I walk them through the steps. If they come in, newly diagnosed. I go with them to the doctor. They'll come back to me thank you, you saved my life. No, I didn't save your life, you saved your own life. Cause you took that step and moved on.”

# PART 2 – The System: A story of navigating the system

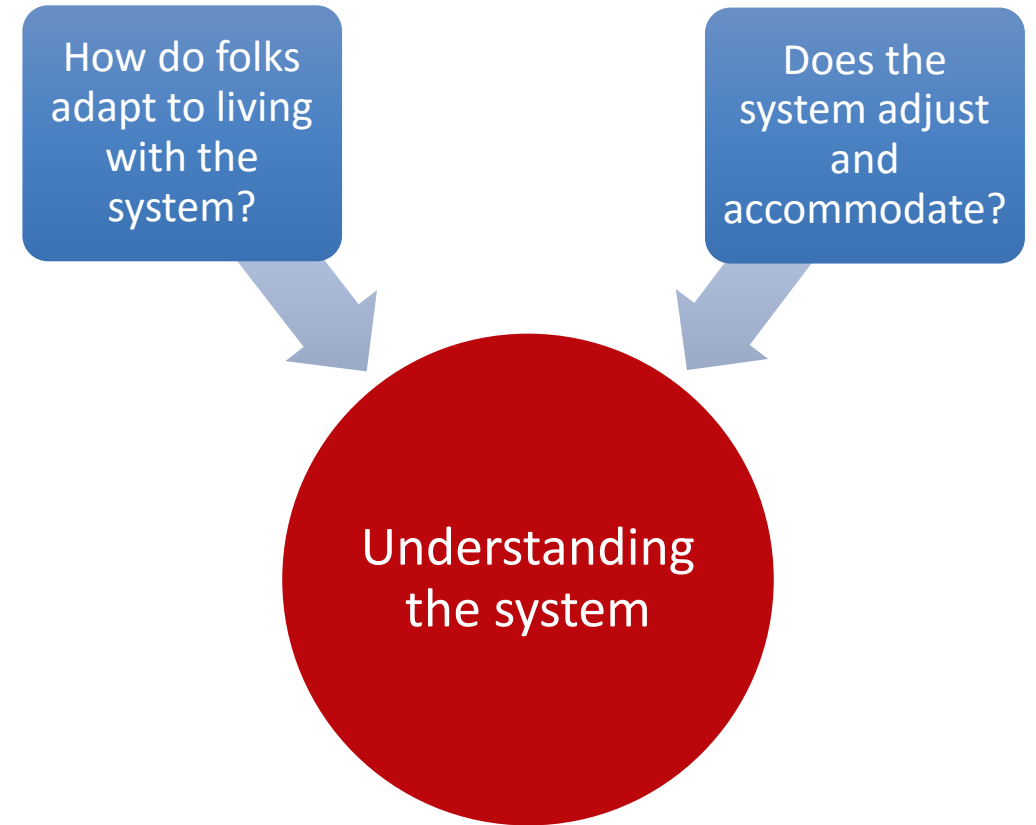
- ◉ The ‘journey’ of life with HIV requires navigating the housing and health (including mental health treatment) systems. Similar to aspects of the personal side of their journeys, navigating these systems begins with working to understand them and is then followed by adapting to working within the confines of these systems. Ideally, over time the systems also evolve to adjust and accommodate to societal changes and changes within the HIV community.
- ◉ “The doctor sits down and discusses with you what’s going on with you. The whole patient, not only just a medical patient, but find out what’s going on with their psychological patient. Of course, he can’t treat you, but then he can refer you to other people that can-, yes, it’s probably the team- it’s a whole team concept that can get you better health. And you need to find a doc- if you’re not getting that from your doctor, then it’s time to find someone else.”



# PART 2 – The System: A story of navigating the system (cont'd)

## Understanding the system

*“One of the main problems in this city is to find a case worker who wants to help you and who is Hispanic. There aren’t many. They are hard to find. Why? Because the system doesn’t pay for it.”*

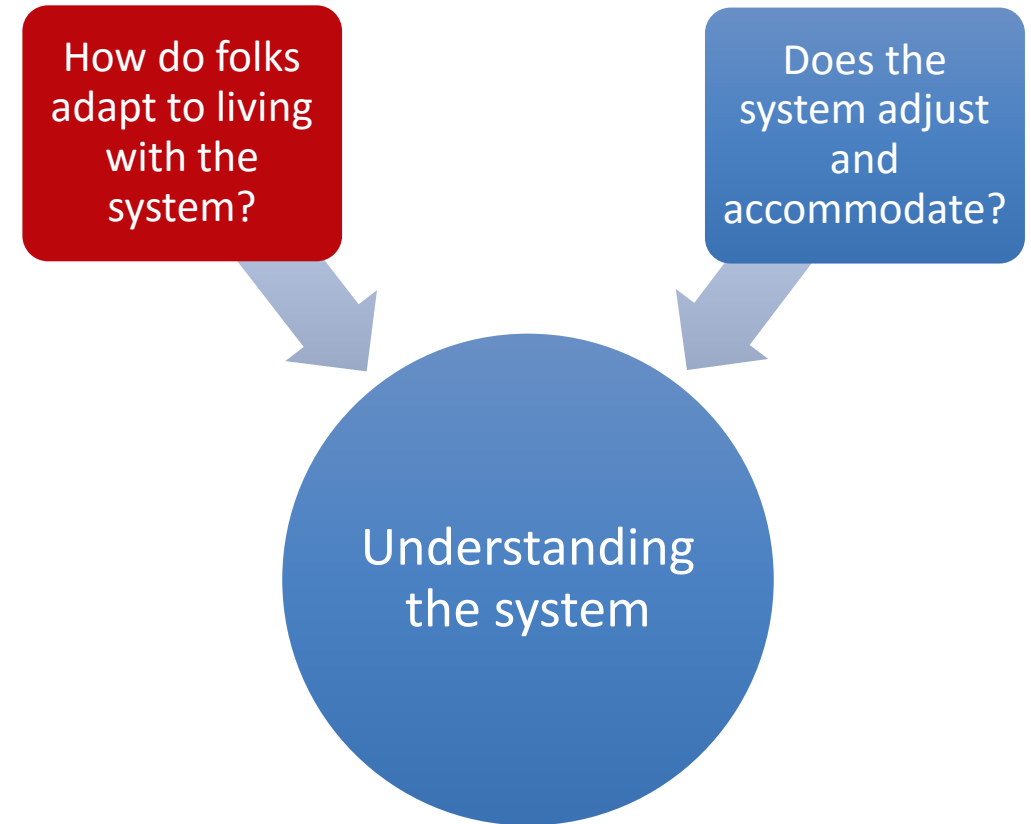


# PART 2 – The System: A story of navigating the system (cont'd)



## How do folks adapt to living with the system?

*“Unfortunately, the bureaucratic system is set up in a way to discourage you. But you can't get discouraged...There are a lot of opportunities to get housing out here. But you have to do the footwork. You may have to show up five or six times, but you can't get discouraged. They tell you to come back for a reason...When things become available it will be there. But you have to continue to show up.”*



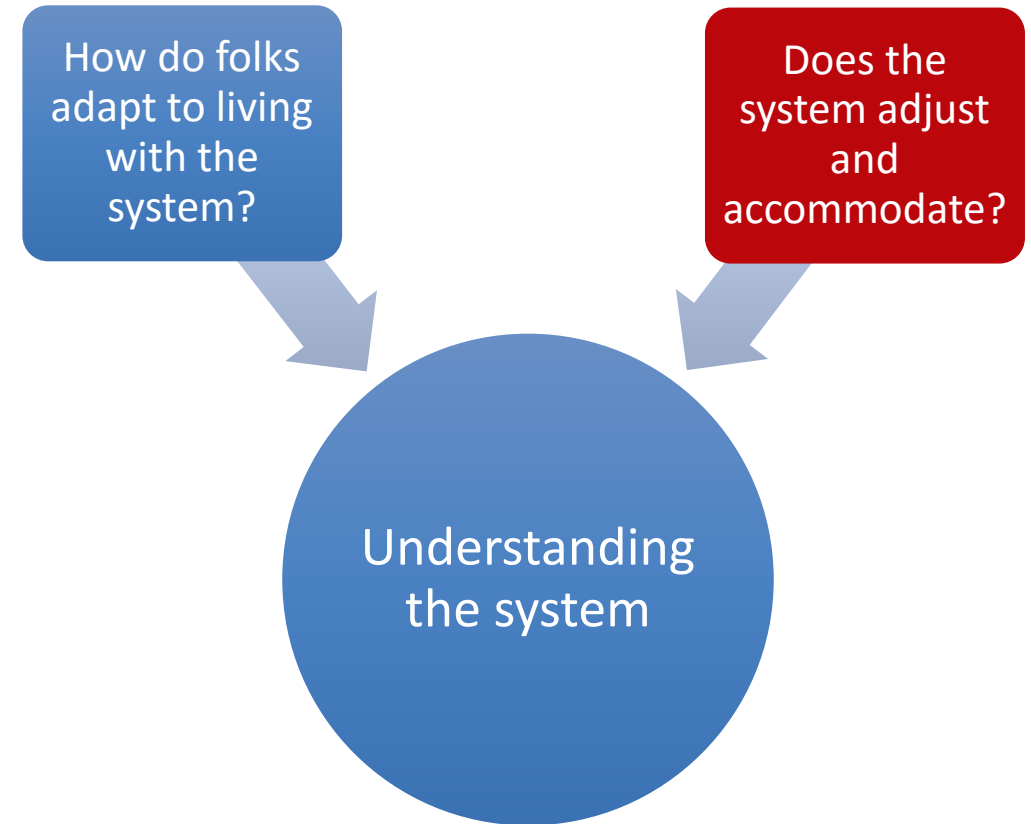


# PART 2 – The System: A story of navigating the system (cont'd)



## Does the system adjust and accommodate?

- **[YES]** *“My doctor is very good and she knows me and my case personally. So, I really don’t want to see other doctors and I really don’t have a whole lot of need to.”*
- **[NO]** *“What I really need is more mental health attention. There’s that problem of a good one being available. They have 10-15 HIV doctors on staff and they have two psychologists. One’s a nurse practitioner and the other’s a PhD. So, that’s a problem. It’s just not enough resources.”*



# A Life with HIV is an Evolving Journey



PLWH continue to adapt to what they have learned about the disease and advocate for others. The advocacy is directed to other PLWH and younger generations so that they remain HIV free.

*“We're all veterans with HIV. I've been positive since '83. To me the only thing that I could remind everyone here is **the nature of HIV is constantly changing**, services and what have you. It's important for us to gather all this information and then pass it onto each other and hopefully it will be passed onto the younger generations who think they're indestructible sometimes.”*

*“Having the virus for a long time, being a long-term survivor, I believe it's mine and anybody else's job to teach and prevent the spreading of the disease since we know more and we can teach more, especially to the younger community and how it affects our bodies...I mean when I was diagnosed, they said I was only going to live ten years. Because of that, learning what's going on now, to take the medication and be alive and do what I need to do to survive. We need to pass it on and teach the younger generation that's coming up to not to have it.”*

# Focus Group Recommendations



## Implement service changes to address social isolation

- Implementing **Remote Counseling** in RWPA-funded mental health, supportive counseling, and harm reduction programs

## Sponsor more client-focused events

- *Long-Term Survivors Day* event

## Increase coordination between State-funded and City-funded programs

## Develop benefits navigation training for clinicians and case managers

## Ensure mental health and other services are offered in Spanish

## Direct more attention to women's unique medical conditions that interact with HIV as they age

# Next Steps

Training our Providers

## **Overarching Goal**

To increase access to and utilization of health and social resources among OPLWH in NYC and Tri-county

## **Training objectives:**

To increase the capacity of clinical and non-clinical staff to:

1. Assess the needs of OPLWH
2. Address cultural, linguistic, economic, and social barriers among OPLWH
3. Link OPLWH to appropriate and adequate health and social services and resources
4. Develop clinical strategies for addressing needs of OPLWH
5. Develop strategies to improve coordination of geriatric care for OPLWH

# Approach to OPLWH Training Development



- Background research, including qualitative key stakeholder interviews
- Collaboration with Northeast/Caribbean AIDS Education & Training Center
- Iterative curriculum development process
- 5 modules with training manual and slide set
  - One break-out with separate modules for medical providers vs. case managers and navigators
- Online pilot training delivered to gather feedback
- Training of Trainers component
- Training introduces a Resource Guide with an extensive directory of referral resources

# Key Stakeholder Interviews



## Sample and Method

- 11 OPLWH, 9 case managers/navigators, 7 primary care providers
- Semi-structured 45 to 60-minute interviews; recorded, transcribed, analyzed

## Results Highlights

- 12 categories of health needs, 13 categories of social needs; most prominent included changes in cognitive functioning and social isolation
- OPLWH who are long-term survivors have gripping life stories to tell, with much wisdom to impart
- Clinical and non-clinical providers need and want training, resources, and models to properly address the needs of their aging patients
- Quotes from interviews were incorporated into training content

Any questions?



# Acknowledgements



## *Organizations*

ACRIA  
Argus Community  
GMHC  
Griot Circle  
Iris House  
SAGE  
The LGBT Center  
The Long-Term Survivors Wellness Coalition  
Northeast/Caribbean AIDS Education & Training Center

## *Individuals*

Claire Odom  
Frances Silva  
Kate Penrose  
Kylie Waddy  
Luz Santiago  
Mark Brennan-Ing  
Mary Irvine  
Max Sepulveda  
Michael Diaz  
Monica Darcy  
Rafael Ponce  
Scott Spiegler  
Tsetsi Kgama  
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Mari Millery  
Daniel Castellanos

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