



SYNC  
2019

# UTILIZING MULTIPLE STRATEGIES FOR ASSESSING THE NEEDS OF OLDER PERSONS LIVING WITH HIV IN NYC

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# CONFLICT OF INTEREST DISCLOSURE: SARAH KOZLOWSKI, MPH

No conflicts of interest





# AGENDA

- Epidemiologic data on **NYC's older<sup>1</sup> persons living with HIV (OPLWH)**
- **Ryan White Part A (RWPA):** New York City & Tri-County Area
- Learning from our partners
  - Provider Survey
  - Community Forum
- Learning from our clients
  - **NYC HIV & Aging Focus Group Project**
    - Preliminary observations



<sup>1</sup>When we use the term “older” persons living with HIV, we are referring to people aged 50 and older.

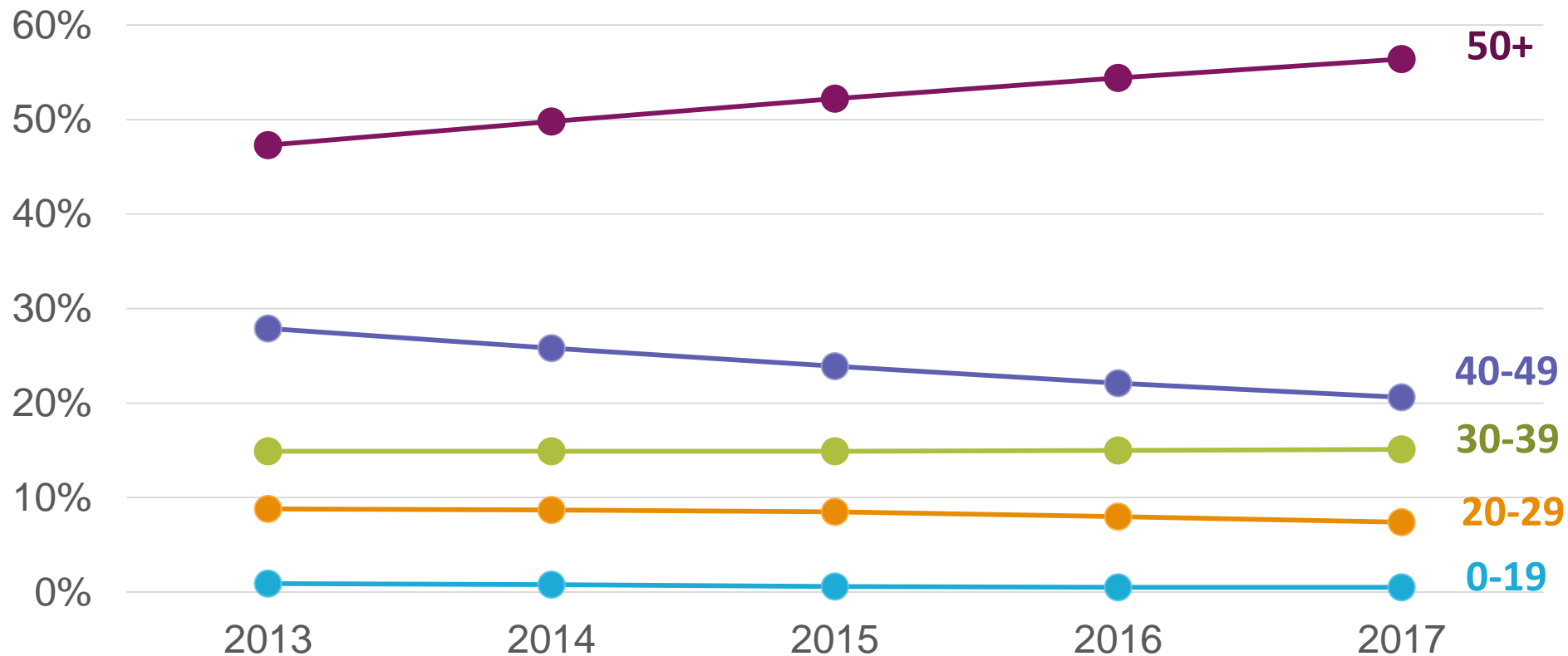


# **BACKGROUND**

NYC's Aging PLWH

# PLWH IN NYC 2013 - 2017

The proportion of PLWH aged 50+ in NYC continues to increase compared to other age groups.



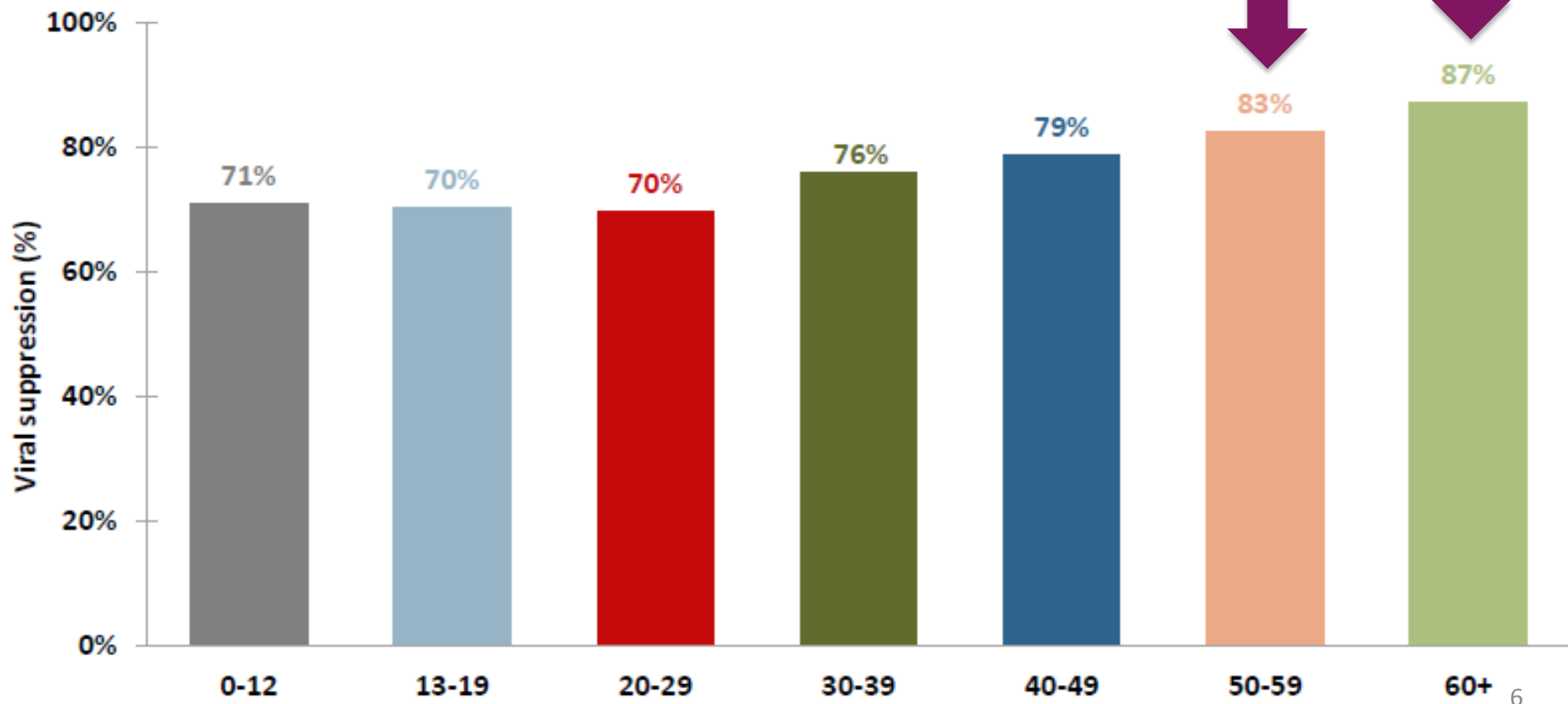
Total all age groups, 2017:  
**125,884**





# VIRAL SUPPRESSION AMONG DIAGNOSED PLWH BY AGE GROUP, 2017

Among diagnosed PLWH in NYC, rates of viral suppression were highest among those aged 50-59 and 60+.



Viral suppression is defined as viral load <200 copies/mL. Data as reported to NYC DOHMH by March 31, 2018.





# LOOKING THROUGH A LENS OF RACIAL & ECONOMIC DISPARITIES

NYC's Aging PLWH

# VIRAL SUPPRESSION RATES BY RACE/ETHNICITY AMONG PLWH UNDER 50 VS. 50+

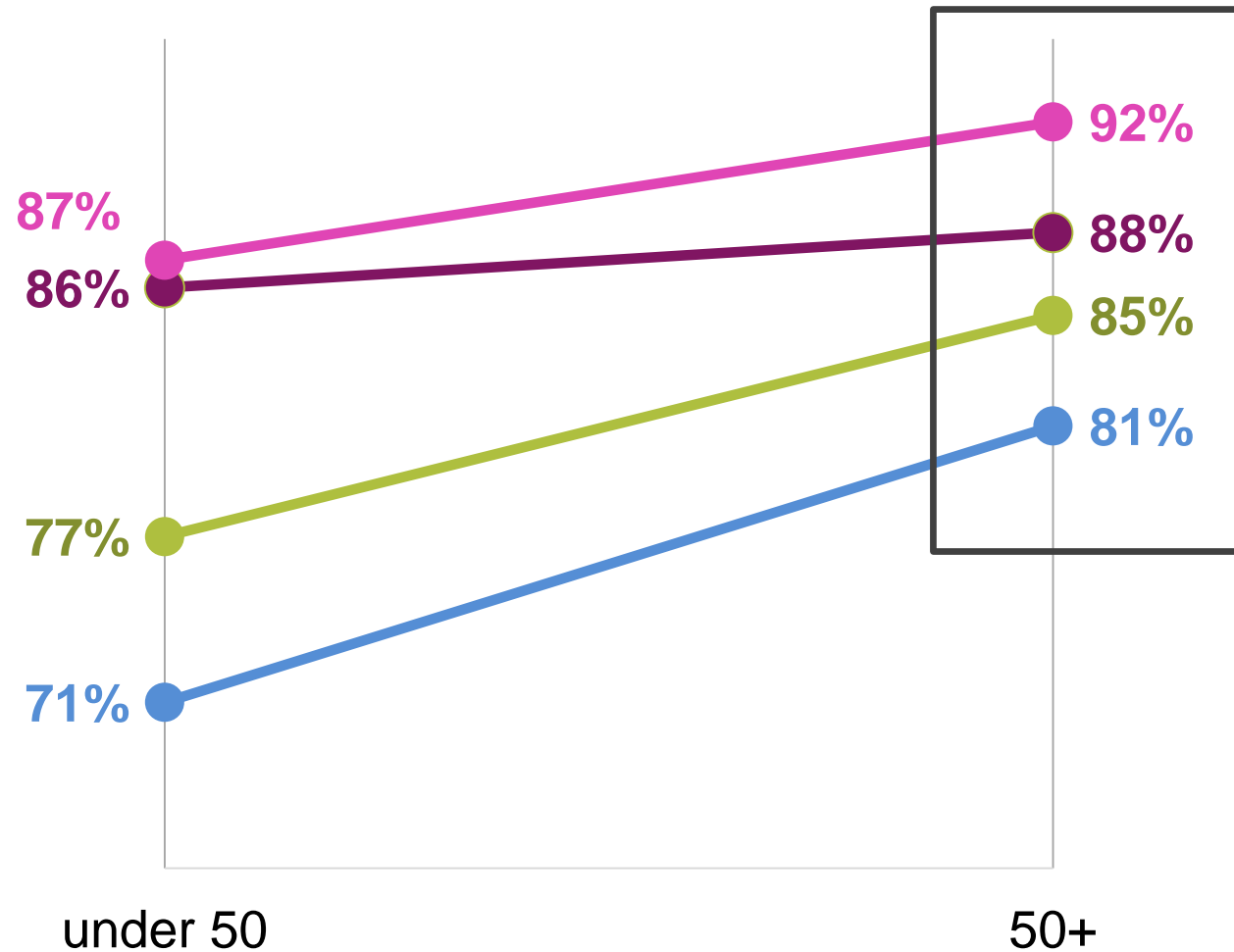
Racial/Ethnic Groups:

White

Asian/Pacific Islander

Latino(a)/Hispanic

Black



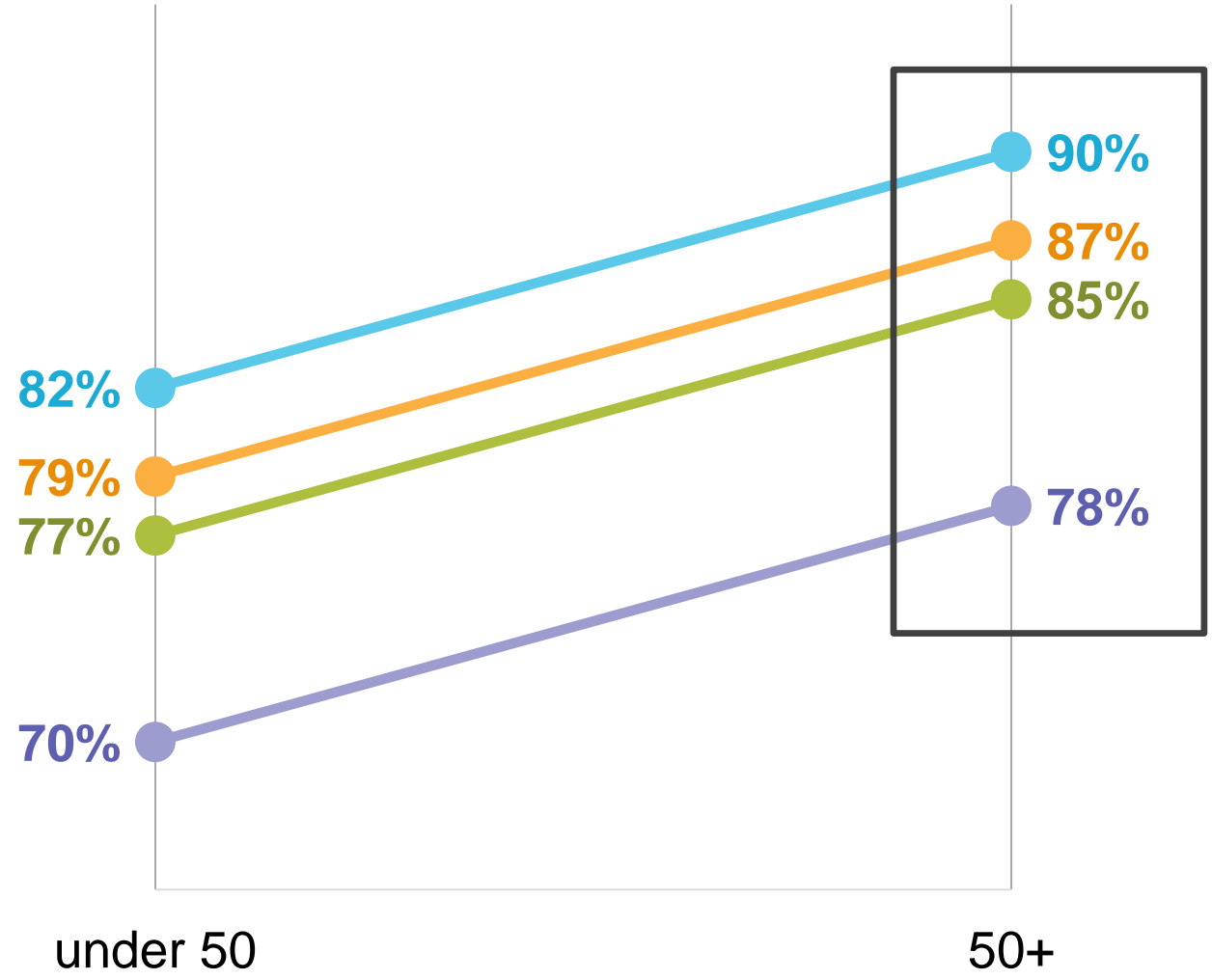




# VIRAL SUPPRESSION RATES BY AREA-BASED POVERTY AMONG PLWH UNDER 50 VS. 50+

## ZIP Code-Based Poverty Levels:

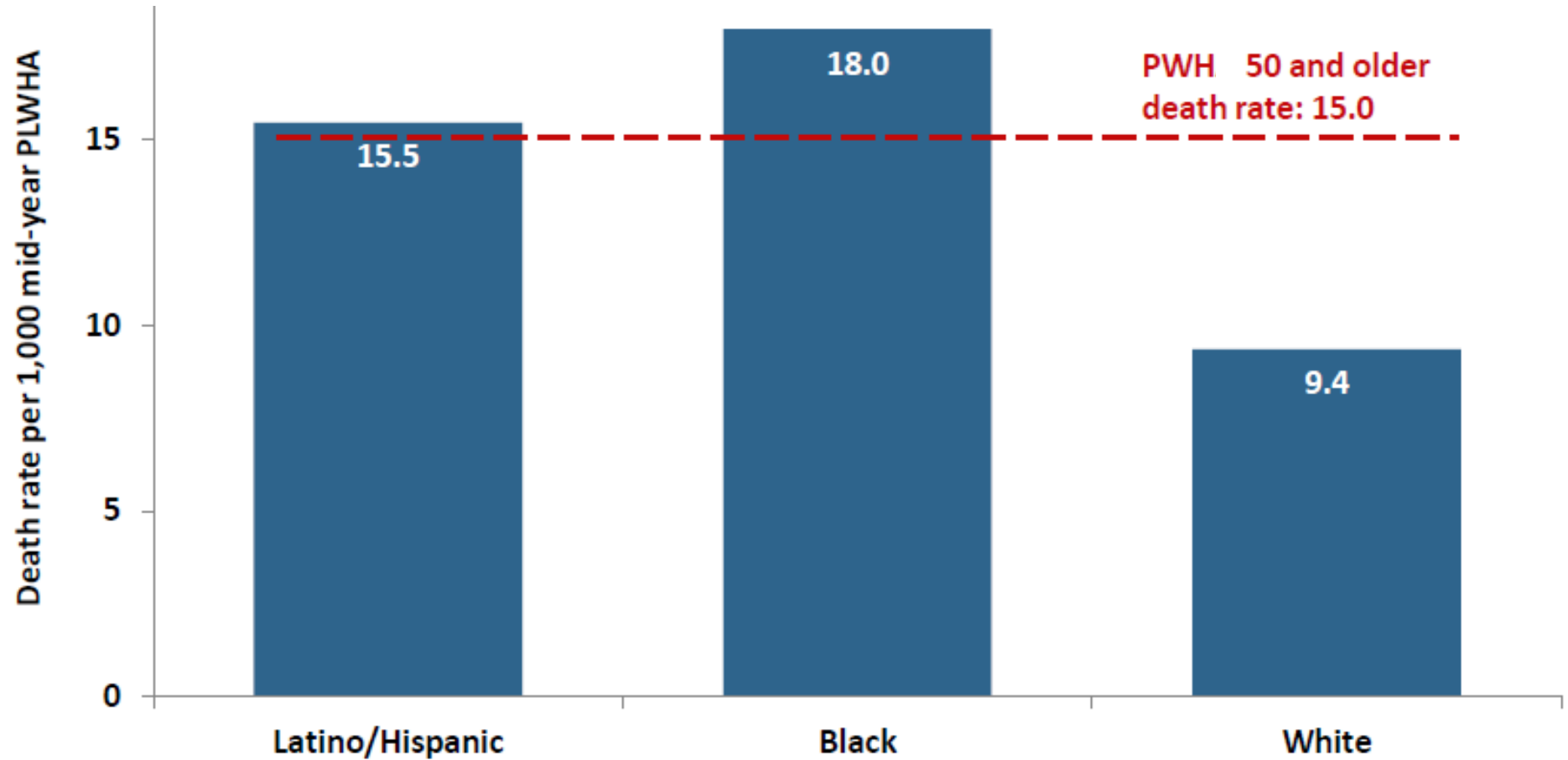
- Low poverty (<10% below FPL)
- Medium poverty (10-<20% below FPL)
- High poverty (20-<30% below FPL)
- Very high poverty ( $\geq$ 30% below FPL)





# DEATH RATES AMONG PWH AGE 50+ IN NYC, 2017

Among persons with HIV (PWH) in NYC in 2017, the death rate among Blacks was the highest among racial/ethnic groups at **3 deaths/1,000 above the average.**




Crude death rates. Death data for 2017 are incomplete.

Native American, Asian/Pacific Islander (API), and multi-racial groups not shown because of small numbers. There were N=8 API, N=6 Native American, and N=2 multi-racial PWH ages 50+ who died in 2017.

As reported to the New York City Department of Health and Mental Hygiene by March 31, 2018.





# ADDRESSING NEEDS THROUGH OUR SERVICE SYSTEM

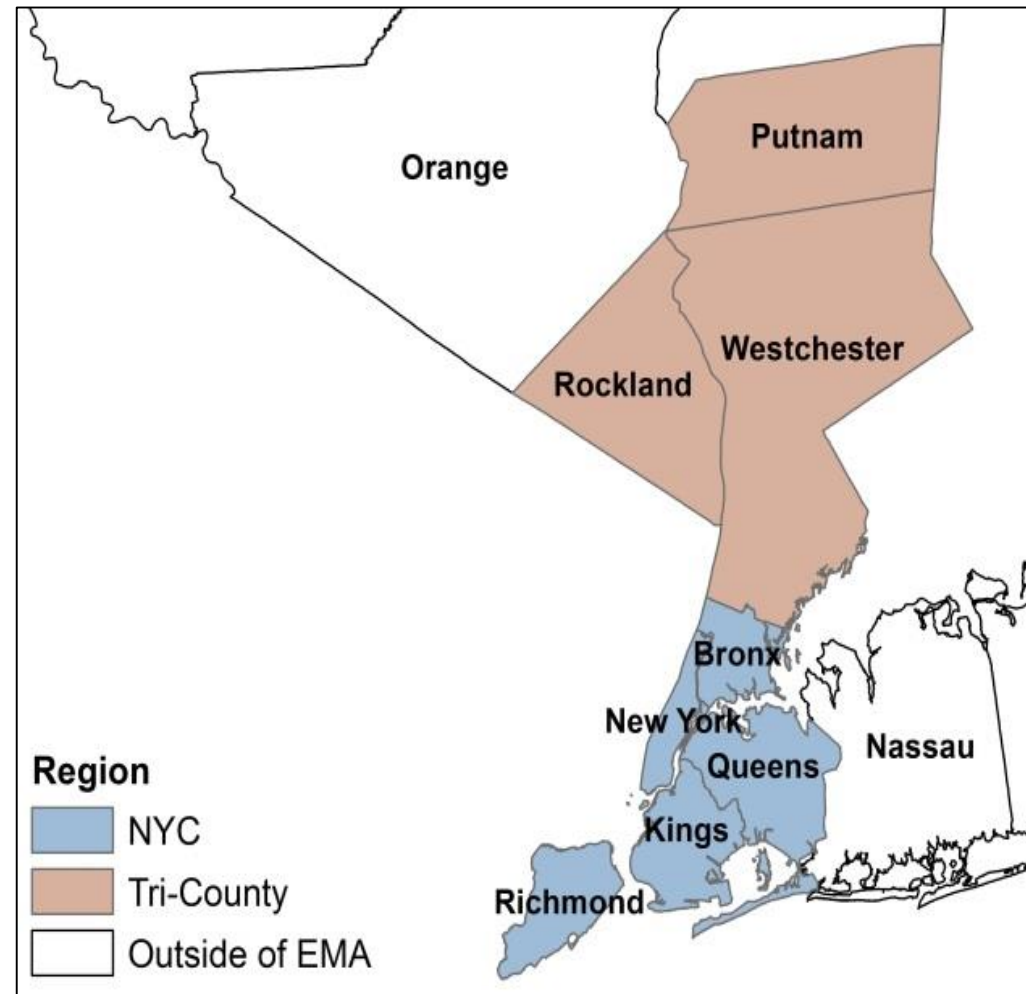
Ryan White Part A

# NY ELIGIBLE METROPOLITAN AREA (EMA) RYAN WHITE PART A (RWPA)

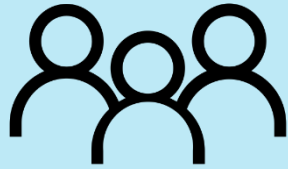
**Ryan White Part A:**  
Emergency assistance to areas hardest hit by the HIV epidemic

- New York City Department of Health and Mental Hygiene (DOHMH) is the grantee for RWPA in the New York EMA

→ **NYC** and **Tri-County area**

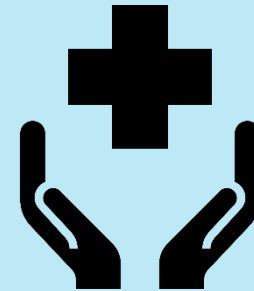


# NY ELIGIBLE METROPOLITAN AREA (EMA) RYAN WHITE PART A (RWPA)



>14,000 HIV-positive individuals served in grant year 2017

The local program provides ~14 service categories, which **predominantly focus on providing supportive services**



Contracts with ~90 service delivery agencies



# OPLWH DEMOGRAPHICS, NY EMA RWPA

Active HIV+ Clients in  
the NY EMA Ryan  
White Part A Services<sup>1</sup>

**14,327**

Total OPLWH:

**7,464**  
**(52.1%)**

<b>Race/Ethnicity</b>	
Black	<b>54.3%</b>
Latino(a)/Hispanic	<b>33.9%</b>
White	<b>9.1%</b>
Asian/Pacific Islander	<b>0.6%</b>
Other <sup>2</sup>	<b>2.1%</b>
<b>Self-Identified Gender</b>	
Man	<b>62.7%</b>
Woman	<b>35.6%</b>
Transgender	<b>1.7%</b>

<sup>1</sup>Clients must have had an open enrollment from 3/1/2017 - 2/28/2018 and received at least one service in a Ryan White Part A program in the NY Eligible Metropolitan Area (EMA) during this time period.

<sup>2</sup>Includes clients identified as Native American/Alaskan Native, other, mixed race, or unknown.





# OPLWH DEMOGRAPHICS, NY EMA RWPA

<b>Insurance Status</b>	
Uninsured <sup>1</sup>	<b>12.9%</b>
Insured – Public	<b>83.9%</b>
Insured – Private	<b>1.9%</b>
Unknown	<b>1.2%</b>
<b>Federal Poverty Level</b>	
<100% Federal Poverty Level	<b>77.7%</b>
≥100% Federal Poverty Level	<b>22.2%</b>
Unknown	<b>0.1%</b>

<sup>1</sup>Includes clients who only receive ADAP/ADAP+ as well..





# LEARNING FROM OUR PARTNERS

A Survey of HIV Care Providers in NYC  
&  
A Community Forum on HIV & Aging





# 2017 NYC DOHMH PROVIDER SURVEY



- Goal: To better understand the needs of **OPLWH in NYC** from the perspectives of **clinical and non-clinical providers**
- Topics explored regarding OPLWH:
  - Resources currently available
  - Barriers and challenges
  - Areas of unmet service need
  - Common referrals

# 2017 NYC DOHMH PROVIDER SURVEY

- 234 providers received the survey
  - 70 complete responses

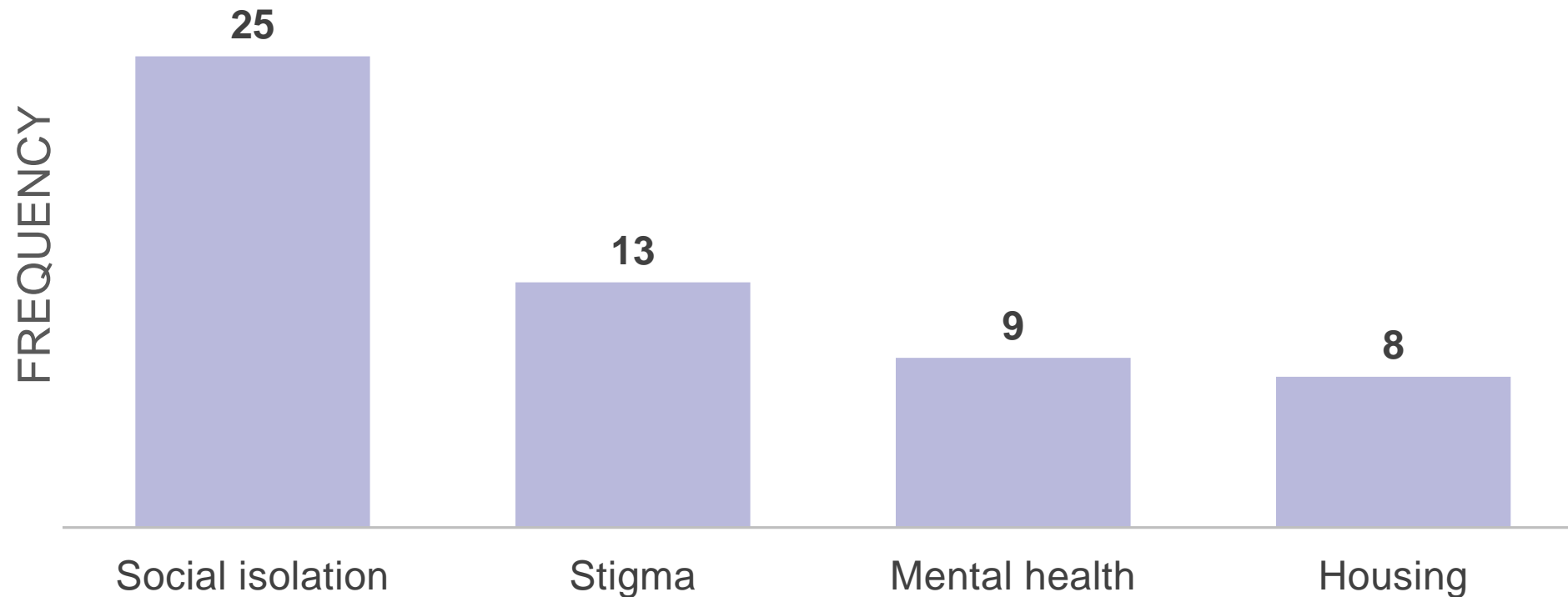


Organization Type	
HIV/AIDS Service Organization	36%
Hospital	31%
Health Clinic	21%
Public Health Non-Profit/CBO (not HIV-specific)	7%
Government	4%
Research Institution	2%



# 2017 NYC DOHMH PROVIDER SURVEY

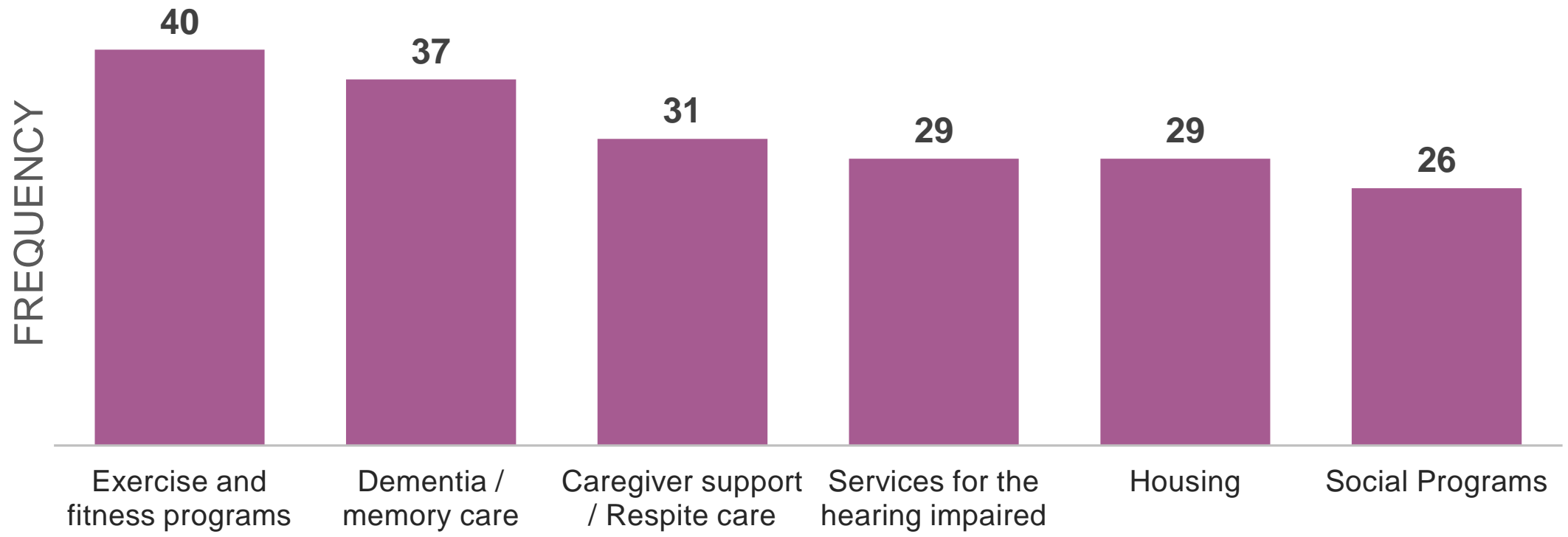
Clinical and non-clinical providers identified **social isolation** as the greatest challenge for OPLWH in NYC.





# 2017 NYC DOHMH PROVIDER SURVEY

Clinical and non-clinical providers identified **fitness programs** and **dementia/memory care** as the most needed services.



# COMMUNITY FORUM ON HIV & AGING, JAN. 2018

- Key needs identified for:
  - Providers
    - Clinical tool for comprehensive assessment/holistic view of patient
  - Patients
    - Research to fill gaps in knowledge on consumer-identified needs
      - What works in the system?
      - What is missing?
    - Qualitative and quantitative data on patients' perspectives to influence future programming





# LEARNING FROM OUR CLIENTS

The NYC HIV & Aging Focus Group Project



# THE NYC HIV & AGING FOCUS GROUP PROJECT

## PURPOSE:

To learn about the **strengths**, **unmet needs**, and **barriers**



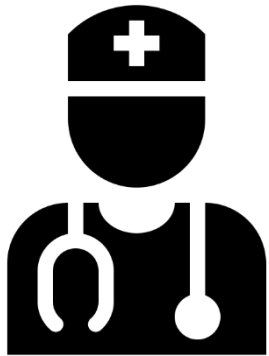
*experienced by NYC's OPLWH*





# THE NYC HIV & AGING FOCUS GROUP PROJECT

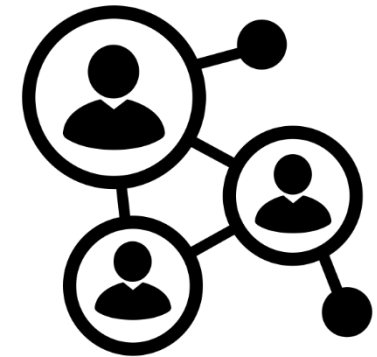
## Topic Domains



Medical Care

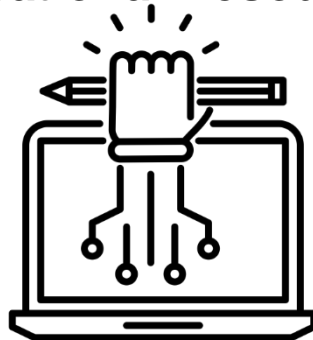


Mental Health Care



Social Support

Educational Resources



Other Needs







# THE NYC HIV & AGING FOCUS GROUP PROJECT

Topic Probes:

What's gotten **EASIER** with age, and what's gotten **HARDER**?





# THE NYC HIV & AGING FOCUS GROUP PROJECT

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.





# THE NYC HIV & AGING FOCUS GROUP PROJECT

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)
<b>English</b>	11	9	11	13
<b>Spanish</b>	10	2	6	N/A





# THE NYC HIV & AGING FOCUS GROUP PROJECT

## 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

Participants from all 5 boroughs!

Average Number of **Years Diagnosed:**

**24**

Percentage of Participants **Publicly Insured:**

**90%**





# THE NYC HIV & AGING FOCUS GROUP PROJECT

*Some preliminary observations from the focus group data...*





# THE NYC HIV & AGING FOCUS GROUP PROJECT



## *Medication Adherence*





# THE NYC HIV & AGING FOCUS GROUP PROJECT



*“The medicine is **so much easier to take** now than it was when I was originally diagnosed. **No side effects.** I personally take my medicine right before I go to sleep, because I’m so busy during the day, things come and go, I like to be on time. So, I know what time I go to bed, the last thing I do before I go to sleep is take my medicine.”*



# THE NYC HIV & AGING FOCUS GROUP PROJECT



*“...what makes it easy for me to take my medication is that **I want to live today.** You know, I’ve lost a lot of friends due to this disease and it’s very important to take your medication every day.”*





# THE NYC HIV & AGING FOCUS GROUP PROJECT



“For me, **it’s getting a little harder**. I’ve been HIV positive since I was a teenager. I never thought I was going to live this long. Honestly, I just- **I get tired of it**. I try not to think about it. But- but it’s getting harder emotionally. And like [Redacted] said, I- **I’m undetectable and sometimes I think, well, I’m okay and I shouldn’t take it this week**. And I started doing that and my CD4 count dropped like a hundred.”





# THE NYC HIV & AGING FOCUS GROUP PROJECT



*Mental Health Care*





# THE NYC HIV & AGING FOCUS GROUP PROJECT



MODERATOR: *“Would you say it’s easier or harder now to access mental health- mental health care?”*

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



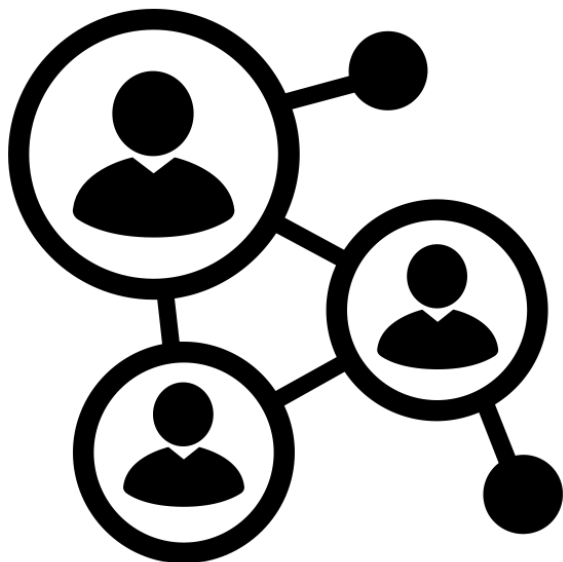
# THE NYC HIV & AGING FOCUS GROUP PROJECT



*“When you have a mental health professional who is very good, that person is always very busy. **And it’s ridiculous to tell someone who’s depressed and anxious, well, we have an appointment for- for 10 weeks from now, that’s just- it’s just- it’s just not- it’s not the focus of a lot of centers where they treat HIV.**”*



# THE NYC HIV & AGING FOCUS GROUP PROJECT



*Social Support*





# THE NYC HIV & AGING FOCUS GROUP PROJECT



*“In my case, it is not difficult. It’s the other way around. **Now that I’m getting older, it’s even easier for me.** And when--I’m very friendly. I’m very friendly, right? And people don’t believe me-- First, they don’t believe my age. And secondly, they don’t believe that I’ve been HIV positive for so many years, and much less that I have lost my children and my two partners, right? ... So, the other way around. **I think that the older I get, the prouder, more seasoned and fascinating I am.**”*



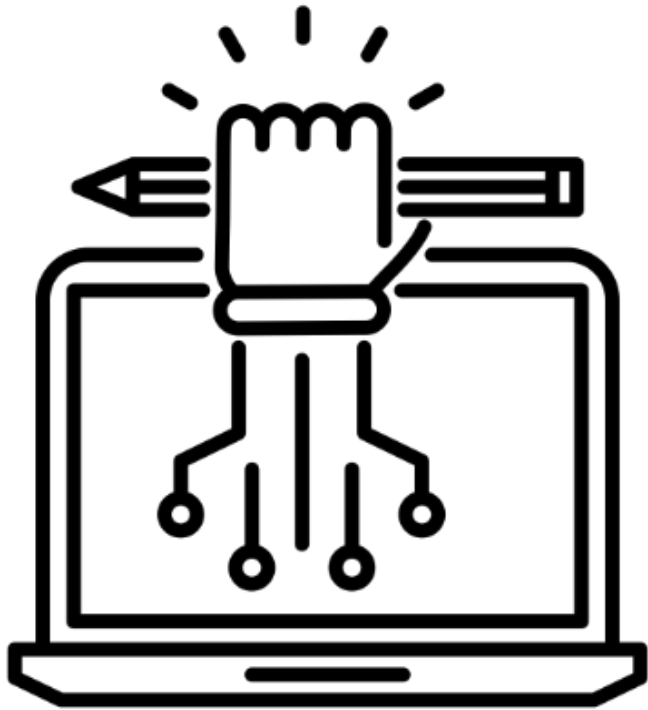
# THE NYC HIV & AGING FOCUS GROUP PROJECT



*“...two months ago, **my husband of 25 years died** of liver cancer so, even though I do support groups and I’m all up in [the] HIV community, I decided I needed a therapist ... And he’s- the doctor’s looking at me and he said, how can you be depressed? He said, ‘You’re personable, you dress well, you’re always on vacations, you’ve won awards.’ I mean, he’s just listing all my pluses, so he does not believe I’m depressed or upset. So, so I said, you know .. **I’m all this until I go home and close the door, then the makeup comes off, my teeth [come] out. I live by myself.**”*



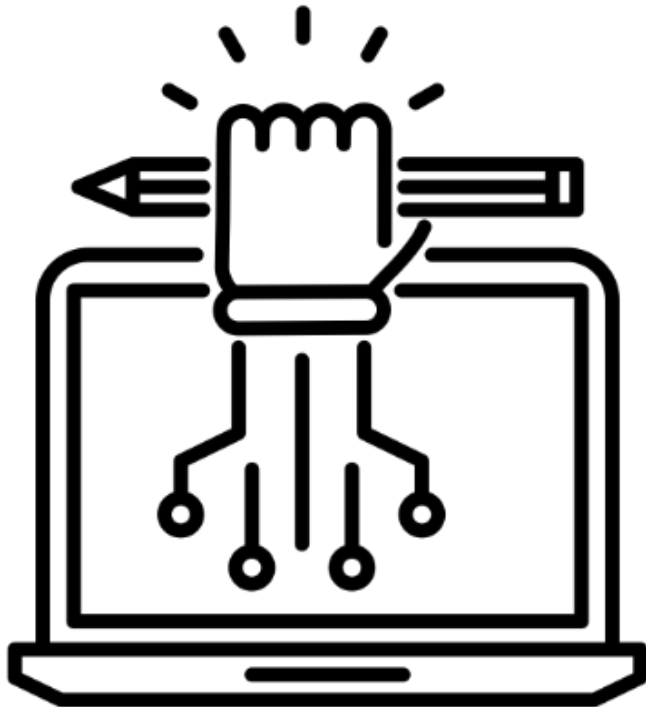
# THE NYC HIV & AGING FOCUS GROUP PROJECT



*Educational Resources*



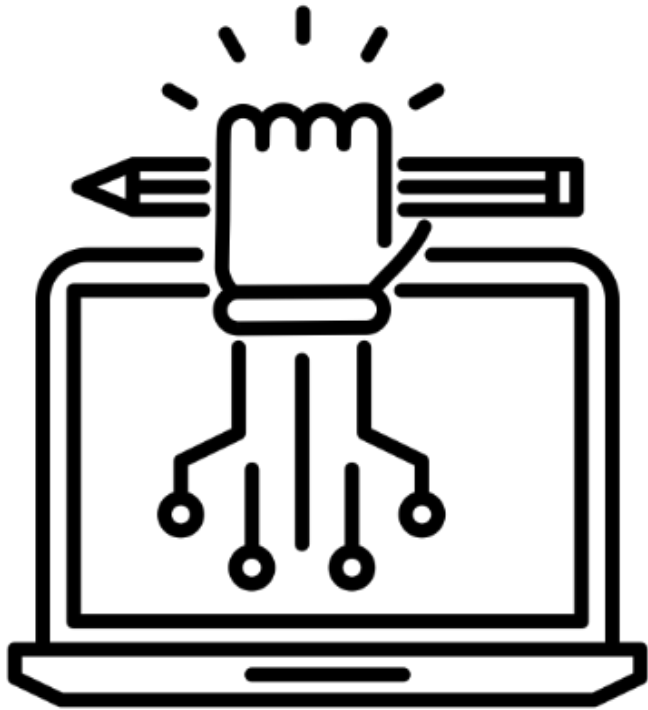
# THE NYC HIV & AGING FOCUS GROUP PROJECT



## How OPLWH learn about resources

- Google
- Smartphones
- Word of mouth, other PLWH
- Support groups
- Trainings
- Social workers

# THE NYC HIV & AGING FOCUS GROUP PROJECT

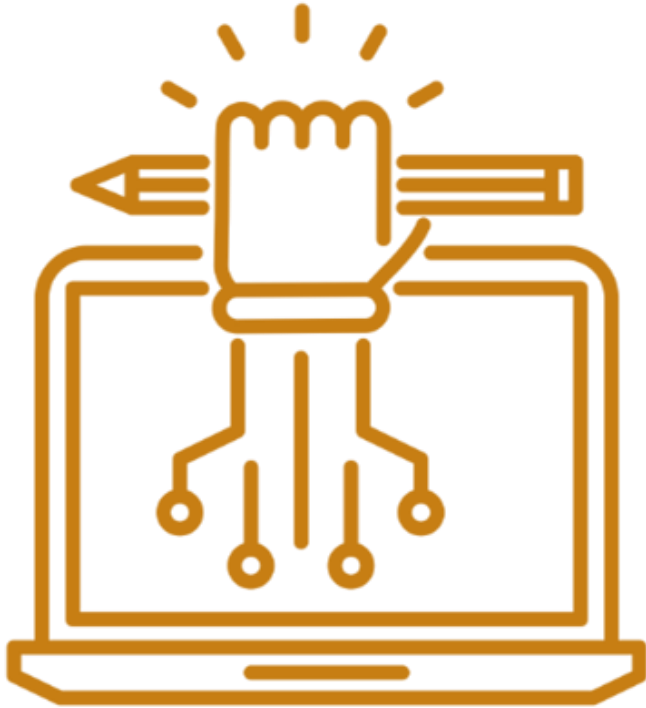


## Types of resources accessed

- HIV supportive services
- Housing
- Legal assistance
- LGBT-specific resources
- English classes
- Exercise/fitness (e.g. Silver Sneakers)
- General services for older persons (e.g. AARP)

# THE NYC HIV & AGING FOCUS GROUP PROJECT

*Some barriers:*



*Okay, 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.***

*It's just- you got to know the right questions to ask to get that information. And the people that's in the know, some of them will give it to you, some of them won't give it to you. **If you want to know, you just have to keep pressing.***





# NEXT STEPS

In-depth qualitative analysis of focus group data

Service changes to address social isolation

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

More client-focused events

- *Long-Term Survivors Day* event

Increased coordination between State-funded and City-funded programs

Development of benefits navigation training for clinicians and case managers



# ACKNOWLEDGEMENTS

## *Organizations*

ACRIA  
Argus Community  
GMHC  
Griot Circle  
Iris House  
The LGBT Center  
The Long-Term Survivors Wellness Coalition  
SAGE

## *Individuals*

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

