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 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

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

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

Total all age groups, 2017: 125,884
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

<table>
<thead>
<tr>
<th></th>
<th>under 50</th>
<th>50+</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>87%</td>
<td>92%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>86%</td>
<td>88%</td>
</tr>
<tr>
<td>Latino(a)/Hispanic</td>
<td>77%</td>
<td>85%</td>
</tr>
<tr>
<td>Black</td>
<td>71%</td>
<td>81%</td>
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</table>
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** (≥30% below FPL)
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.
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 Services¹

14,327

Total OPLWH:

7,464 (52.1%)

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
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<tbody>
<tr>
<td>Black</td>
<td>54.3%</td>
</tr>
<tr>
<td>Latino(a)/Hispanic</td>
<td>33.9%</td>
</tr>
<tr>
<td>White</td>
<td>9.1%</td>
</tr>
<tr>
<td>Asian/Pacific Islander</td>
<td>0.6%</td>
</tr>
<tr>
<td>Other²</td>
<td>2.1%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Self-Identified Gender</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Man</td>
<td>62.7%</td>
</tr>
<tr>
<td>Woman</td>
<td>35.6%</td>
</tr>
<tr>
<td>Transgender</td>
<td>1.7%</td>
</tr>
</tbody>
</table>

¹Clients 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.
²Includes clients identified as Native American/Alaskan Native, other, mixed race, or unknown.
### OPLWH DEMOGRAPHICS, NY EMA RWPA

#### Insurance Status

<table>
<thead>
<tr>
<th>Status</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Uninsured(^1)</td>
<td>12.9%</td>
</tr>
<tr>
<td>Insured – Public</td>
<td>83.9%</td>
</tr>
<tr>
<td>Insured – Private</td>
<td>1.9%</td>
</tr>
<tr>
<td>Unknown</td>
<td>1.2%</td>
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#### Federal Poverty Level

<table>
<thead>
<tr>
<th>Level</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>&lt;100% Federal Poverty Level</td>
<td>77.7%</td>
</tr>
<tr>
<td>≥100% Federal Poverty Level</td>
<td>22.2%</td>
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<tr>
<td>Unknown</td>
<td>0.1%</td>
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</table>

\(^1\)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

<table>
<thead>
<tr>
<th>Organization Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV/AIDS Service Organization</td>
<td>36%</td>
</tr>
<tr>
<td>Hospital</td>
<td>31%</td>
</tr>
<tr>
<td>Health Clinic</td>
<td>21%</td>
</tr>
<tr>
<td>Public Health Non-Profit/CBO (not HIV-specific)</td>
<td>7%</td>
</tr>
<tr>
<td>Government</td>
<td>4%</td>
</tr>
<tr>
<td>Research Institution</td>
<td>2%</td>
</tr>
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</table>
Clinical and non-clinical providers identified **social isolation** as the greatest challenge for OPLWH in NYC.
Clinical and non-clinical providers identified **fitness programs** and **dementia/memory care** as the most needed services.
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
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

- 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 917-751-4816 to find out if you're eligible to participate.

Live in the 5 boroughs

- 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 917-751-4816 to find out if you're eligible to participate.
The NYC HIV & Aging Focus Group Project

7 focus groups, **62 total participants**

<table>
<thead>
<tr>
<th>Language</th>
<th>Cisgender men who have sex with men (MSM)</th>
<th>Cisgender men who have sex with women (MSW)</th>
<th>Cisgender women</th>
<th>Transgender &amp; gender non-conforming (TGNC)</th>
</tr>
</thead>
<tbody>
<tr>
<td>English</td>
<td>11</td>
<td>9</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Spanish</td>
<td>10</td>
<td>2</td>
<td>6</td>
<td>N/A</td>
</tr>
</tbody>
</table>
## General Demographics

<table>
<thead>
<tr>
<th></th>
<th>1st Most Represented Group</th>
<th>2nd Most Represented Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Borough of Residence</td>
<td>Bronx</td>
<td>Brooklyn</td>
</tr>
<tr>
<td>Age</td>
<td>60-69</td>
<td>50-59</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td>Black</td>
<td>Latino/Latina</td>
</tr>
</tbody>
</table>

**Average Number of Years Diagnosed:** 24  
**Percentage of Participants Publicly Insured:** 90%
Some preliminary observations from the focus group data...
Medication Adherence
“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.”
“...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.”
“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 get tired of it. I try not to think about it. But- but it’s getting harder emotionally. And like [Redacted] said, 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.”
Mental Health Care
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.”
“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.”
Social Support
“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.**”
“…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
### 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)
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