VIRTUAL 2020 NATIONAL RYAN WHITE CONFERENCE ON HIV CARE & TREATMENT

Mobilizing People and Resources to Address HIV & Aging

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2020

Today's presentation

- Mari -- Initial steps by NECA AETC and NYC EMA to address the challenge of aging HIV population
- Daniel -- In their words: key lessons learned from clients & providers about service needs and models
- Daria -- Change needed moving ahead

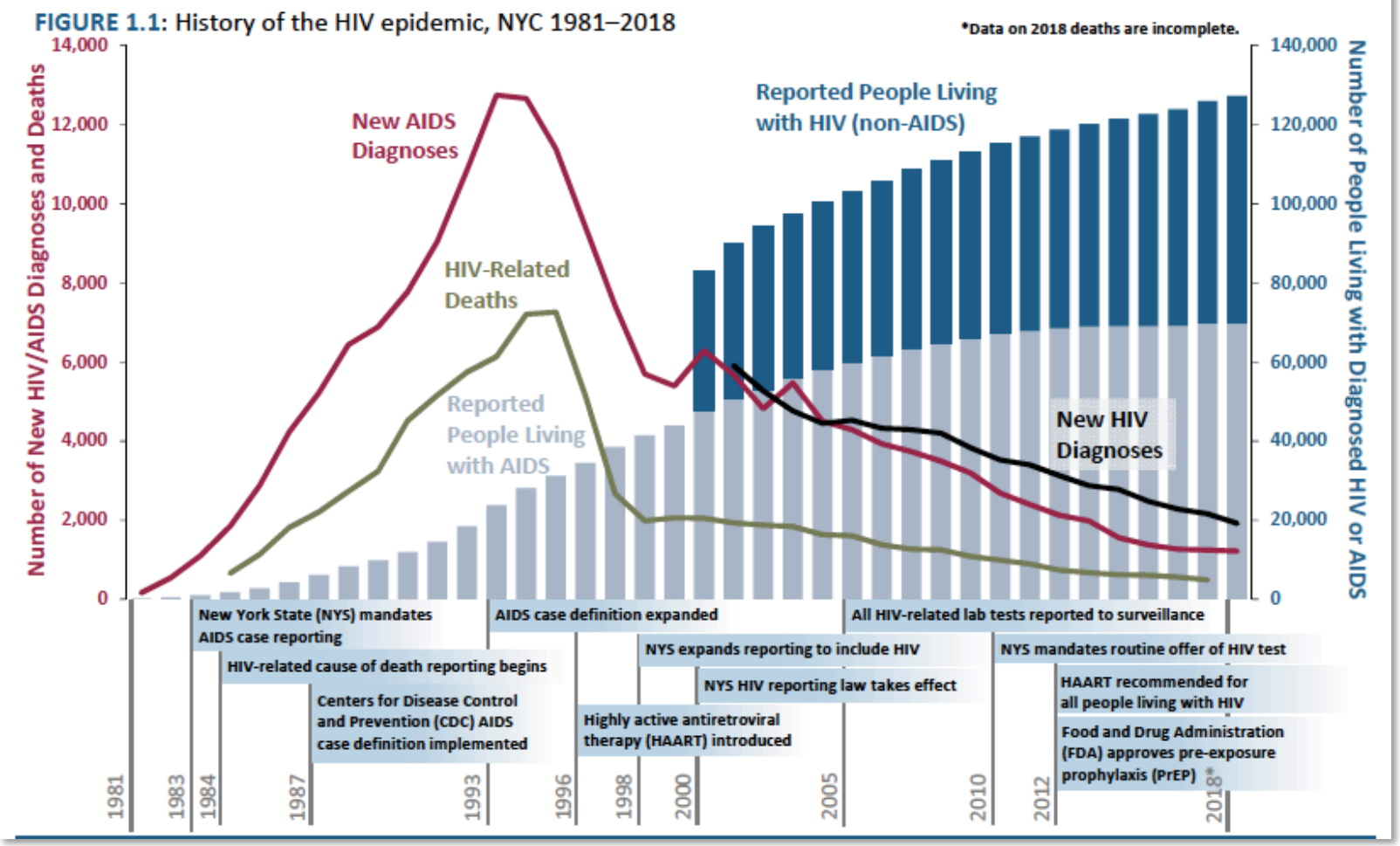
PLWH 50 years of age and older

	Total PLWHI	% <50	% >50	% 50-59	% >60
US (2017)[i]	1,003,782	51.7%	49.3%	30.8%	18.6%
NYS excl NYC (2018)[ii]	108,683	45.1%	54.9%	31.6%	23.3%
NYC (2018)[iii]	127,287	42.3%	57.7%	32%	25.7%

[i] Centers for Disease Control and Prevention. *HIV Surveillance Report, 2018 (Preliminary)*; vol. 30. http://www.cdc.gov/HIV/library/reports/hiv-surveillance.html. Published November 2019.
[ii] Bureau of HIV/AIDS Epidemiology AIDS Institute. *New York State HIV/AIDS Annual Surveillance Report, 2018.* New York State Department of Health: Albany, NY. December 2019.
[iii] HIV Epidemiology Program. *HIV Surveillance Annual Report, 2018*. New York City Department of Health and Mental Hygiene: New York, NY. November 2019.

HIV epidemiological changes in NYC

HISTORY OF THE EPIDEMIC



HIV Epidemiology Program. *HIV Surveillance Annual Report*, 2018. New York City Department of Health and Mental Hygiene: New York, NY. November 2019.

Historical changes in health and clinical needs through the HIV/AIDS Epidemic

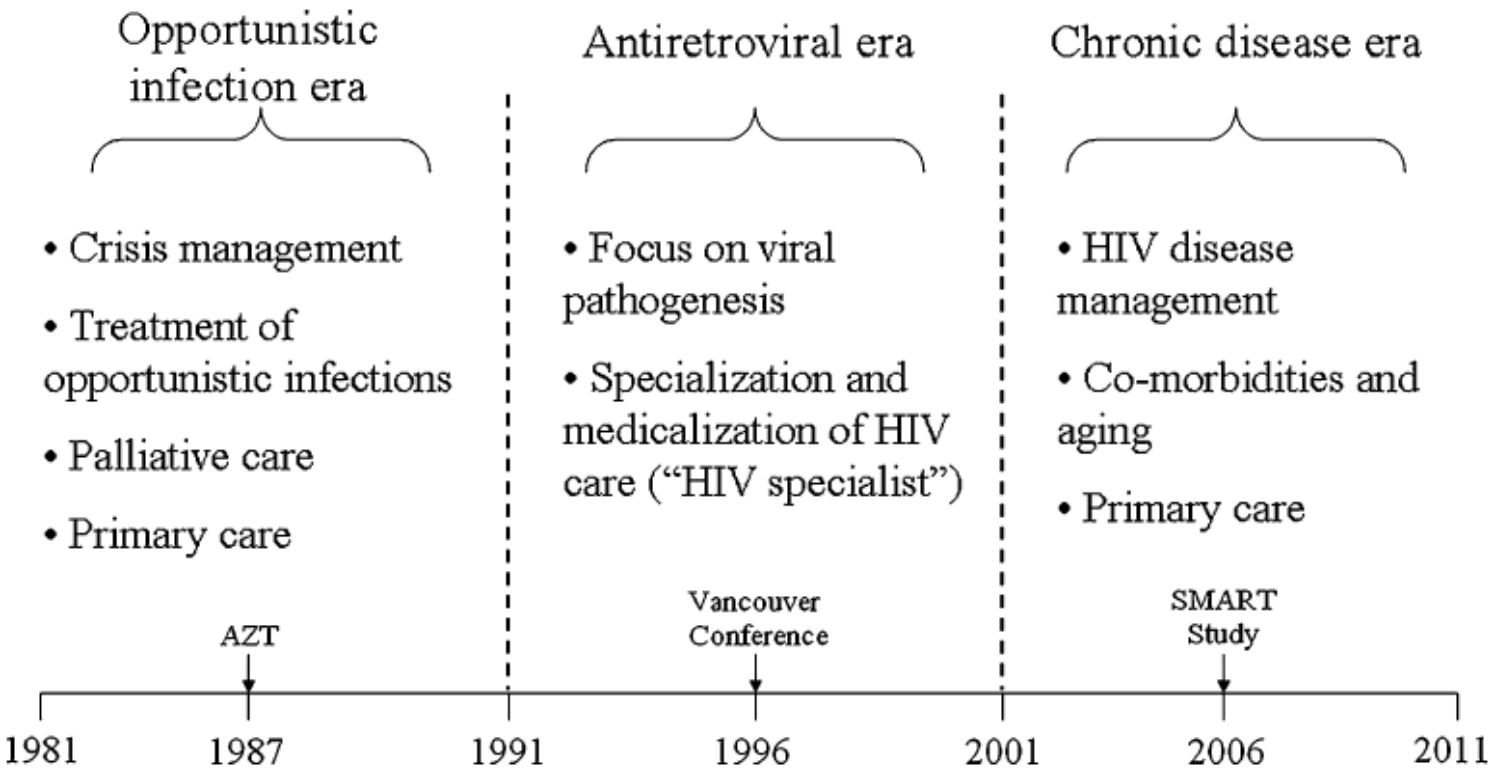


FIGURE 1. The HIV/AIDS epidemic: major clinical themes over 3 distinct eras, 1981–2011.

NECA AETC/NYC EMA Response

- Formative research to understand needs
  - 27 key stakeholder interviews
- Iterative training curriculum development process
  - 5 modules with training manual and slide set
  - Includes one break-out module for medical providers vs. case managers/navigators
- Pilot training of clinical and non-clinical providers
- Training-of-trainers component under development
- Resource guide component
  - Comprehensive listing of medical and support service resources in NYC EMA
  - Includes general aging related resources

Resource Guide Example Page

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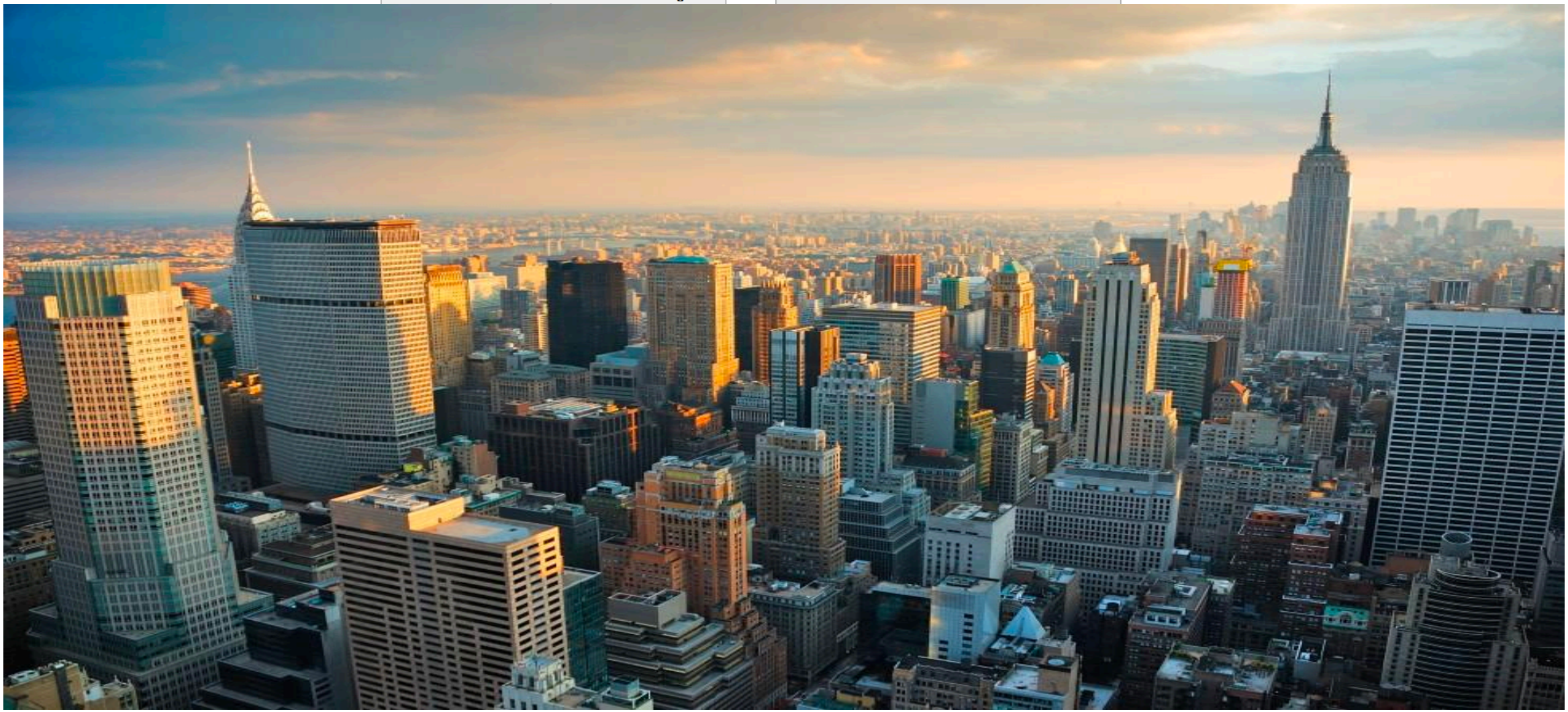
30 YEARS

The NYS Health Insurance Information Counseling &

Voces Latinas



Training Content Examples

Example from Trainer Manual:

Frailty among HIV- and HIV+ individuals[21]

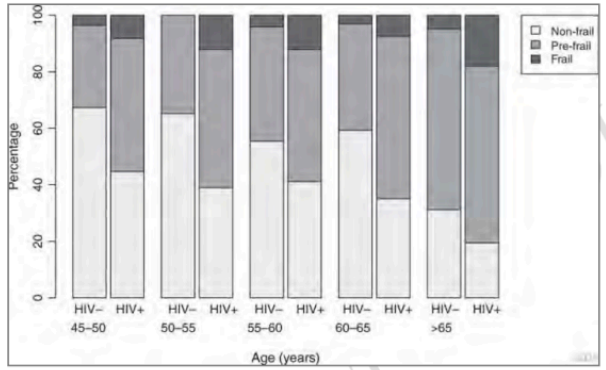


Figure 6. Frailty among HIV- and HIV+ individuals (Kooij et al., 2016)

Note:
Fried frailty phenotype was systematically assessed among 521 HIV-infected and 513 HIV-uninfected individuals.

Key point of chart

73. Provide the following key point.

- PLWH experience greater pre-frailty and frailty than their HIV- counterparts across all ages.

74. Ask the following question:

In your professional experience providing services, what's the impact of frailty issues on service provision?

Example exercise from concluding module that integrates and applies content to participants' work settings:

Handout 13. Steps to address the aging needs of PLWH

What are four concrete and specific steps that your setting could implement to address the aging needs of your patient population living with HIV? Two in the next 6 months and two within a year.			
In the next 3 - 6 months			
Task	Challenges	Steps	Resources needed
Example: Assess frailty concerns among current patients	*Lack of information on frailty*	*Conduct interviews with PCP and patients* *Partner with academic institution to analyze secondary data on frailty concerns*	*Staff to analyze data*
In the next 6 – 12 months			
Task	Challenges	Steps	Resources needed
Example: Establish protocols for addressing frailty among current patients	*Lack of staff training* *Having time to conduct frailty screenings*	*Consult with clinic team to develop realistic goals and objectives* *Request a training from academic institution*	*Time off to attend training* *List of specialists for referrals*

2. In their words: key lessons learned from clients & providers about service needs and models

- Major aging issues and service needs
- Long-term trauma, cultural and linguistic appropriate services (CLAS), and emergency preparedness plans
- Strengths, challenges, and limitations of current models of care and the continuum of care
- Creating a vision for practice transformation

Perceptions on aging

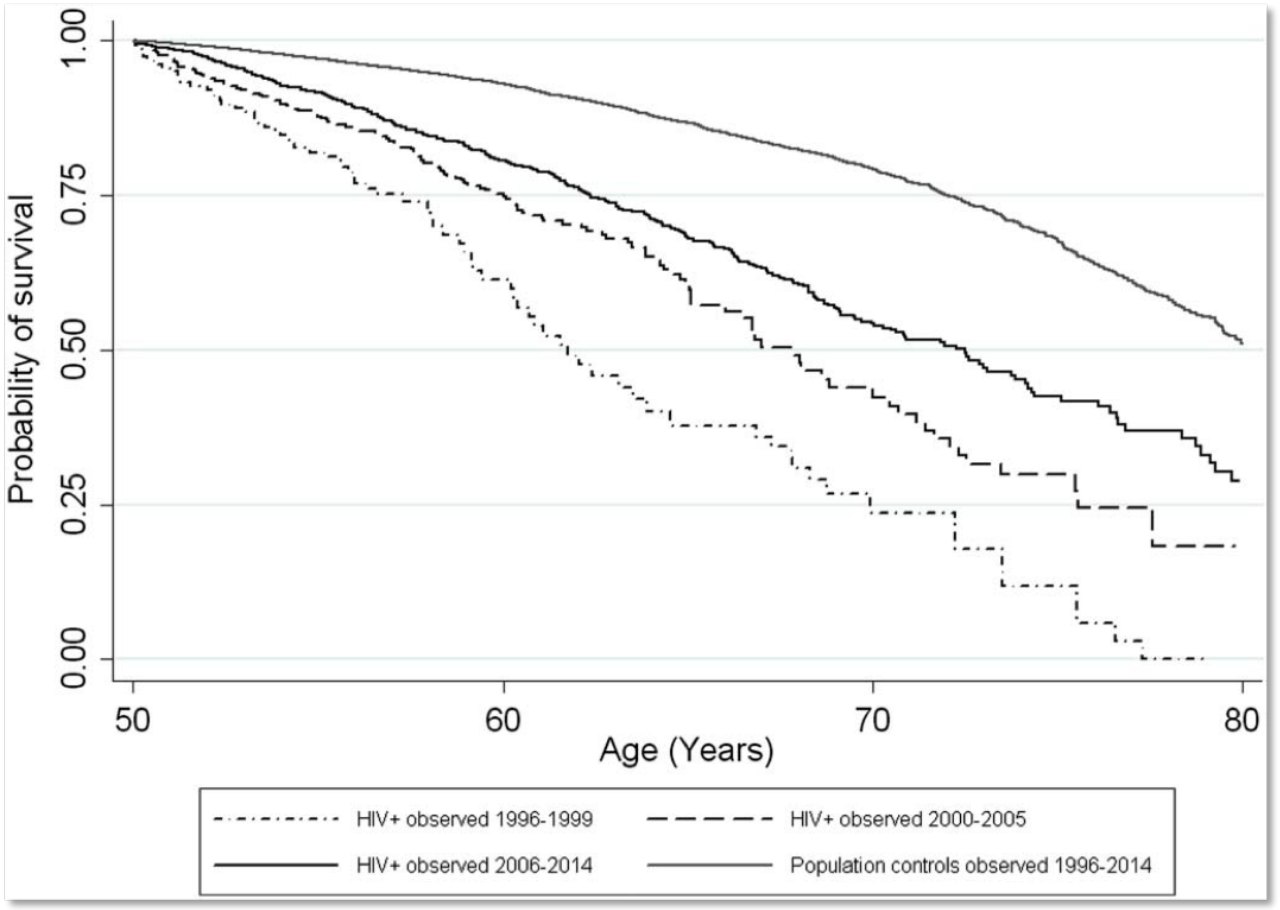
- *They need to see geriatric doctors that can help them. But a lot of people don't like to go to geriatric clinics because they feel, "Oh, I'm not that old." But now 50 is old [laughter]. Especially if you're living with HIV. 50 is old. (Consumer, Female, Latina, 65)*

- *I think some people are reluctant to accept that it's aging. Like they want to blame everything on HIV, like "oh, this is only happening to me because of HIV." But it's like you're also getting older, and I think there's maybe like a lack of acceptance. (Service Provider)*

- *I do not believe that there's a reflex referral for a patient over age 50, say or 55 to automatically get routed for geriatrics consult, that's kind of as needed based on the primary care provider's perspective. (Primary Care Provider)*

OPLWH Project: qualitative Interviews with 11 consumers, 9 service providers, and 7 PCP (NYCDOH, 2020)

Life expectancy (Legarth et al, 2016)



Gap between those who are HIV- and those diagnosed with HIV for more than 20 years (added)

Aging changes

- *I just wanted to go get some tests done neurologist and a cardiologist because I've been getting dizzy a lot. I can't even really climb the ladder anymore. I fell off doing that [laughter]. Yeah, I had the sofa on my side. So thank goodness I fell backwards on the sofa, so it kind of saved me and so on. (Consumer, Female, Latina)*

- *Much has appropriately been written about the isolation, especially of our MSM population above the age of 50 and 60, completely traumatized by the death of so many of their friends and peers and community, and living in oftentimes increasingly isolated situations and insufficient support or access to ongoing support of mental health services. (Primary Care Provider)*

Physical changes

Body system	Health Impact
Blood vessels and arteries stiffen.	Increasing risk of cardiovascular disease
Bones tend to shrink in size and density.	Making them prone to break
Muscles generally lose strength, endurance and flexibility.	Affecting coordination, stability and balance
Age-related structural changes in the large intestine occur.	Increasing constipation.
The brain undergoes physical changes.	Cognitive and executive function impact.
Vision and hearing capabilities gradually diminish.	Difficulties adapting to light and follow conversations.
Gums pull back. Individuals might also experience caries, osteoporosis of the jaw, and tooth loss.	Causing pain and discomfort and increasing risk of malnutrition and pneumonia.
The skin thins and becomes less elastic and more fragile.	Making it drier and more prone to injury.
The overall metabolism slows down.	Causing weight gain.
Sexual needs and performance might change.	Creating anxiety over performance.
Cellular senescence (aging) occurs.	Increasing cancer risks, loss of function and fitness.

Phycological and social changes

- There is an increased focus on reviewing life goals.
- Physical changes may impair the level of socialization.
- Neuropsychiatric changes might make it harder to learn.
- Aging changes may increase the risk of depression and anxiety.
- Loss of friends and family members impact the available social network, sometimes causing isolation.
- Aging changes the individual's role within the family.
- Retirement increases the time spent at home.

Key themes on aging

- There are many diverse social and cultural views about what constitute old age. For some, old means over 65 years of age; for others being 50 and unable to live independently.
- Patients may feel older or younger than what their physical or mental conditions indicate.
- Furthermore, OPLWH and staff may not be clear about the impact of HIV on their health and social well-being versus the impact due to the aging process.

Key health and social concerns

- Mobility impairment and frailty
- Long-term trauma
- Multiple sources of stigmatization
- Multi-morbidity and polypharmacy
- Isolation

Long-term trauma
NYCDOHMH's OPLWH Project

Most PLWH experienced traumatic events with lasting impact on their well-being, often related to systems of oppression, e.g., racism, classism, sexism, genderphobia, or xenophobia.	
System induced traumatization and re-traumatization	• Child welfare • Shelter system • Justice system • Health care system
Historical cumulative traumatic experiences across generations and within the community	• Long histories of socio-economic inequalities, racism, sexism, etc. • Generational homelessness and poverty • Histories of substance use, community violence, and incarceration • Disproportionate impact of HIV in their communities
Traumatic family and individual experiences	• Homelessness • Incarceration, • Substance abuse • Interpersonal violence • Family loss

Multiple stigmatization

- *So they've kind of got both issues going on. When they hang out in the HIV world, then they're very reticent about their criminal justice world. When they hang out in criminal justice world, they tend to be reticent about their HIV status. So there's not a safe place where the two overlap. (Service Provider)*

- *I think that the issues of stigma are still very real. So, sometimes they're not treated well in other settings or they're afraid that they will be not treated well especially if their referral says HIV on it or something like that or it says opioid use or methadone. (Primary Care Provider)*

Multiple stigmatization (cont.)

- Stigmatization increases isolation and decreases social integration.
- Often overlooked is the impact of multiple sources and experiences of stigmatization, especially for OPLWH from communities already stigmatized because of their race/ethnicity, income, immigration status, or sexual orientation.
- Long-term experiences of multiple stigmatization have a synergistic negative effect on OPLWH's ability to engage in services and/or make healthier decisions.

Long-term survivors

I was so determined to live. I lived through four PCPs, TB, neuropathy, wasting syndrome. I was like 90 pounds. I was bed-bound. It was very traumatic back then. Because there was nothing available, only the AZTs. So that's what they gave me. I needed two blood transfusions from that. But that was the only thing that was helping me raise my T cells.

My T cells was zero. And I needed something. So the AZT raise my T cells immediately to like 10. To me, that was a lot. 10 is better than none. Yeah. But my viral load was in the millions. It affected many people because they lost friends. They lost family members. A lot of people would drink or get high because they didn't want to deal with the reality.

(Latina, Female, 65)

The impact of disasters and emergency events on OPLWH

OPLWH might be more susceptible to the effects of disasters and emergency events.

For instance, after Hurricane Katrina, PLWH experienced

- Increased symptoms of PTSD
- Treatment and medication interruptions
- Higher levels of viral load due to stress
- Greater lack of basic resources

Policies enacted to address COVID-19 have the potential to impact OPLWH wellbeing, including:

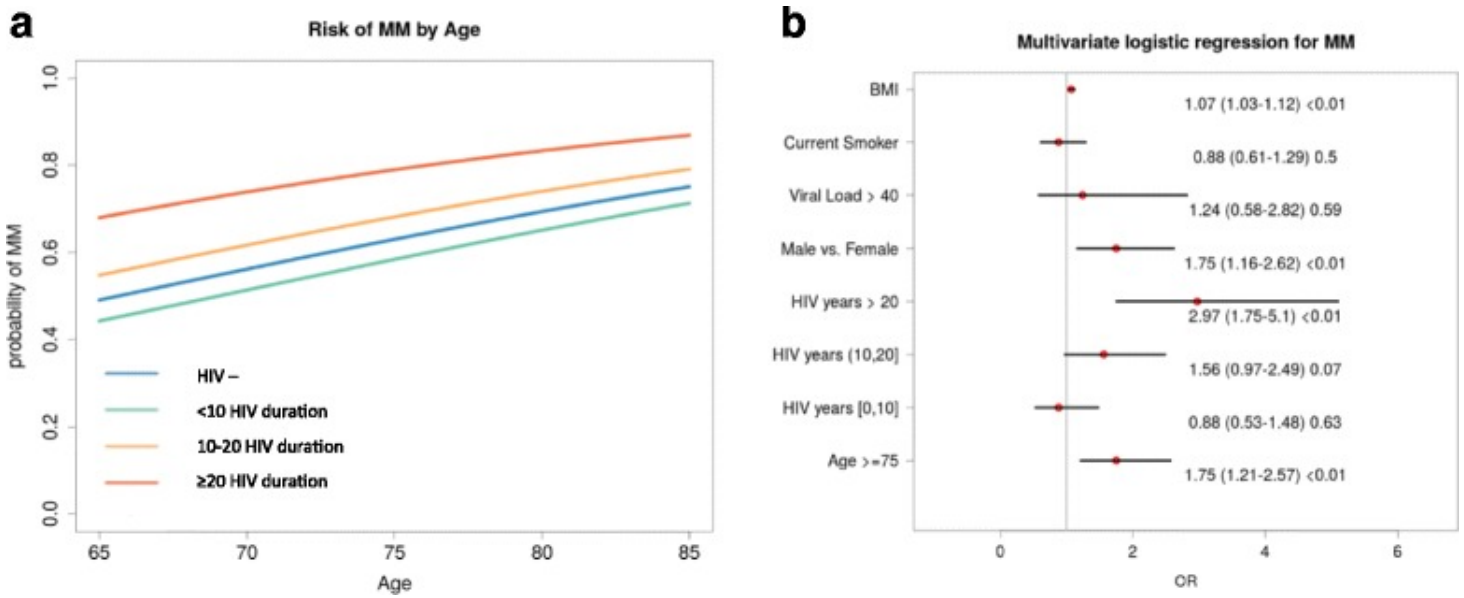
- Increased social isolation and loneliness due to social distancing measures in public venues and service settings
- Challenges to continuity of care due to restrictions on clinic visits
- Disruption in access and adherence to HIV medications

Multi-morbidity

- *Some people start dealing with heart troubles. Some people start dealing with liver problems. Cancer. There's a lot of other things that just go in normal with life, with aging. And so those people need to be able to go see specialists for that. […] Then you find out that if your Medicare or Medicaid, they only provide for certain services. And if you need something like a bone graft to get teeth, they don't pay for that. And so a lot of times you see people without teeth and their diets are affected by it. (Consumer, African American, Male, 67)*
- *So, we're seeing a high degree of diabetes, hypertension, hyperlipidemia, and worsening kidney function. So, some of them are on dialysis. And with all those comorbidities, they also require a lot of subspecialty follow up. Some of it is related to the comorbidities. So, it might be within cardiology, renal. other components might be following up for colon cancer screening, or ophthalmology-- just healthcare screenings, and general mammograms, and so forth. (Primary Care Provider)*

- *OPLWH Project: qualitative Interviews with 11 consumers, 9 service providers, and 7 PCP (NYCDOH, 2020)*

Multi-morbidity (cont.)



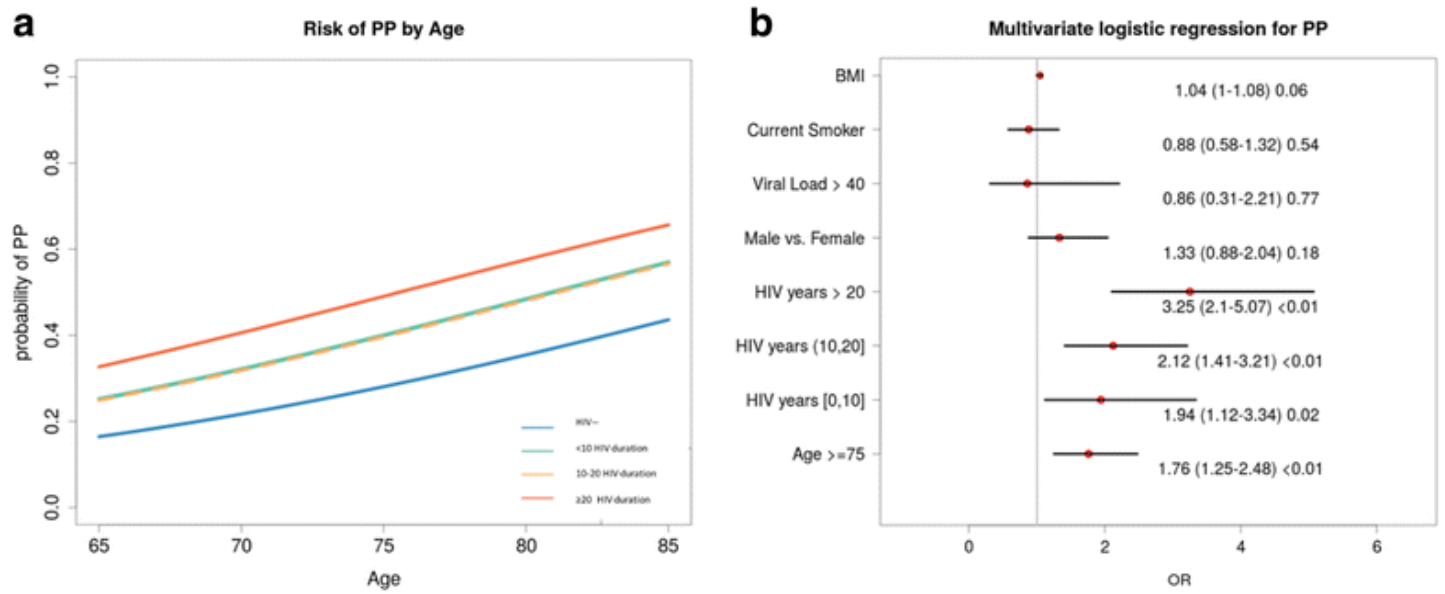
a *Probability of MM per year above the age of 65. The HIV positive patients are stratified by duration of HIV infection (< 10, 10–20 and > 20 years).* ***b*** *Multivariable logistic regression models to detect the independent predictors of MM. Abbreviations – MM: Multimorbidity (Guaraldi et al., 2018)*

Polypharmacy

- *The drug drug interactions and poly pharmacy are a significant issue for many people, older adults with HIV, and I think we don't have that specific resource which could be useful. I think we managed without it, and I would say one of the major things that our geriatrician does when she sees our patients is focus on poly pharmacy -which medications are not essential or can be eliminated . So that's helpful for some people . But you know that not everyone sees a geriatrician. (Primary Care Provider)*
- *[Medication reconciliation] is very time-consuming. It's not done as part of a routine medical visit because it's going to take a lot of time to go each one-by-one of the medications and then look at them in combination and then decide which of these can be continued, which of these should be stopped, which need to be changed, based on a conversation with a patient and/or their family about goals and looking for interactions and appropriateness.*

- *OPLWH Project: qualitative Interviews with 11 consumers, 9 service providers, and 7 PCP (NYCDOH, 2020)*

Polypharmacy (cont.)



a *Probability of PP per year above the age of 65. The HIV positive patients are stratified by duration of HIV infection (< 10, 10–20 and > 20 years).* ***B*** *Multivariable logistic regression models to detect the independent predictors of PP. Abbreviations – PP: polypharmacy (Guaraldi et al., 2018)*

Clinical and programmatic challenges (examples)

- Clients feeling overwhelmed with multiple conditions and treatment regimens
- Early onset of aging issues or advanced aging that require prevention, screening and/or treatment
- Additional workload on non-clinical and clinical staff (e.g., arranging for transportation, specialty care, conducting frailty screenings)
- Limitations of insurance coverage for specialized services and resources (e.g., wheelchairs, aide services)

Challenges of current models of care & HIV continuum of care

- *I think the biggest challenge really is the medical complexity. At this point, I'm certified in internal medicine and infectious disease, and I feel like caring for these complex patients really relies on both because often times even with HIV being well controlled, many of these patients of mine tend to have just multiple medical problems that can be difficult to address in one scheduled visit. (Primary Care Provider)*

- *And we see, oftentimes, patients who come in to us and their viral load is under control, but they have a whole list of other medical problems that need to be addressed. And it takes a very, very, very long time. And the diseases are longer and longer while the requirements for the practitioners are more significant. And the understanding at the facilities is that these are easy diseases because the patient has HIV controlled. (Primary Care Provider)*

Challenges of current models of care & HIV continuum of care (cont.)

- Lack of culturally and linguistic appropriate services (CLAS)
- Focusing only on HIV clinical outcomes, particularly viral suppression
- Balancing primary care versus ID medicine versus geriatric care
- Having resources to provide screenings, case management, and referrals for comorbidities and reconciliation of polypharmacy
- Having to prioritize among the various presenting morbidities and trying to reduce drug burden for patients

Infectious disease doctors or HIV specialists function as primary care doctors managing non-HIV conditions for which they might lack training, time, or resources.

Current strategies to integrate HIV & geriatric care

- *There are many [PCP] who will focus on mobility and exercise and either have a referral protocol for physical therapy or maybe want to set up an exercise program or have some linkage with the local senior center. It may be some other aspect of geriatric care. It might be the only resource that they have is pharmacists. So that everybody over the age of 55 is going to get a pharmacy review once a year. (Primary Care Provider)*

- *Part of our annual visit, we have a neurocognitive screen that we do. It's kind of like a Mini-Mental. […] And if anything comes out abnormal, this has happened in the past, we tend to refer accordingly. (Primary Care Provider)*

Current strategies to integrate HIV & geriatric care (cont.)

- Discussing HIV and aging with patients and staff within a culturally appropriate framework, a health promotion framework, and an strengths-based approach
- Maintaining updated information on key multi-morbidity and polypharmacy issues among patient population
- Establishing institutional priorities and guidelines for screening and treatment of particular multi-morbidities and key polypharmacy interactions
- Integrating team-based activities geared to identify and manage aging-related needs
- Establishing collaboration with HIV specialty pharmacists, specialty care providers

A new vision for care?

The way that we've been delivering care for people with HIV doesn't necessarily work that well either because we sort of built these systems when people had advanced immunosuppression, they had very complicated and tightly toxic regimens with high pillow burdens, they had lots of opportunistic infections, they had a poor life expectancy.

And so, they needed all of these different things and now we have these multidisciplinary clinics, but what they need isn't the same. They still could benefit from a multidisciplinary approach, but I think that the perspective of how we then assess what their needs are and then deliver care based on their needs, hasn't really kept up. (Primary Care Provider)

A new vision for care? (cont.)

We made a mistake in dismantling the long-term care system when effective antiretrovirals came about. We should have kept it. We should not have dismantled it. And now, there's no system in place for people with HIV if they need more services in the community. And eventually, we'll need skilled nursing home care or assisted living facilities. All that infrastructure which was available in the '80s and early '90s is gone, and we've got to rebuild it again. (Primary Care Provider)

Potential directions?

- Increasing technology-based care
- Increasing Differentiated Service Delivery (DSD)
- Adopting Geriatric 5 Ms (Mind, Mobility, Medication, Multi-complexity, and Matters most)
- Rethinking the composition of HIV Care team
- Addressing the siloing of HIV and geriatric services
- Tailoring/segmenting the treatment cascade

2. In their words: key lessons learned from clients & providers about service needs and models

- OPLWH present and will present a variety of health, psychological, and social issues besides HIV.
- A central question is how to involve/integrate geriatric care within current model of HIV care or to develop new ones.
- Changes in policy and funding are necessary to support this integration.

Resources and references

- Handout 3. “Culturally and Linguistically Appropriate Services (CLAS) What, Why and How” from the Office of Minority Health available at https://thinkculturalhealth.hhs.gov/assets/pdfs/class-infographic-what-why-how.pdf
- Guaraldi G, Malagoli A, Calcagno A, et al. The increasing burden and complexity of multi-morbidity and polypharmacy in geriatric HIV patients: a cross sectional study of people aged 65 – 74 years and more than 75 years. *BMC Geriatrics*. 2018;18(1):99.
- Legarth, R. A., Ahlström, M. G., Kronborg, G., Larsen, C. S., Pedersen, G., Mohey, R., ... & Obel, N. (2016). Long-term mortality in HIV-infected individuals 50 years or older: a nationwide, population-based cohort study. *JAIDS Journal of Acquired Immune Deficiency Syndromes*, 71(2), 213-218.

How do we get there?

A paradigm shift to address the needs of OPLWH

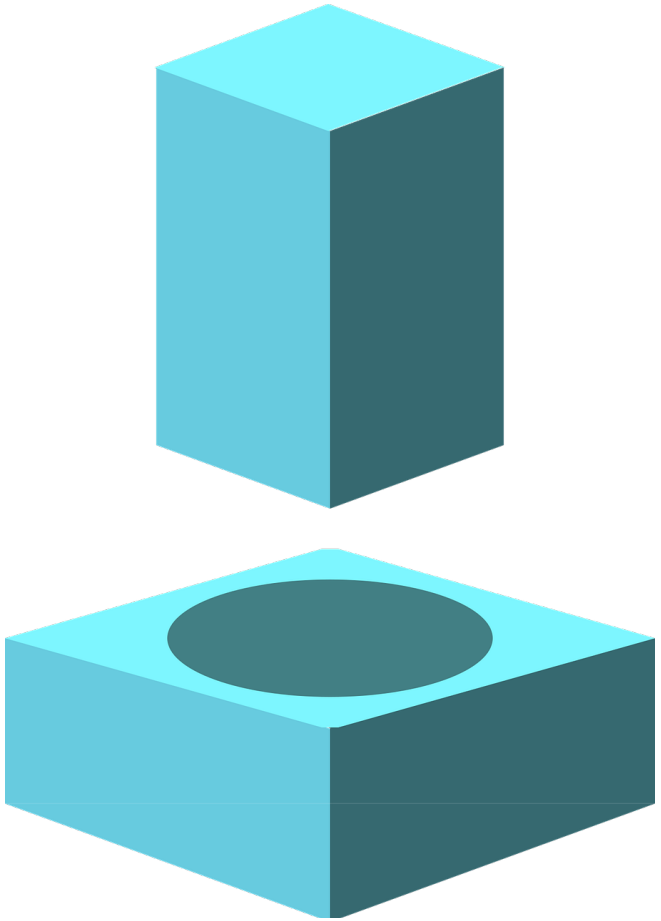
- Examining the strengths and limitations of the HIV continuum of care perspective
- Examining current models of care—from guidelines to physical settings
- Practice transformation
- Policy and funding transformation

Examining the strengths and limitations of the HIV continuum of care

Examining systems of Care

- Guidelines and implementation
- Physical structures
- Role of all health care team members
- What do our partnerships look like?

  Are they the right ones?



Transformation

Practice transformation approach

- Systems analyses
- Multiple perspectives
- Systematic application of tools
- Roles
- HIE

What are four concrete and specific steps that your setting could implement to address the aging needs of your patient population living with HIV?
Two in the next 6 months and two within a year.

In the next 3 - 6 months

Task	Challenges	Steps	Resources needed
Example: Assess frailty concerns among current patients	Lack of information on frailty	Conduct interviews with PCP and patients Partner with academic institution to analyze secondary data on frailty concerns	Staff to analyze data

In the next 6 – 12 months

Task	Challenges	Steps	Resources needed
Example: Establish protocols for addressing frailty among current patients	Lack of staff training Having time to conduct frailty screenings	Consult with clinic team to develop realistic goals and objectives Request a training from academic institution	Time off to attend training List of specialist for referrals

Policy and Funding

- Are the funded services meeting the needs?
- How do our policies/funding reflect that the majority of PLWH are over 50?
- Addressing the silos of care and policy

Knowledge is necessary but not sufficient

Structural issues need to be addressed to affect practice change

Change cannot be achieved without commitment and prioritization