Taking Global Action Toward Improved Care, Quality of Life, and Empowerment for Older People with HIV

iCOPe HIV Interactive Dialogue

27 January 2023

Founding iCOPe HIV Members

The Glasgow Manifesto was developed by the founding members of the International Coalition of Older People with HIV (iCOPe HIV): European AIDS Treatment Group (EATG, Belgium), National AIDS Treatment Advocacy Project (NATAP, USA), *Realize* (Canada), and UTOPIA_BXL (Belgium). For more iCOPe HIV or the Glasgow Manifesto, contact:

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UTOPIA BXL

realize
FOSTERING POSITIVE CHANGE FOR PEOPLE LIVING WITH HIV AND OTHER EPISODIC DISABILITIES

EATG European AIDS Treatment Group

Zoom Housekeeping

- Please keep your microphones muted
- The webinar is being recorded
- Interaction
  - Use the chat function to share ideas and feedback throughout
  - Polls will enable all to provide input, results shared in real time
  - During the group discussion, ‘raise your hand’ to speak
- Technical Help: Send chat message to Janet London or Roger Musselman

Jules Levin

Executive Director, Founder

NATAP – National AIDS Treatment Advocacy Project

www.natap.org

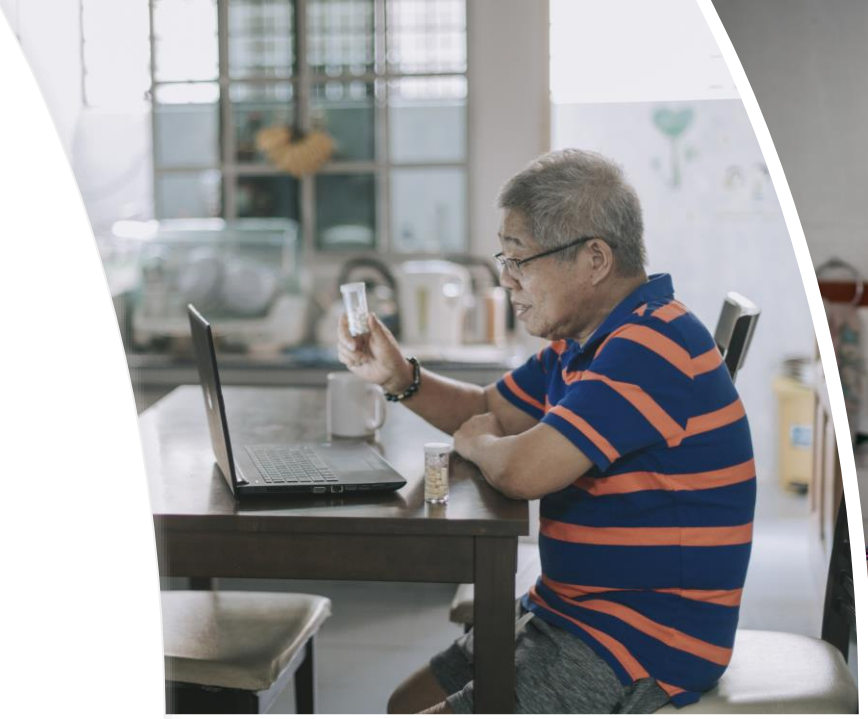
Focus on Aging & HIV Policy & Education for 17 years

HIV+ for 40 years, 73 years old

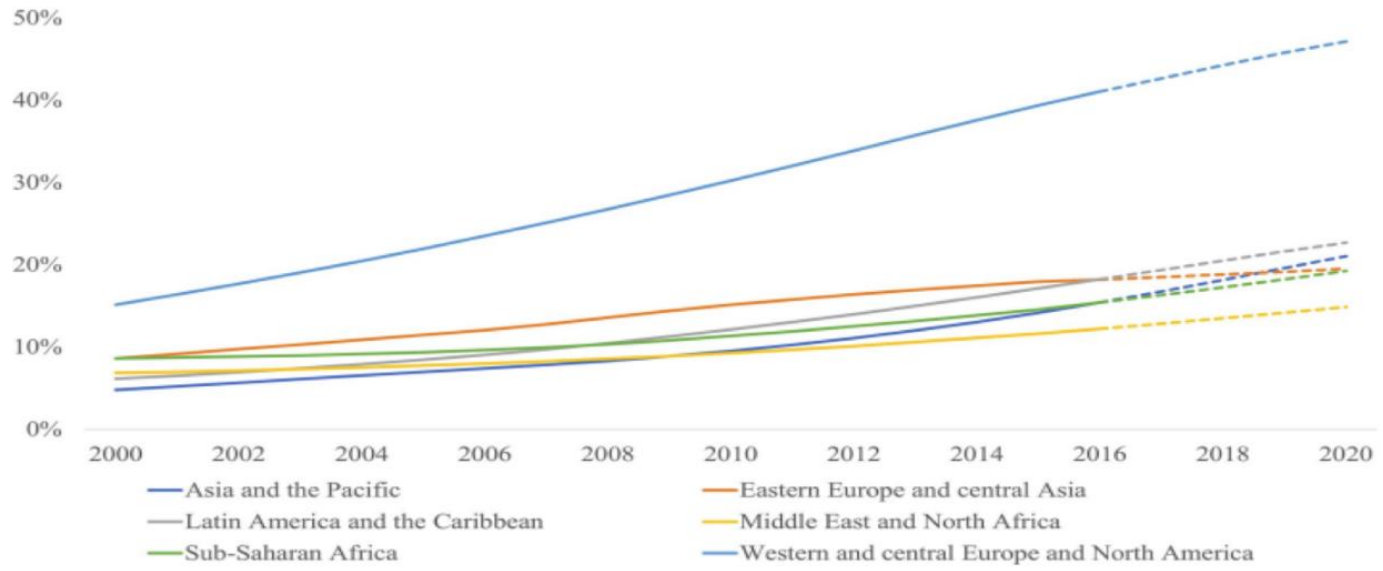
Today’s Agenda

- iCOPe Founding Members
- The Impact of HIV on Older People
- The Glasgow Manifesto
- HIV, Aging and Older Adults Around the World – Regional Snapshot
- iCOPe HIV Proposed Vision and Priorities
- Facilitated Discussion & Polls

The Impact of HIV on Older People



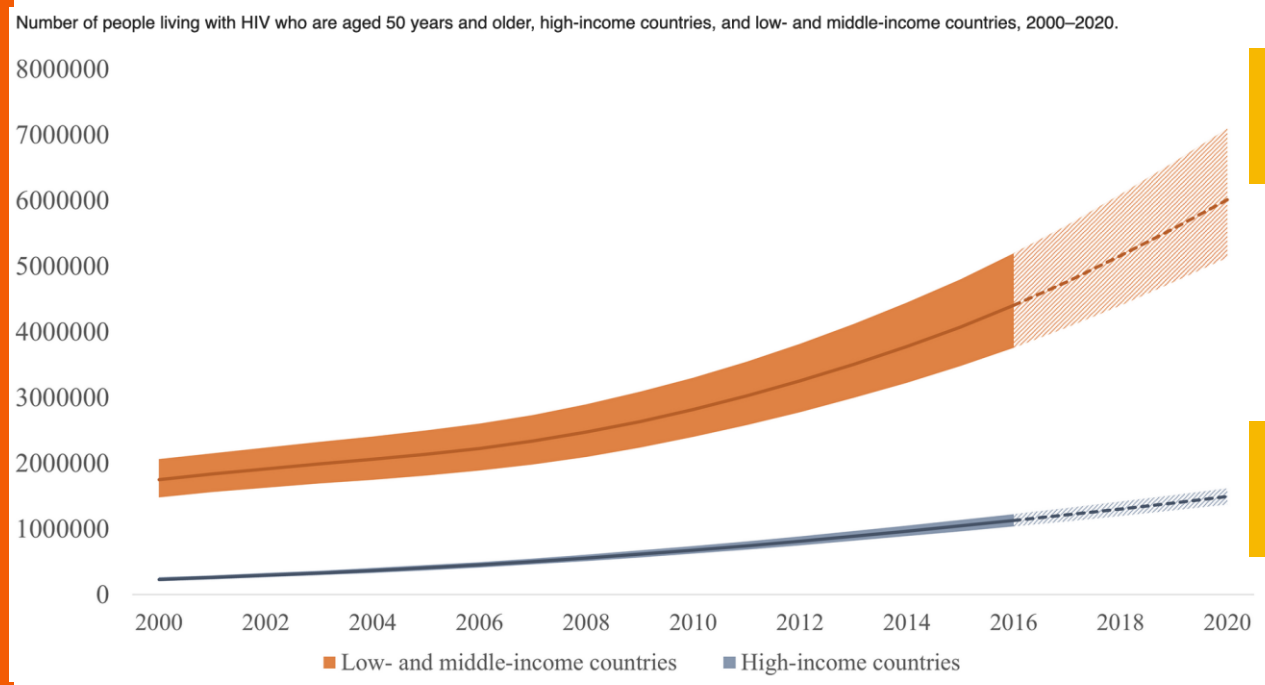
The number of people living with HIV who are 50+ is increasing…



Autenrieth CS, Beck EJ, Stelzle D, Mallouris C, Mahy M, Ghys P. Global and regional trends of people living with HIV aged 50 and over: Estimates and projections for 2000-2020. *PLoS One.* 2018;13(11):e0207005-e0207005.

- Globally, there were 5.7 million [4.7 million–6.6 million] PLHIV50+ in 2016.
- The proportion of PLHIV50+ **increased substantially from 8% in 2000 to 16% in 2016** and was expected to increase **to 21% by 2020.**
- In 2016, **80% of PLHIV50+ lived in low- and middle-income countries** (LMICs). While the proportion of PLHIV50+ was greater in high income countries, **LMICs have higher numbers of PLHIV50+ that are expected to continue to increase.**
- From 2000-2016, proportions doubled in Eastern and Southern Africa, Eastern Europe and Central Asia, and Western and Central Europe and North America; tripled in Latin America and the Caribbean; and quadrupled in Asia and the Pacific regions.

…especially in low- and middle-income countries

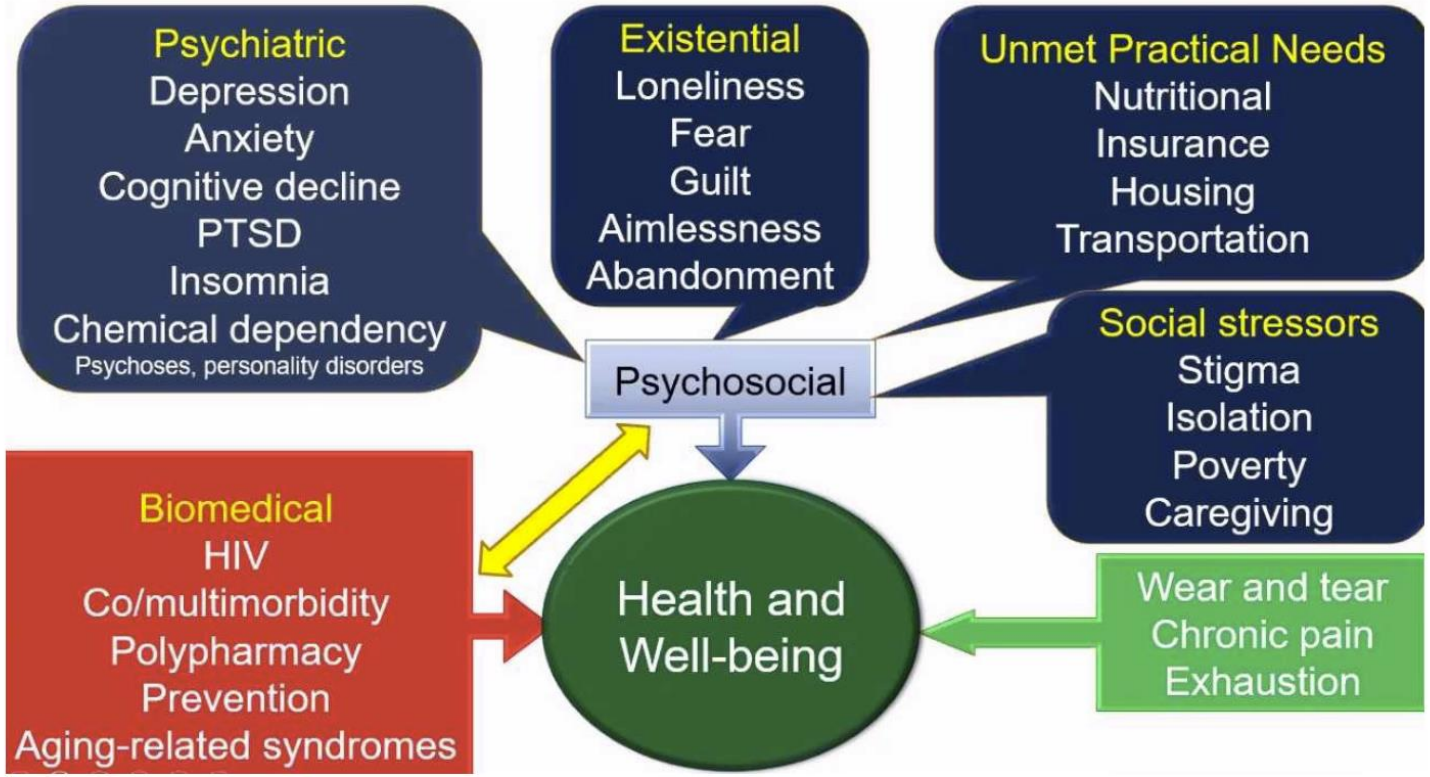


Low and middle income countries

High income countries

- In 2016, 80% of PLHIV50+ lived in low-and middle-income countries (LMICs).
- Between 2000 and 2016, the number of PLHIV50+ in LMICs increased from 1.8 million to 4.5 million and it was estimated it would reach 6.5 million by 2020.
- Between 2000 and 2016, the proportion of PLHIV50+ in LMICs increased from 7% to 14%, compared with an increase from 15% to 33% in high income countries for the same time period.

Aging & HIV Syndrome



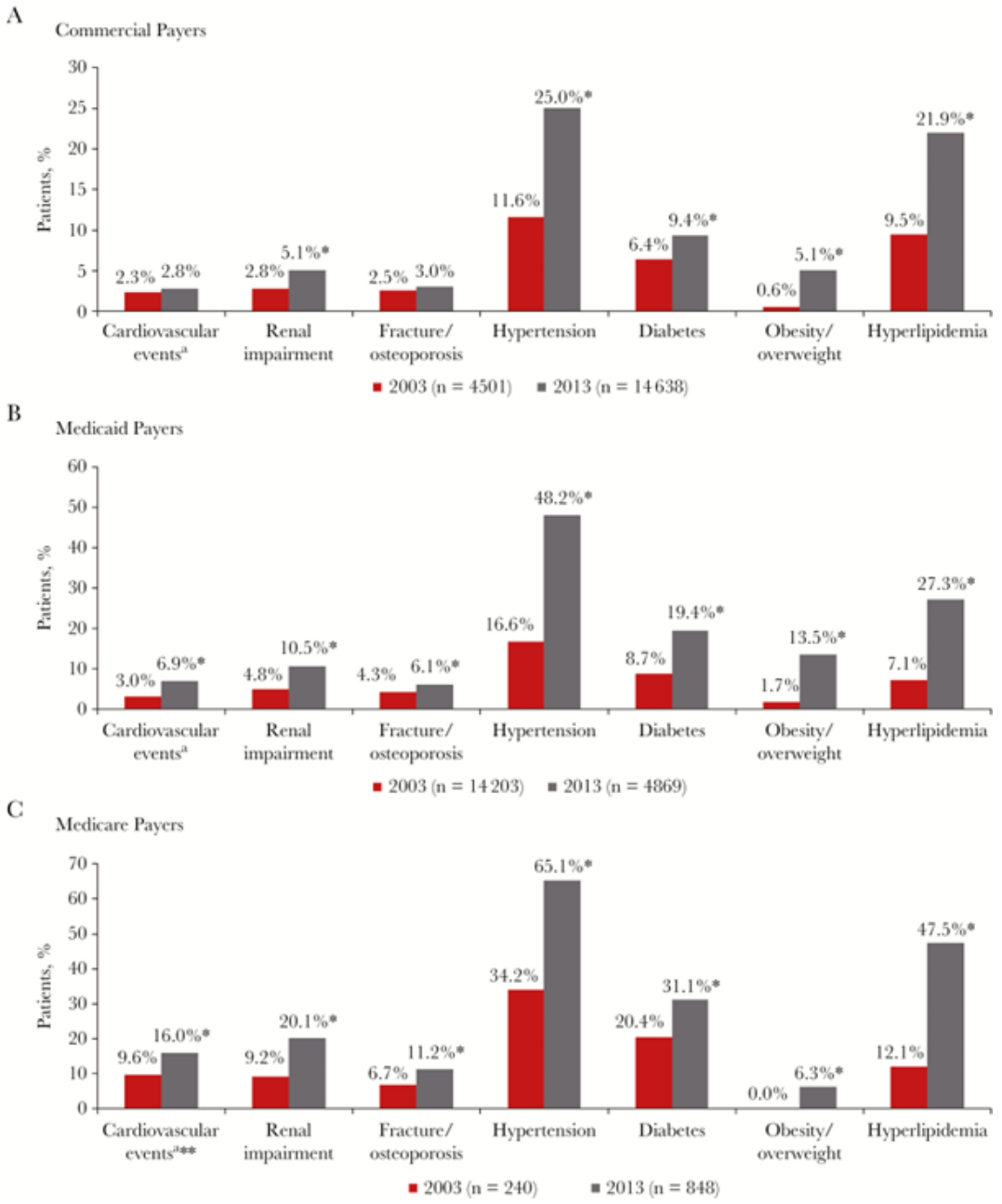
Eugenia Siegler, Cornell.

Older People Living with HIV Experience Higher Rates of Key Comorbid Non-AIDS Events

Commercial Payers

Medicaid Payers (low income)

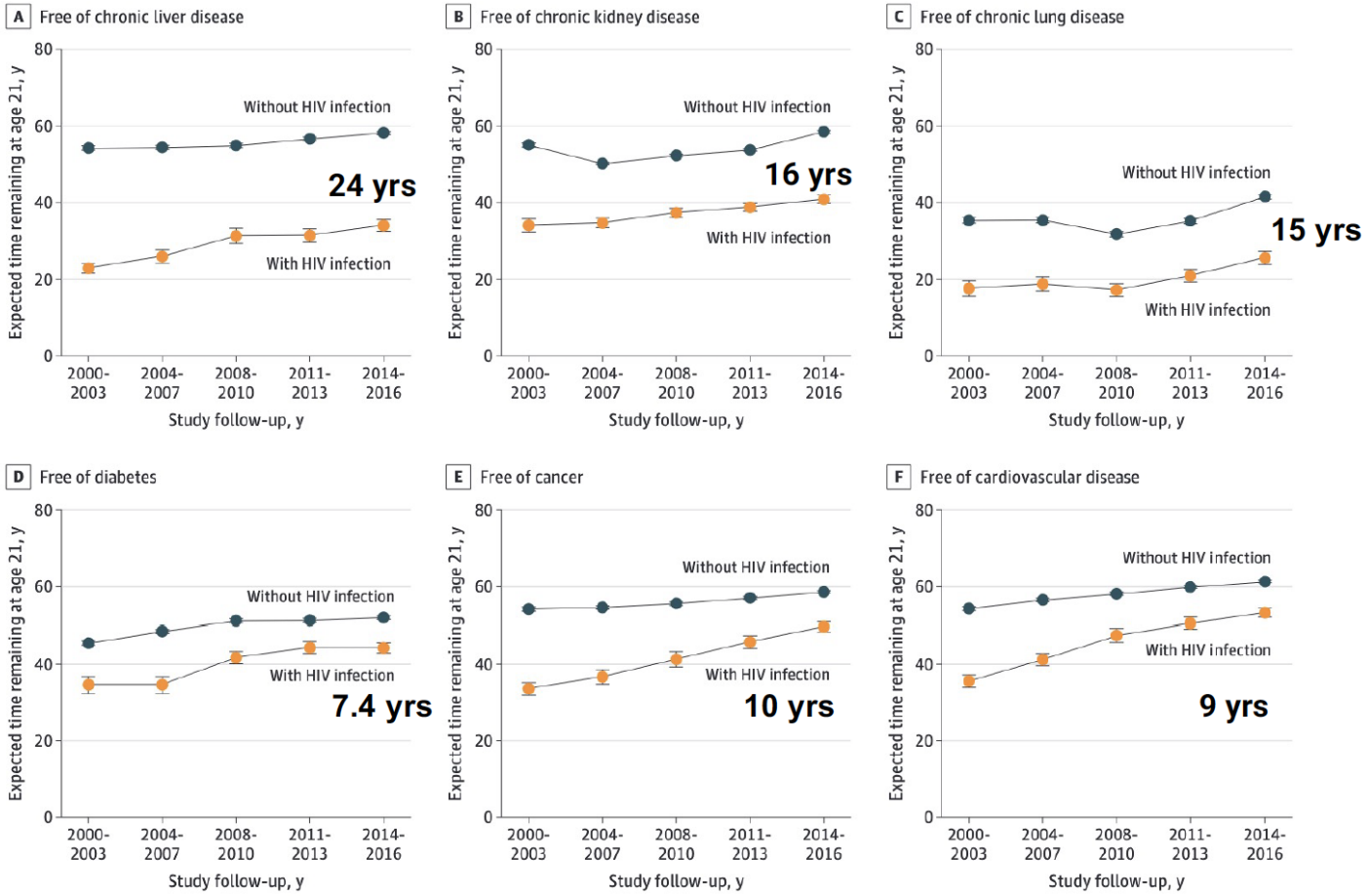
Medicare Payers (age 65+)



Gallant. 2017 JID

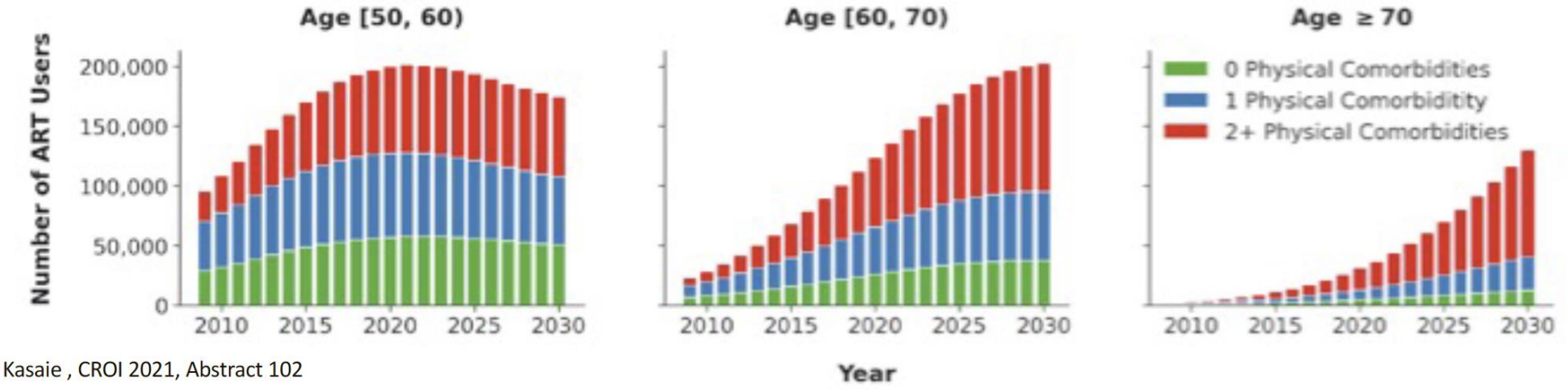
Earlier Onset of Comorbidities

Figure 2. Comorbidity-Free Life Expectancy at Age 21 Years for Individuals With and Without HIV Infection Stratified by Comorbidity, Kaiser Permanente, 2000-2016



Multimorbidity to increase markedly among People Living with HIV in next 10 years

- Older age-groups experience an **increase** in **population size** and **prevalence of multimorbidity**
- Among those ≥ 70yrs, the projected prevalence of multimorbidity increases from 58% (in 2020) to 69% (in 2030), corresponding to an additional 71,000 individuals living with 2+ physical comorbidities beside HIV by 2030

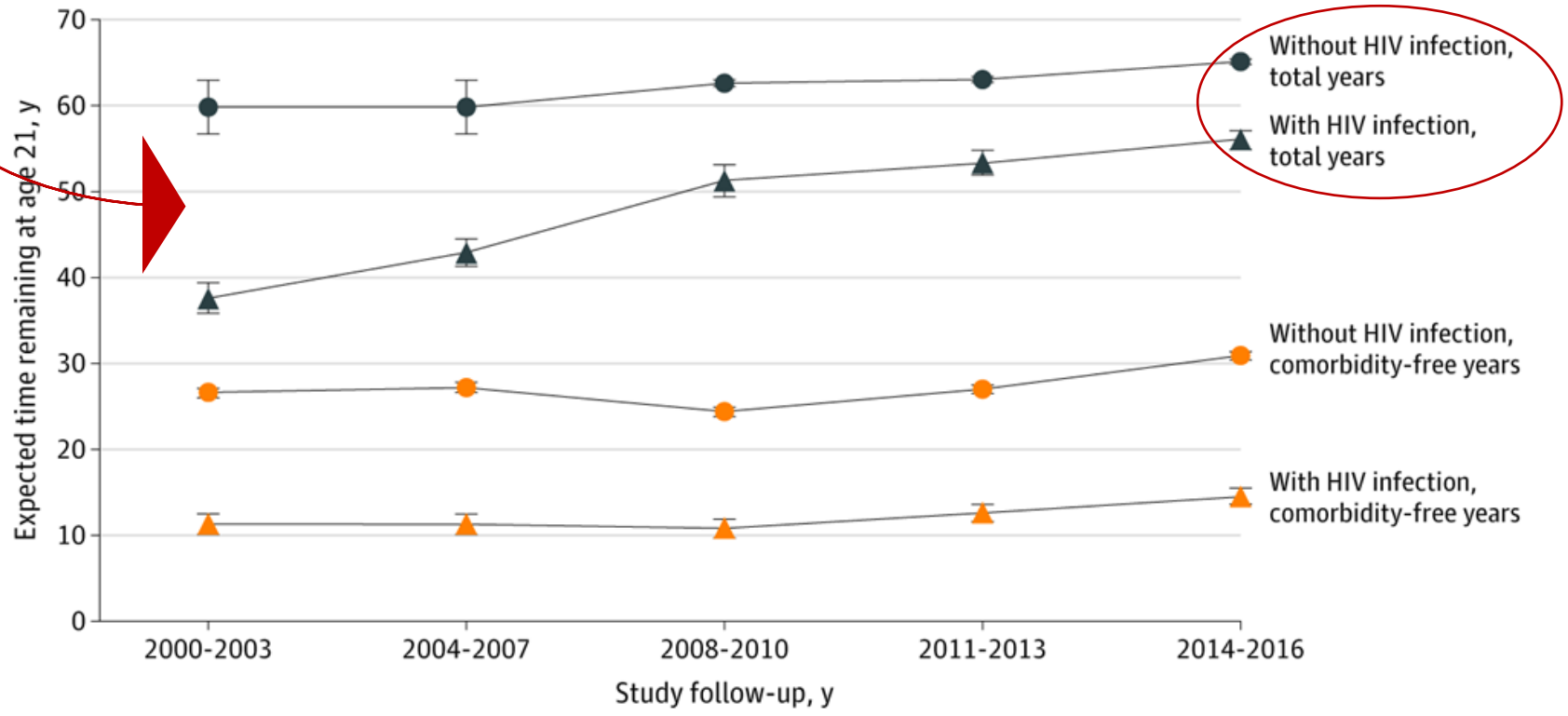


Kasaie , CROI 2021, Abstract 102

People Living with HIV have lower life expectancy

Improved from 22 years different (2000-2003)

To 9 years different (2014-2016)
**CD4 nadir >500; 6-year gap*



People living with HIV had a life expectancy 9 years less than those without HIV (age 77 vs. 86)

Study participants

- Mean age 41 years
- 87% male, 70% gay/bisexual/men who have sex with men
- 25% non-Hispanic Black, 24% Hispanic
- People living with HIV were more likely to experience poverty, substance use disorders, smoke; less likely to be obese or overweight

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Founder, President

UTOPIA_BXL

https://positivehealthhiv.be

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realize

FOSTERING
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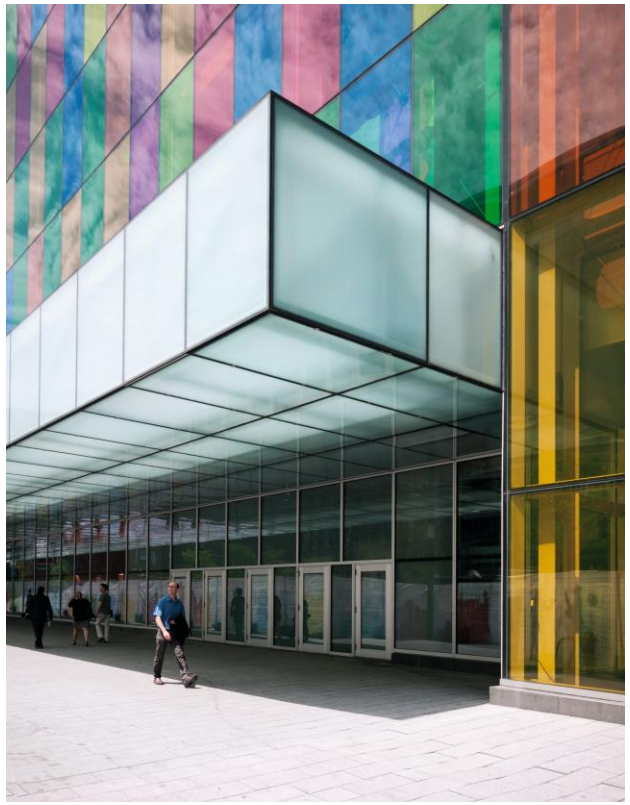
The Glasgow Manifesto

The Glasgow Manifesto – Why?

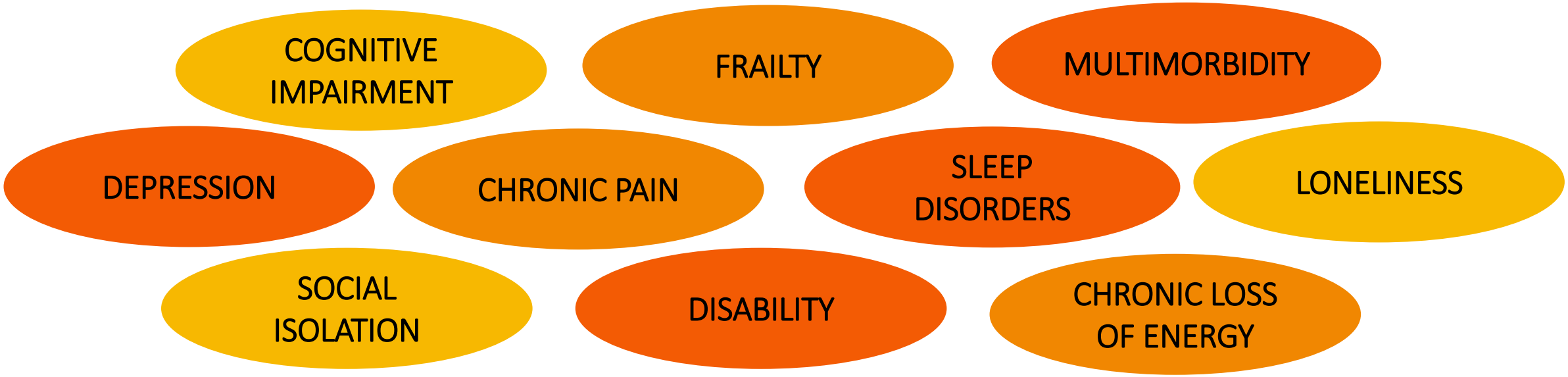
- Based on the experience of The Silver Zone in the Global Village at AIDS2022: we decided it was time to give voice to the neglected needs of older people living with HIV, **this is how the iCOPe HIV initiative started**
- We feel the challenges many of us face in our daily lives are not well acknowledged and our needs are not being addressed
- We are a silent majority. Global estimates show that in the near future most people living with HIV will be aged >50 and an increasing proportion aged >65



HIV care has not evolved with us and
we feel we have been left behind.

If we don’t take action today, quality of life and lives may be lost!

Many will STRUGGLE, coping with MULTIMORBIDITY and other chronic health conditions



Experiencing **AGEISM** in addition to HIV stigma and other forms of STIGMA and DISCRIMINATION

HIV Glasgow 2022 – 23-26 October

- During an EATG session ‘Ageing with HIV: from knowledge to action’, our **Call to Action: The Glasgow Manifesto** was launched
- We have received over **125 endorsements** from organizations and institutions globally, reflecting the great interest in the issues highlighted and underscoring the **urgency of action needed**
- We call on all stakeholders to work in partnership ***with us*** to fund and implement these calls to action

https://www.realizecanada.org/documents/the-glasgow-manifesto/

Key points from The Glasgow Manifesto

- Develop **new models of care** for older people living with HIV to address the health and social complexity we experience, including our **sexual** and **mental health** needs
- Raise awareness among service providers of our **distinct clinical and social needs**
- Responses from community which are age-affirming, address **ageism** and increase **intergenerational** understanding
- Change policy to respond to the unmet housing, food and/or resource needs of older people living with HIV who experience disability
- More **targeted research and education** on older people living with HIV, with community involvement
- **Include older people living with HIV** in decision-making about the HIV response, including **priority-and target-setting, funding allocation, and messaging** about the impact of HIV

We all deserve age-friendly and age-affirming information, care, services, and support that considers not only the impact of our HIV status, but also our gender identity, sexual orientation, race and ethnicity.

Older people living with HIV can no longer be ignored and must NOT be left behind.

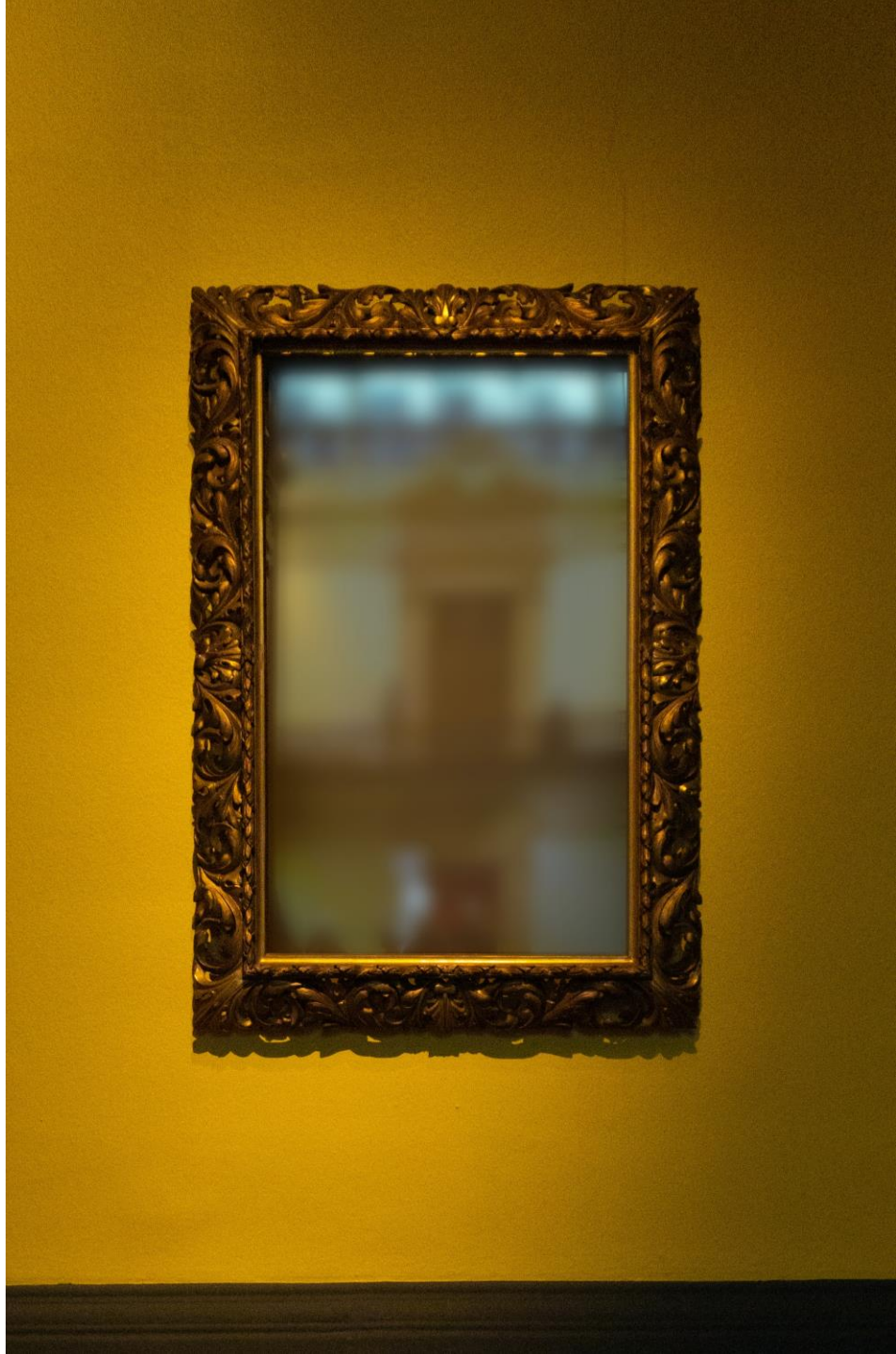
They are once again experiencing the uncertainties of the future, just like in the old days

HIV, Aging and Older Adults Around the World

Regional Snapshots

Framing the Snapshots

- What does it mean to age with HIV in your region?
- What are a few key issues facing older people living with HIV in your region?
- What initiatives are in place in your region, if any, to address these issues?



Dr. Luciana Spadaccini

Researcher, Fundación Huésped

Argentina

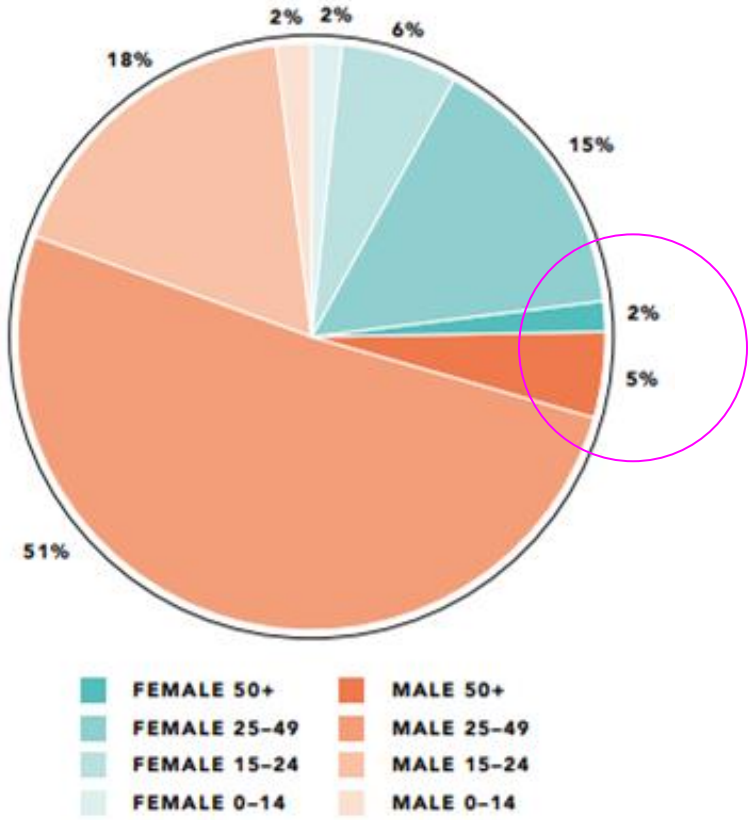
FUNDACIÓN HUÉSPED

PREVENCIÓN•CIENCIA•DERECHOS

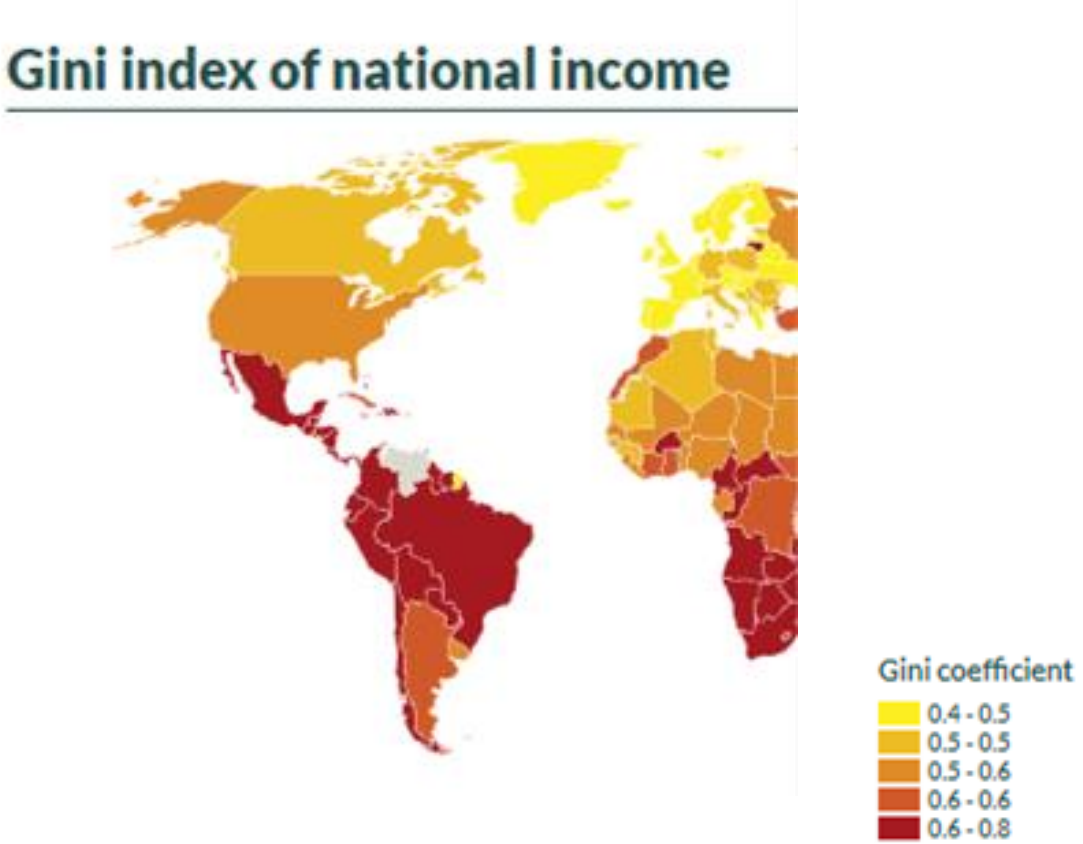
LATAM situation

2.2 million people were living with HIV (2021)

New HIV infections by population



In Danger: UNAIDS Global AIDS Update 2022



World inequality database. 2021

Living with HIV in Argentina

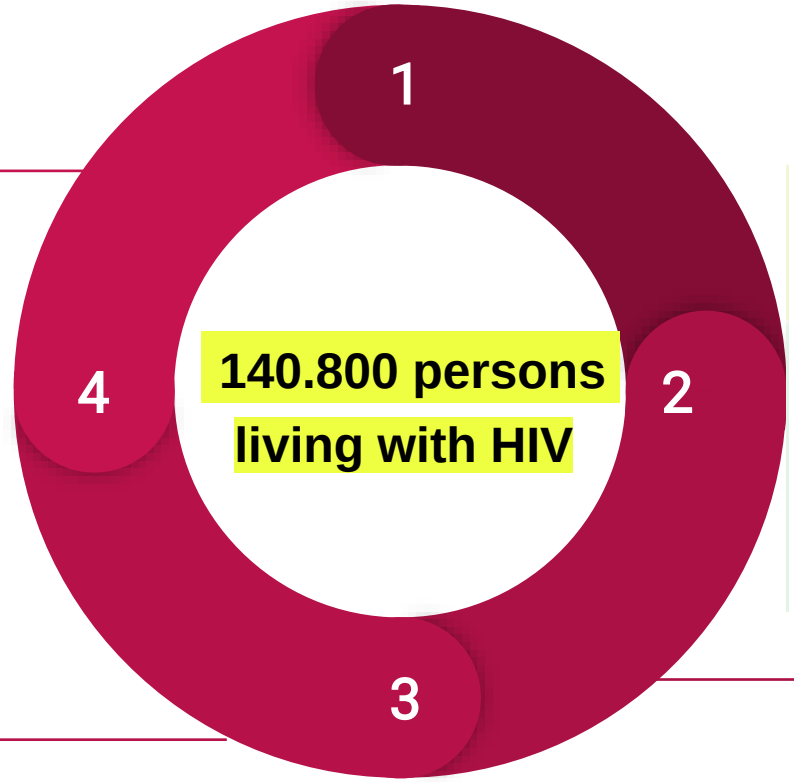
5300 new infections per year

14% are ≥ 60 years

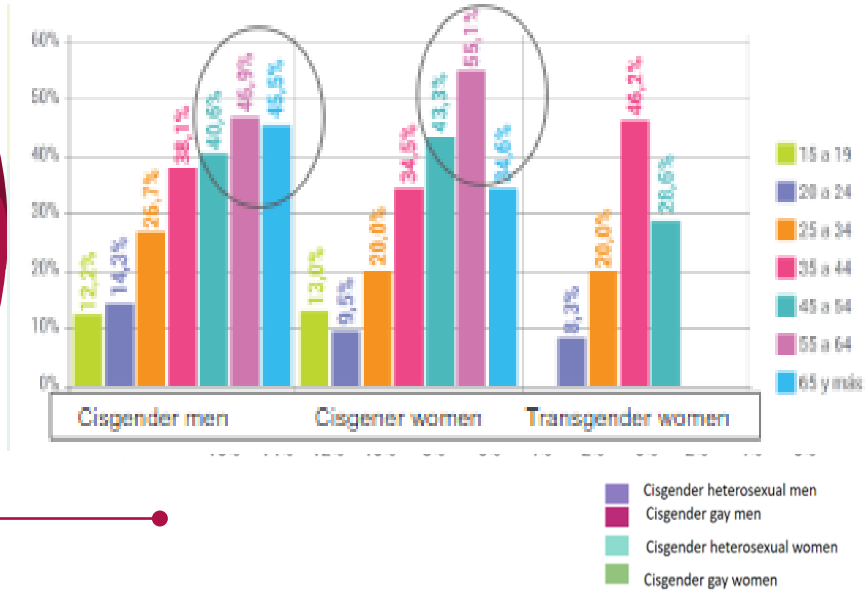
State pension and poverty rate in 2022

	Poverty condition		
Age	Indigence	Poverty	Total
15-29	11,4	32	43,3
30-64	7,3	24,7	32
≫ 65	1,9	10,1	12

https://www.indec.gob.ar/uploads/informesdeprensa/eph_pobreza_09_2223ECC71AE4.pdf



Late diagnosis increases with age



65% assist to the public health system

Male/female prevalence ratio:2,4

13% is unaware of the diagnosis

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Boletín N° 39 Respuesta al VIH y las ITS en la Argentina. Año XXV-Diciembre de 2022

Initiatives towards research

1. Cohort of 200 persons living with HIV older than 50 years
2. Haiti, Honduras, Mexico, Peru, Chile, Brazil and Argentina
3. Started in december 2022
4. Explore: ARV therapy, CD4/VL status, comorbidities, frailty and neuropsychiatric syndromes.

Caribbean, Central and South America network for HIV epidemiology

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Thank you for your attention

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Brent Allan

Global Community Engagement Advisor, Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM)

Australia

Eastern Europe & Central Asia (EECA)

Anton Basenko

Programme Manager, Quality of Life, European AIDS Treatment Group (EATG)

Ukraine

EATG European AIDS Treatment Group

Anton Basenko

Biography

Based in Brussels now, but formerly from Kyiv, Ukraine. Master's degree in international economy. Globally known activist of the community of people who use drugs and OST patients, people living with HIV and lived experience with HCV. Since 2010 started his work in HIV and TB-service, Harm Reduction and advocacy field in local and national NGOs in Ukraine. Since 2013 worked for international Alliance for Public Health, coordinating international and national projects of HIV, TB, viral hepatitis prevention and treatment among key populations as well as advising on Communities, Rights and Gender issues. Author of different articles, guidelines and publications for communities and professionals. Founder of PUD.UA. Board member of INPUD and EKHN. Member of the Communities Delegation of the Global Fund Board and CCM of Ukraine. Since 2021 he is a Programme Manager on Quality of Life in EATG team.

HIV | HIV Quality of Life | Hepatitis C | HCV Treatment | HCV Elimination Strategies | HCV Prevention Strategies | Tuberculosis | TB Treatment

European AIDS Treatment Group, Belgium

Want to know more? Just google @Anton Basenko
Хотите знать больше? Просто загуглите @Антон Басенко

HIV Infection and AIDS Mortality in EECA Region

EECA is the region with the fastest-growing HIV epidemic in the world

1.6 million people are living with HIV in the region (70% in Russia) and around 140 000 are newly infected each year.

43 % increase in new infections between 2010 and 2020.

30 % increase in mortality

90 % of new infections --among key populations
people who inject drugs and their sexual partners --45% of HIV infections in the region

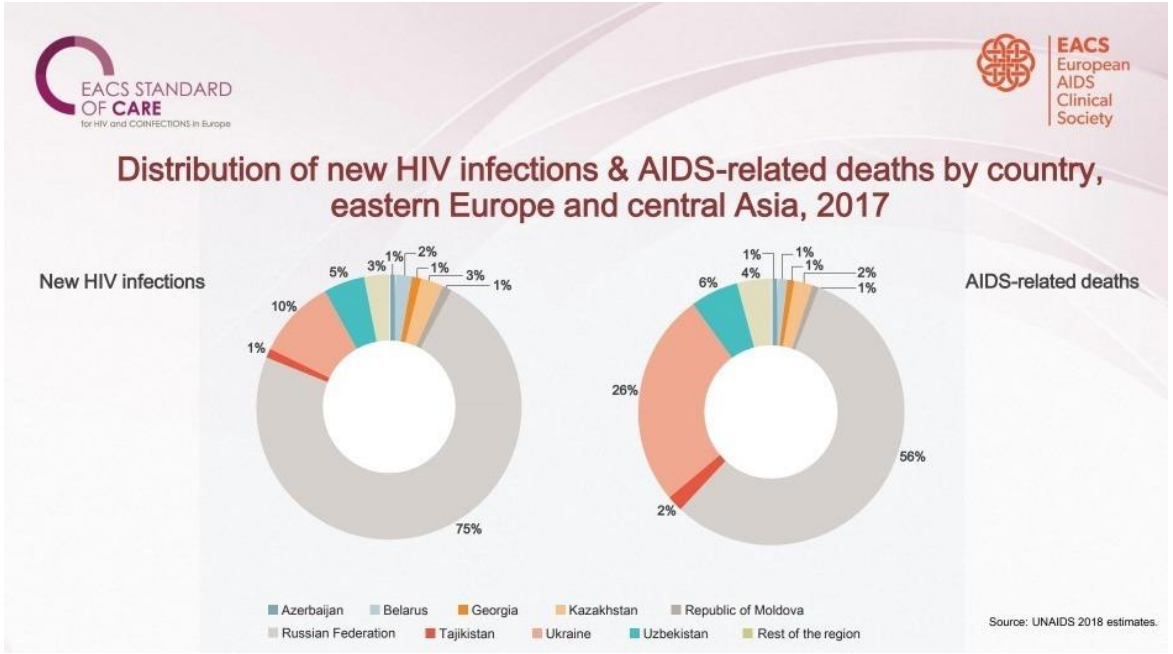
The region is quite heterogeneous:

The Russian Federation has the biggest contribution to HIV incidence.

Size is not the point!

Ukraine, --the second most populous country in the region,-- is successful in stabilizing the epidemic and containing the epidemic among people who inject drugs. Ukraine accounts only for 10 % of new infections.

Across the region, major political, policy, legislative, cultural and technical barriers prevent and delay people at risk from accessing prevention (Prep, self-testing) and accessing treatment.

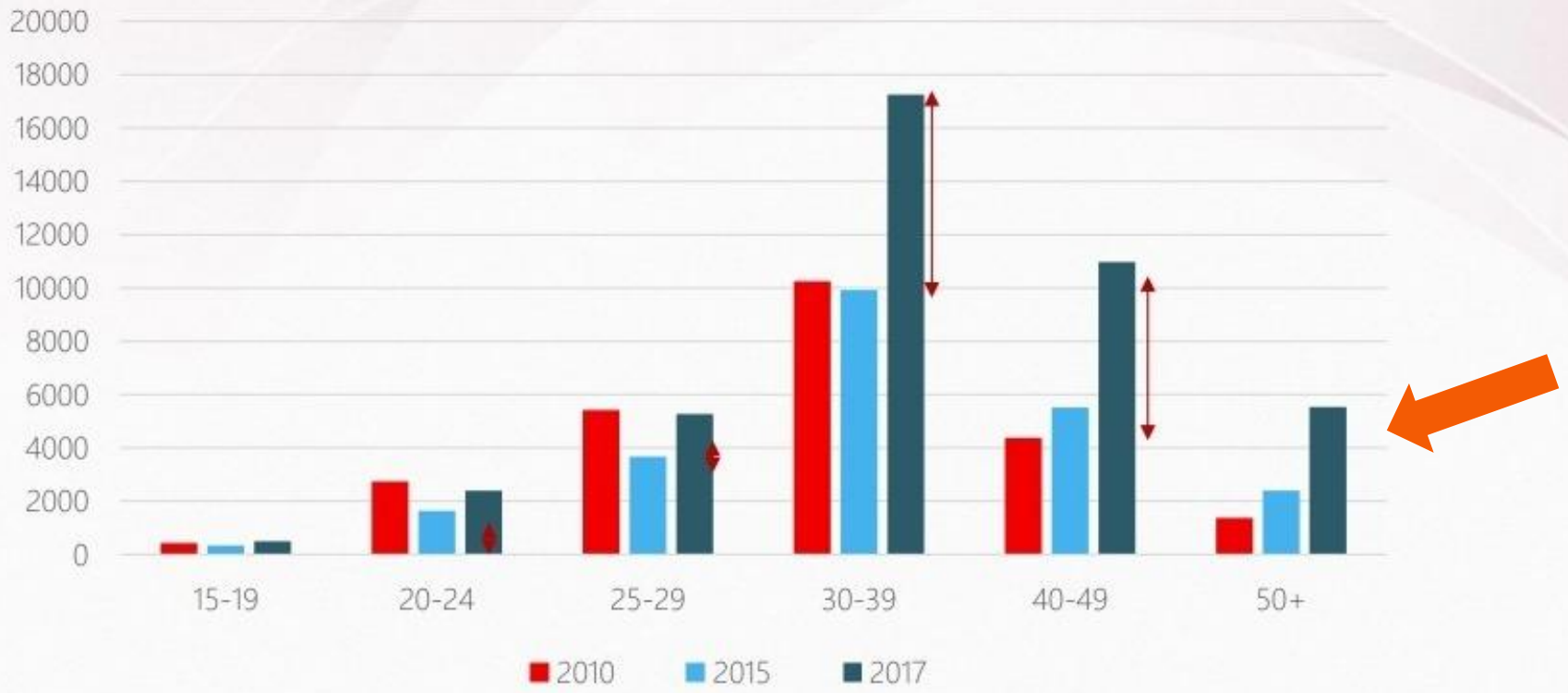


Source: Lena Kucheruk, EECA HIV Sustainability Summit 2022 (left slides); UNAIDS 2018 estimates (right slide)

EACS STANDARD OF CARE
for HIV and COINFECTIONS in Europe

EACS European AIDS Clinical Society

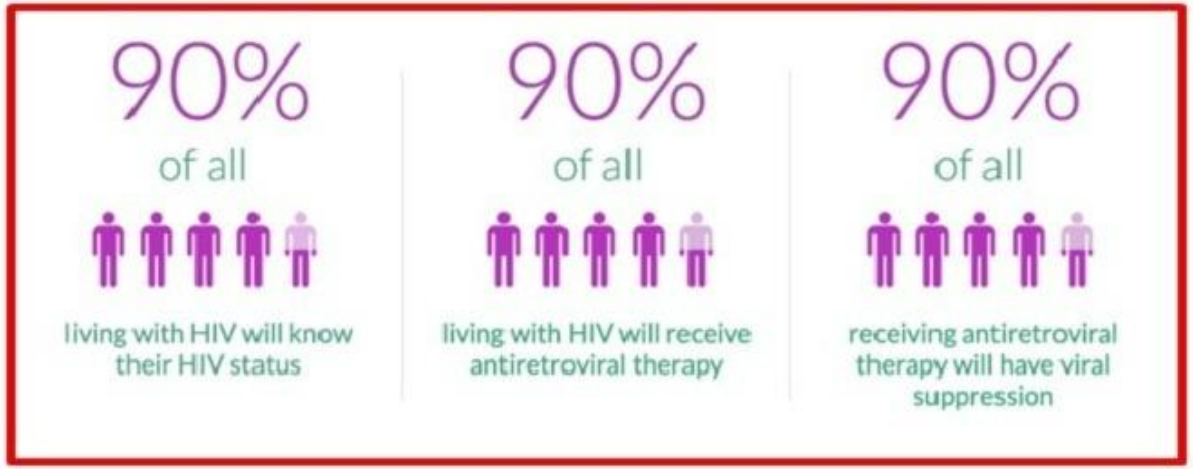
Age distribution of newly registered HIV cases in EECA (2010/2015/2017)

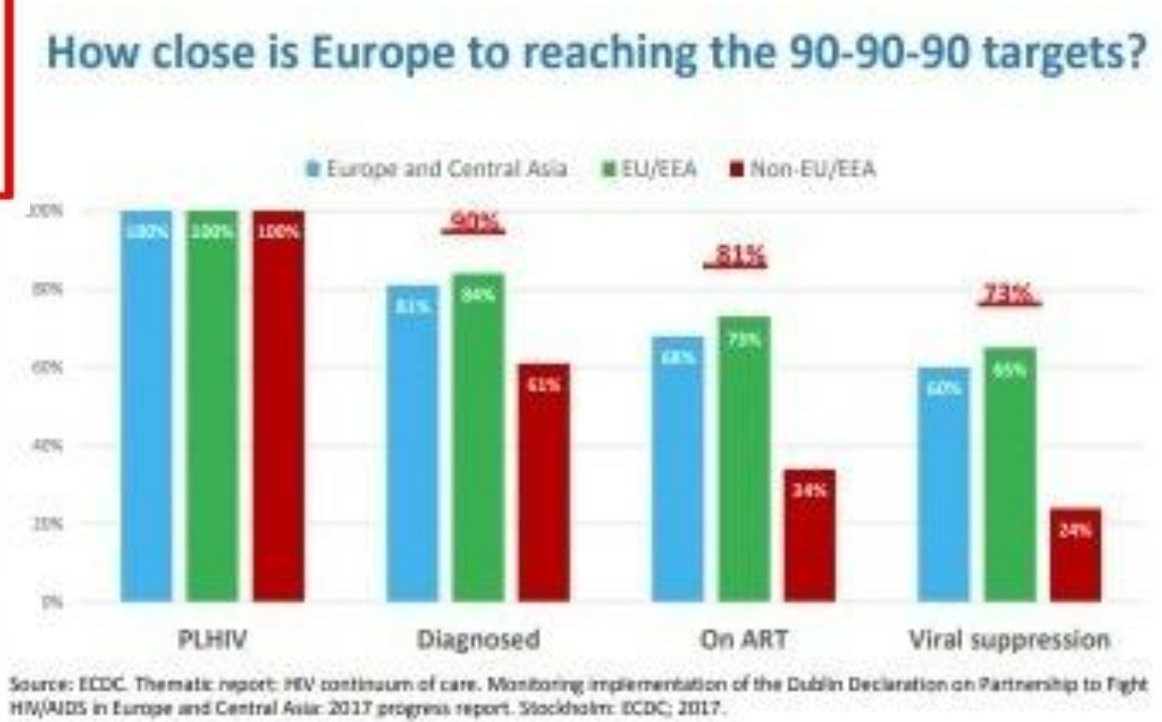


Source: UNAIDS, Vinnay Saldannha, EACS SOC;

Ageing and HIV data in EECA

90/90/90 Paradigm of Thinking





HIV, Hep C and Drug Use

HIV and Hep C among PWID

Drug use accounts for around 50% of new infections, but unprotected sex is set to become the main driver in the coming years.

One in seven people who inject drugs (PWID) is **living with HIV** and **one in three** is infected with **hepatitis C.**

Drug use and harm reduction

The region is home to an estimated **3,7 M** people who use drugs—that is **1/4** of all people who inject drugs **worldwide**.

Access to harm reduction and health services remains limited.

Source: Lena Kucheruk, EECA HIV Sustainability Summit 2022

Jules Levin

Executive Director, NATAP

Unites States of America (USA)

NATAP NATIONAL AIDS TREATMENT ADVOCACY PROJECT

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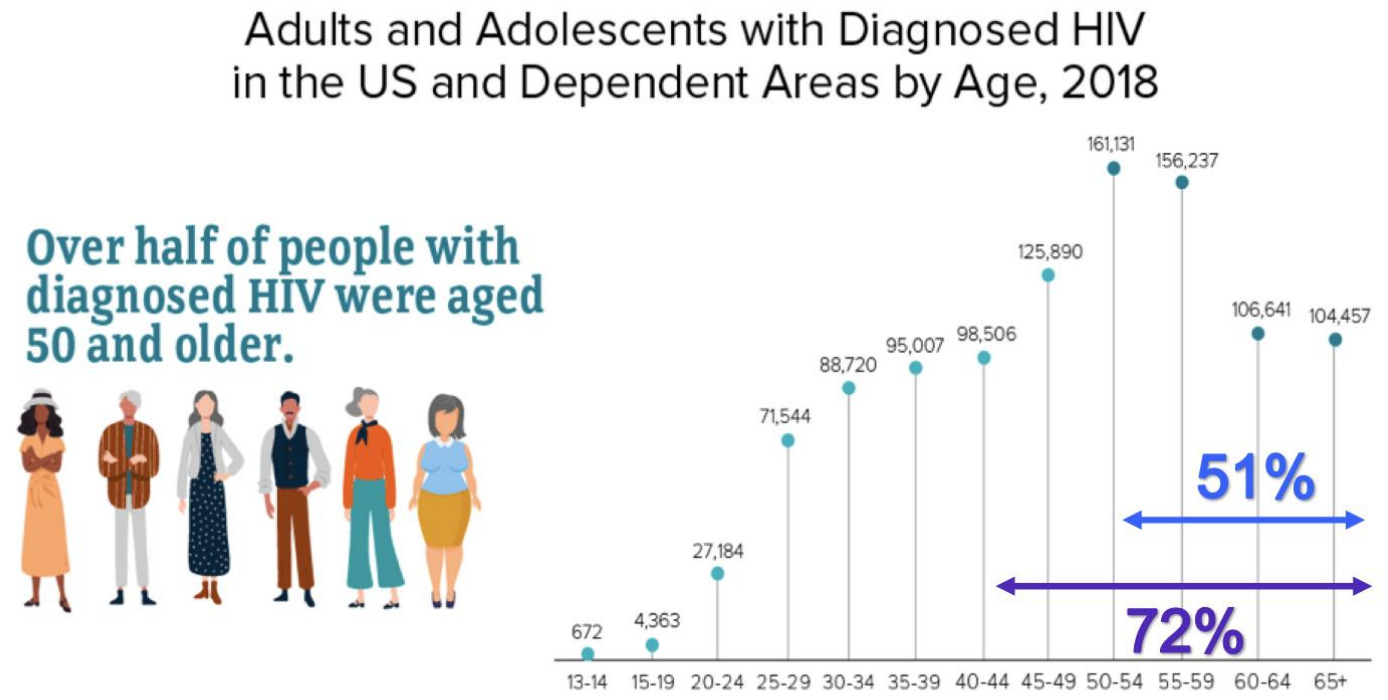
HIV & Aging Demographics - USA



Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2018 (updated). *HIV Surveillance Report* 2020;31.

- 210,000 people living with HIV in USA are over 60
- By 2030 its expected 70% will be over 50

- In NYC 30% are over 60; 50% will be over 60 by 2030

What does it mean to age with HIV in your region?

- Many older people living with HIV, and in particular the elderly (age 65+), are suffering accelerated or premature aging by 10 years
- Many of us live with more comorbidities and burden increases as we age
- We are at increasing risk for premature death, mortality – REDUCED SURVIVAL, worse quality of life, worse physical function – inability to perform normal daily activities like food shopping, food preparation – FRAILTY, and we are at increased risk for cognitive impairment & brain fog. – Becoming DISABLED and being put in long term care facilities
- Quality of life is horrible for many

What are some key issues facing older people living with HIV?

- Medicare beneficiaries 65+ years old with HIV infection are 8x more likely to have 5+ comorbidities
- People living with HIV 65+ years old are at higher risk of comorbidities than other fee-for-service Medicare beneficiaries; this has implications for the cost and health management of people living with HIV 65 years and older.

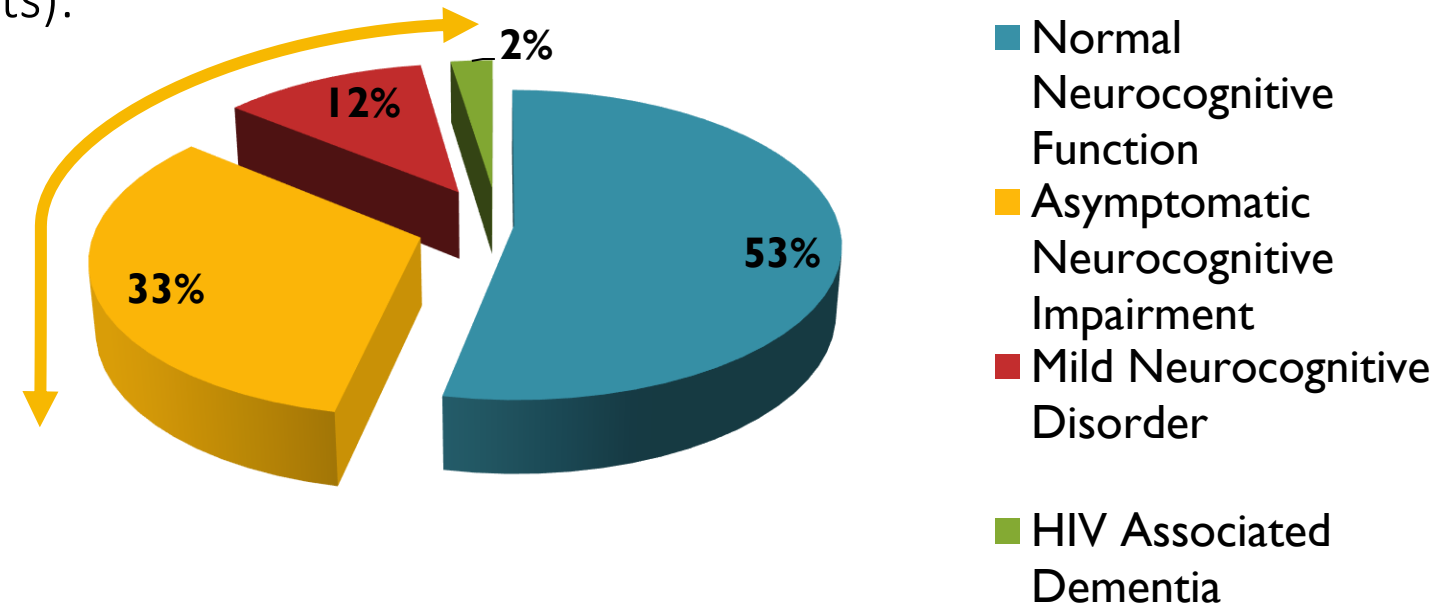
Table 2. Prevalence and unadjusted odds ratios for each of the five chronic conditions and for the number of chronic conditions as an index in Medicare beneficiaries at least 65 years old, with and without HIV infection[a].

Chronic condition[b] ($N = 29\,060\,418$)	HIV− number (%)	HIV+ number (%)	HIV+ vs. HIV− OR (95% CI)
Hypertension	21 460 895 (73.9%)	21 146 (85.5%)	2.08 (2.00, 2.15)
Hyperlipidemia	17 039 249 (58.7%)	17 759 (71.8%)	1.79 (1.74, 1.84)
Ischemic heart disease	13 476 065 (46.4%)	15 190 (601.4%)	1.84 (1.79, 1.89)
Rheumatoid/osteoarthritis	12 310 604 (42.4%)	14 277 (57.7%)	1.86 (1.81, 1.90)
Diabetes	9249 614 (31.9%)	12 181 (49.3%)	2.08 (2.02, 2.13)
Number of chronic conditions[c]			
0	3646 397 (12.6%)	1030 (4.2%)	Reference
1	3803 118 (13.1%)	2241 (9.1%)	2.09 (1.93, 2.25)
2	5883 662 (20.3%)	3760 (15.2%)	2.26 (2.11, 2.42)
3	7282 313 (25.1%)	5493 (22.2%)	2.67 (2.50, 2.85)
4	5981 919 (20.6%)	6742 (27.3%)	3.99 (3.74, 4.26)
5	2438 274 (8.4%)	5469 (22.1%)	7.94 (7.43, 8.49)

What are some key issues facing older people living with HIV?

- Current challenge (2020): persistent mild forms of neurocognitive impairment in treated HIV
- 1555 person USA urban CHARTER cohort - 71% on antiretroviral therapy (excluding most 'confounded' participants):

Many individuals with 'co-morbidities' in this cohort.



Adapted from: Heaton, et al. *Neurology.* 2010;75; 2087.
Also: Robertson, et al. *AIDS* 2007, 21:1915; Simioni, et al. *AIDS* 2010, 24: 1243.

What are some key issues facing older people living with HIV?

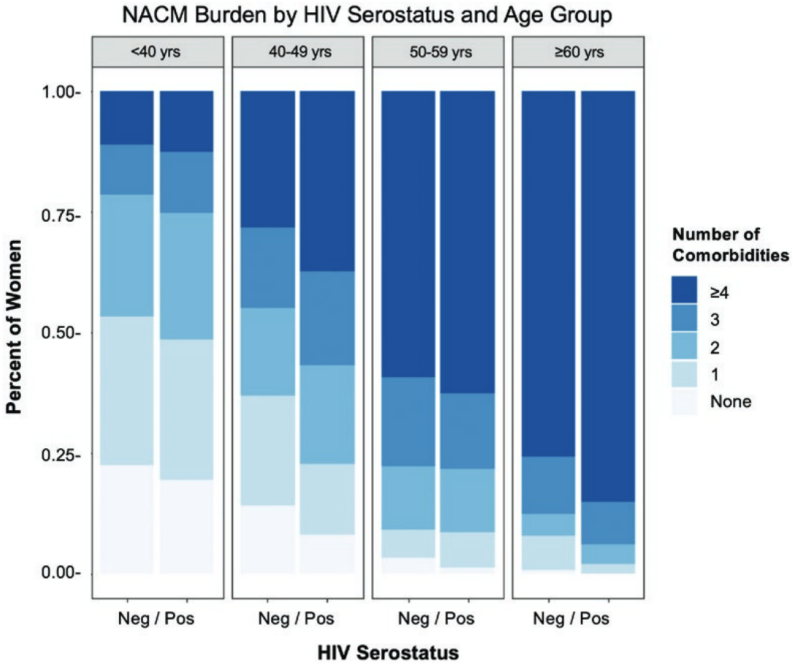
- African-Americans & Hispanics have 3.5x higher rates of comorbidities
- People living with HIV have 7x higher rates of 5 comorbidities

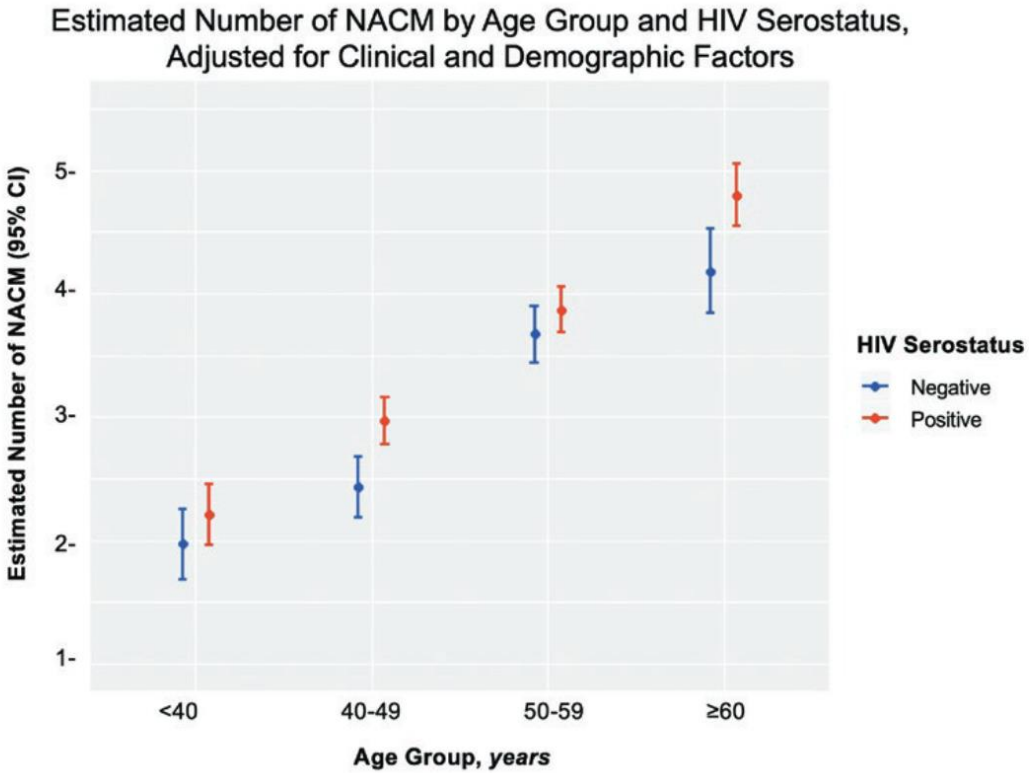
Table 4. Adjusted odds ratios for the number of chronic conditions as an index among Medicare beneficiaries at least 65 years old with HIV infection[a].

HIV+ vs. HIV− ($N = 29\,060\,402$)	aOR (95% CI)	Wald χ^2 *P*value
Number of chronic conditions[b]		
0	Reference	Reference
1	2.38 (2.21, 2.57)	<0.0001
2	2.63 (2.46, 2.83)	<0.0001
3	2.98 (2.46, 2.83)	<0.0001
4	4.13 (3.87,4.41)	<0.0001
5	7.07 (6.61, 7.56)	<0.0001
Sex		
Male	2.11 (2.06, 2.17)	<0.0001
Female	Reference	Reference
Age (for each year younger)	0.94 (0.93, 0.94)	<0.0001
Race/ethnicity		
Unknown race	0.77 (0.40, 1.48)	0.43
Non-Hispanic white	Reference	Reference
African-American	3.86 (3.75, 4.00)	<0.0001
Other race	1.16 (0.98, 1.37)	0.09
Asian/Pacific Islander	0.62 (0.60, 0.70)	0.18
Hispanic	3.41 (3.29, 3.54)	<0.0001
Native American	0.70 (0.54, 0.91)	0.007
Had dual coverage	2.31 (2.24, 2.38)	<0.0001
ESRD	1.44 (1.23, 1.68)	<0.0001

CI, confidence interval; ESRD, end stage renal disease; aOR, adjusted odds ratio.
[a]HIV+ beneficiaries were those with ICD-9-CM, or DRG codes with a diagnosis of HIV, HIV− were beneficiaries without these codes.
[b]Chronic health conditions were defined by ICD-9-CM, diagnosis or procedure codes, or HCPCS codes.

What are some key issues facing older people living with HIV?



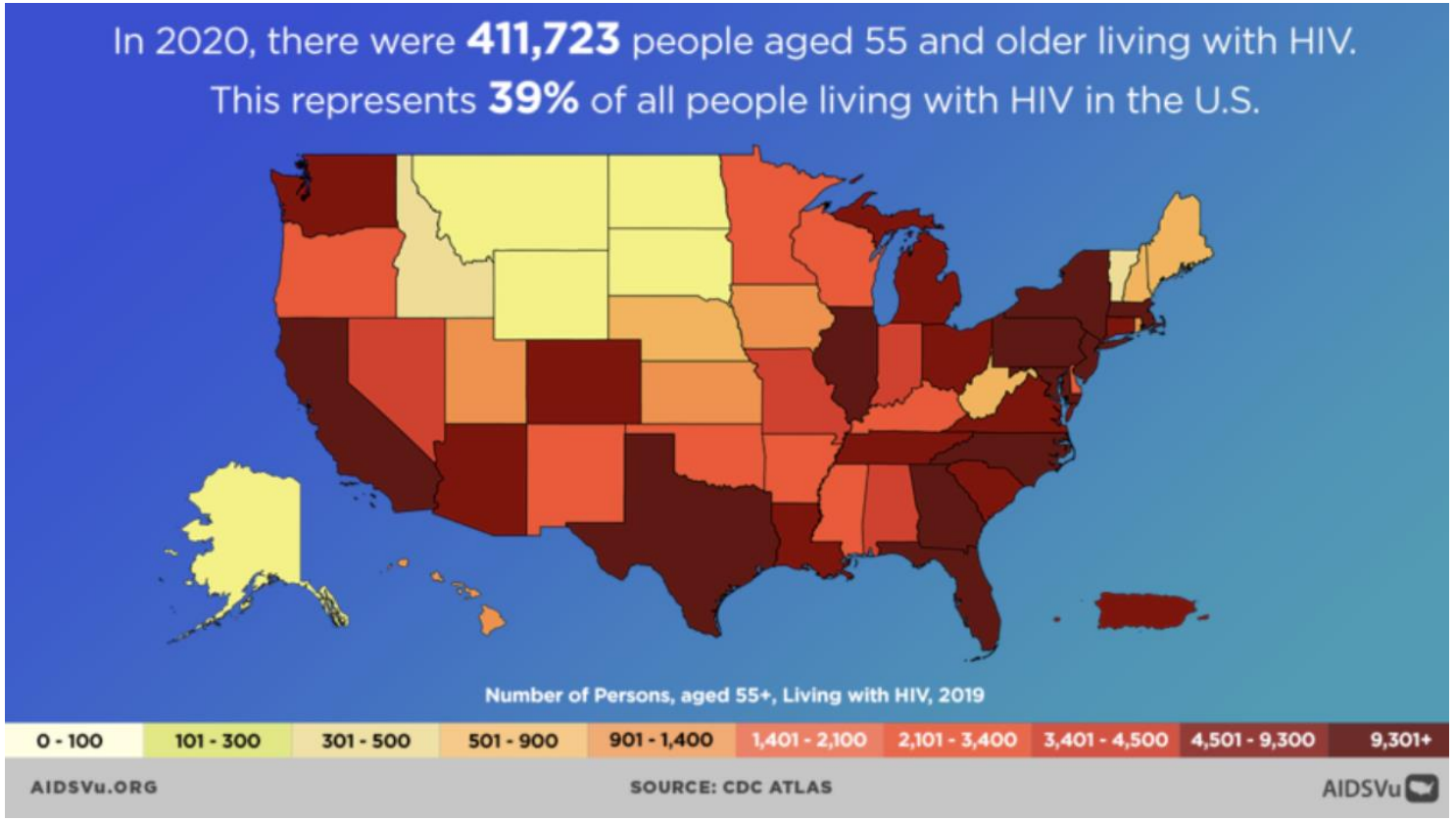


Estimated Number of NACM (95% CI)				
	<40 years	40-49 years	50-59 years	≥60 years
HIV+ women	2.21 (1.96-2.46)	2.97 (2.78-3.15)	3.87 (3.69-4.05)	4.80 (4.55-5.05)
HIV- women	1.97 (1.68-2.26)	2.44 (2.19-2.68)	3.67 (3.44-3.90)	4.19 (3.85-4.52)
P value (HIV+ vs HIV-)	0.1420	<0.0001	0.0888	0.0009

WIHS Study

- HIV+ women have greater non-AIDS comorbidity burden than HIV- women
- Number of comorbidities increases with age

What are some key issues facing older people living with HIV?



In 2020, Americans aged 55 and older represented 39% (411,723) of all people living with HIV in the U.S. rural South

What are some key issues facing older people living with HIV?

Table 2. Type of Impairment Present Among Participants with at Least One IADL Impairment

Type of Impairment	Total (N=178)	IADL impairment at baseline: 1 impaired category (N=115)	IADL impairment at baseline: ≥2 impaired categories (N=63)
Housekeeping difficulty	48%	39%	63%
Transportation difficulty	36%	25%	56%
Shopping difficulty	28%	10%	59%
Laundry difficulty	20%	4%	48%
Finance management difficulty	14%	10%	21%
Cooking difficulty	15%	7%	29%
Difficulty in using the phone	12%	2%	30%
Difficulty with medications	5%	2%	11%

ACTG HAILO Study CID Johs et al 2017.

Unable to Perform Normal Daily Activities of Living

Study participants:

- ACTG N=1015, median age=51; 15% >60

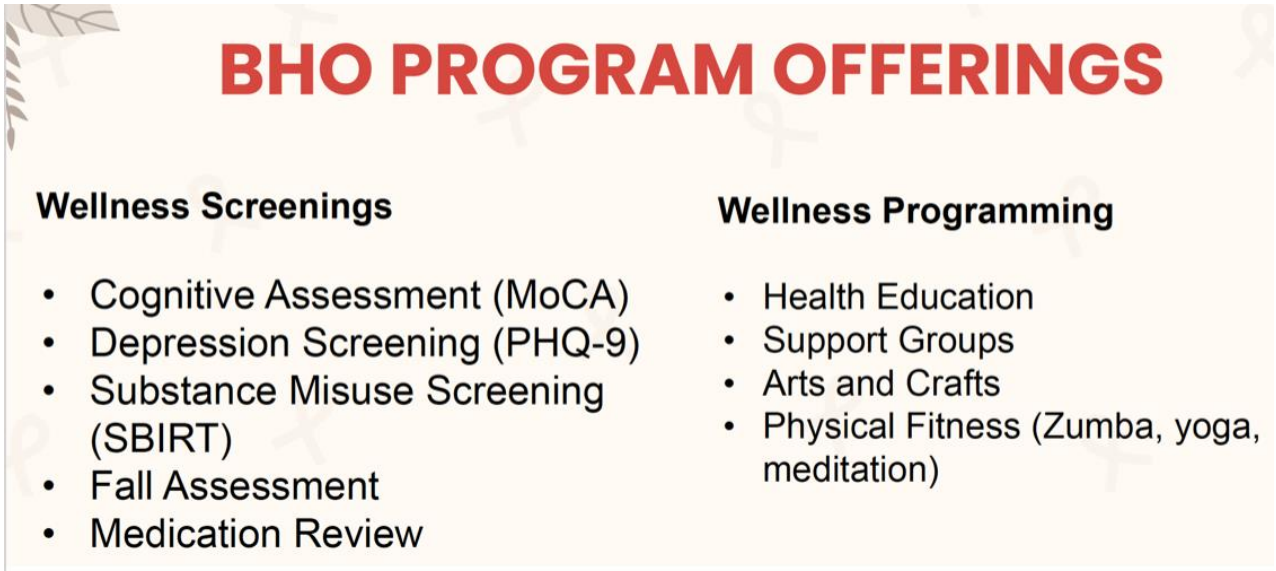
Findings:

- Strong association between disability and
  - Neurocognitive impairment (comorbidity most strongly associated with iADL risk)
  - Socioeconomic status (education, health insurance)/socioeconomic disadvantages
  - Lifestyle factors (smoking, low physical activity)
- Other factors that may contribute: inability to mobilize resources, stigma, ageism, gender identity, no family-alone, no social support, temporary disability

Initiatives in place to address these issues

23 New Aging/HIV clinics Funded & Started in USA as Demonstration Projects

- Geriatric, elder screenings, care, mental health, social support services
- NYS 10, $20 million for 5 years
- NYC 3 clinics
- National 10 clinics, $10 million, 3 years



Initiatives (not) in place to address these issues

Gaps

The HIV healthcare system does not address these problems:

- elder/geriatric screenings
- access to medications for elderly, adequate attention & care coordination

Needs

- Better care
  - funding to support healthcare change to ensure the system meets our needs
  - mental health services
- More education - older & elderly people living with HIV need to understand aging & comorbidities
- Better quality of life

Initiatives (not) in place to address these issues

- New IAS-USA HIV Treatment Guidelines not being implemented

Box 4. Recommendations for Older People With HIV

- Screening for HIV is recommended in older individuals to prevent late diagnosis with advanced disease (evidence rating: AIIa)
- Initiation of ART is recommended as soon as possible after diagnosis, either the same day of diagnosis, first clinic visit, or within 7 days. Assessment of comorbidities, kidney function, and medications will influence the choice of ART (evidence rating: AIa)
- Assessment of polypharmacy and simplification of complex regimens, both ART and comorbidity treatments, is recommended to improve adherence, prevent adverse drug-drug interactions, reduce falls risk, and reduce costs (evidence rating: AIIb)
- Screening for comorbidities, impaired cognitive and function, poor mobility, frailty, and falls risk is recommended for older people with HIV, using validated tools. The frequency of assessment is determined by the baseline assessment (evidence rating: BIII)[1]
- Consideration of integrated care models and Antiretroviral Stewardship models is recommended to improve outcomes and quality of life for people aging with HIV (evidence rating: BIII)

Geriatric Principles of Care

- Assess polypharmacy
- Assess comorbidities, kidney function & medications: simplify complex ART & comorbidity treatments
- SCREEN for comorbidities, impaired cognition & function, poor mobility, frailty, falls risk
- **Consider** Integrated Care Models

Shiba Phurailatpam

Regional Coordinator, Asia Pacific Network of People Living with HIV (APN+)

Thailand

APN PLUS

POSITIVE CHANGE

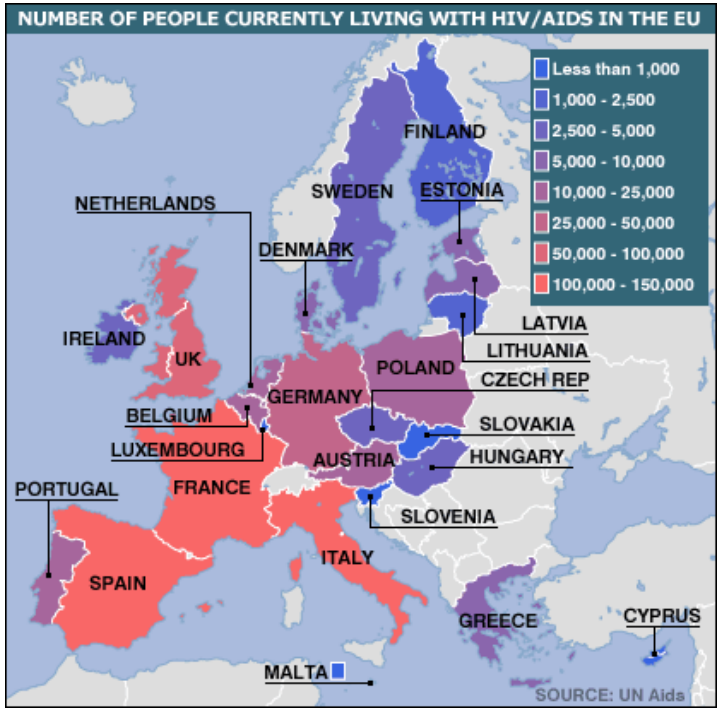
Mario Cascio

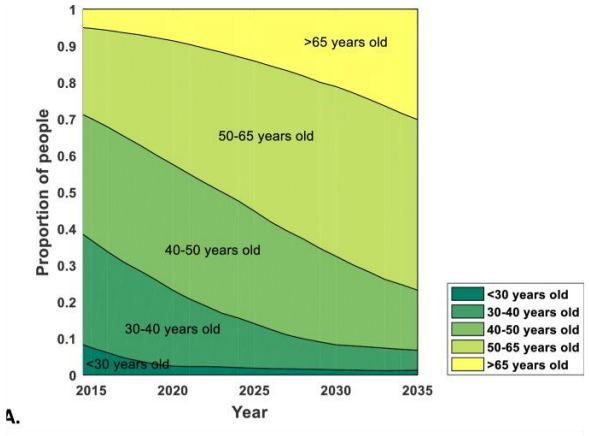
Programme Chair, Quality of Life, European AIDS Treatment Group (EATG)

Italy

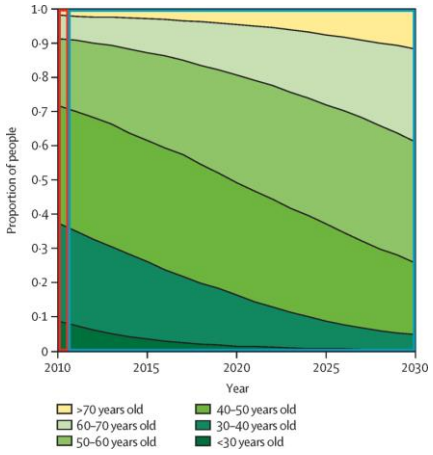
EATG European AIDS Treatment Group

Western Europe: Increasing number of older people living with HIV with multiple morbidities



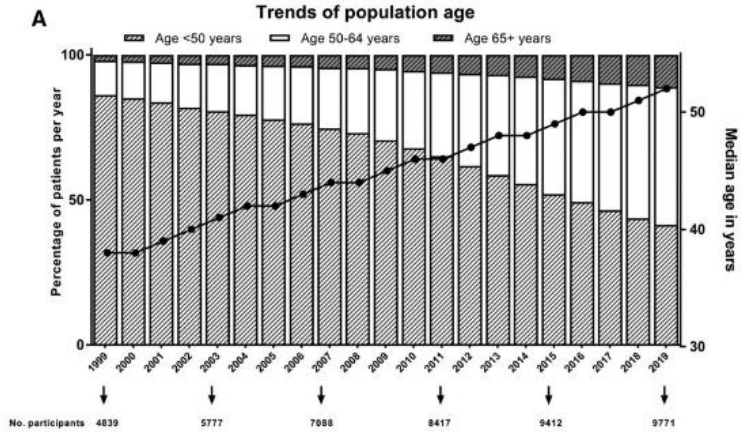


ICONA Cohort*



ATHENA cohort**

- Not just a demographic change; will require a radical change in clinical approach and pose a challenge for the social-welfare system
- It is estimated that by 2035, 76% of people living with HIV followed up in clinical centers will be aged >50 (26% >65) with 89% experiencing at least one comorbiditiy, resulting in doubling of estimated costs for the treatment of comorbidities (Italian ICONA cohort)



Swiss Cohort***

- https://doi.org/10.1371/journal.pone.0186638

** https://doi.org/10.1016/s1473-3099(15)00056-0

***https://doi.org/10.1093/cid/cir626

Increasing awareness of the emerging needs of an aging HIV population

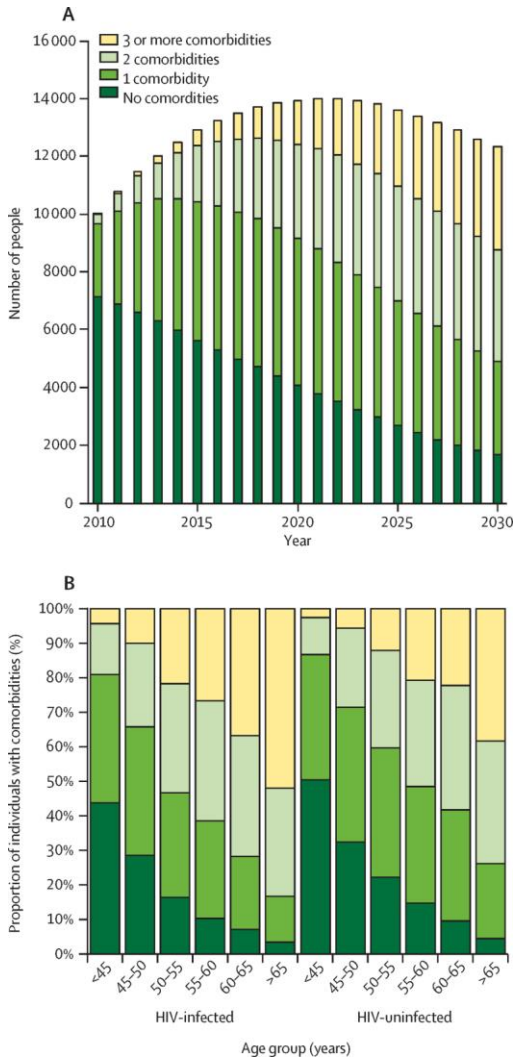
By clinicians:

who in their everyday work are dealing more with the management of comorbidities and other geriatric conditions than with HIV itself

By OALWH:

who are personally experiencing the additional burden of other health conditions such as multimorbidity, mental health problems and geriatric syndromes, strongly impacting their quality of everyday life

Loneliness, social isolation and depression are becoming part of the lives of many elderly people with HIV



https://doi.org/10.1016/j.jad.2018.12.043

https://doi.org/10.1371/journal.pone.0186638

Ongoing discussions on how to adequately address the emerging needs of OALWH

At clinical level:

Healthcare systems across Europe are very diverse from country to country. Healthcare is mostly free in Europe, guaranteeing free access to essential services, but...

Healthcare systems are not adequately structured to respond to the complexity of care for older people with HIV

What we see is:

- Gap between European guidelines (EACS) and everyday clinical practice
- Lack of integrated services, including mental and sexual health
- Lack of staff
- Lack of resources
- Lack of time to dedicate to visits
- Difficulties of HIV specialists, often acting as general practitioners
- Lack of geriatric care
- Lack of foresight and long-term vision of our decision-makers

At community level:

Organizations such as the EATG have conducted campaigns and projects raising awareness on the topic

But in general, PWH are lacking the necessary information on what ageing with HIV could mean to them and what strategies to adopt to keep themselves in good health as they reach older age.

At policy level:

In Western Europe, healthcare is governed by the single countries of the European Union. The EU complements national health policies by supporting local EU governments to achieve common objectives providing funding and guidance.

Advocacy for policy change is needed both at European and National level.

Promising practices: Implementation of integrated services and a person-centred geriatric approach

London, UK

A dedicated clinic to PWH older than 50 years was established at **Chelsea and Westminster Hospital in London, UK** in January 2009 and then extended to HIV services across the directorate.

An evaluation reviewing 10 years of activities showed significant rates of non-HIV-related comorbidities and polypharmacy in PWH > 50
The overall prevalence of polypharmacy and multimorbidity was 46.6% and 69.3%, respectively

Has lead to the implementation of clinical care pathways and new joint HIV/specialty clinics (cardiology, nephrology, neurology, metabolic, menopause, and geriatric) to improve prevention, diagnosis, and management of major comorbidities in people aging with HIV

https://www.thelancet.com/action/showPdf?pii=S2352-3018%2822%2900066-2

Modena, Italy

The **Metabolic Clinic in Modena, Italy** has been active since 2003; aims to ensure that OALWH receive integrated and holistic treatment.

A multidisciplinary staff evaluates patients' anthropometric, immune-metabolic and physical and cognitive functions
Approach combines clinical practice and educational interventions on lifestyle (i.e. exercise and nutrition) to ensure healthy ageing in PWH.

All patients over 50 undergo a "comprehensive geriatric assessment (CGA)" evaluating problems related to age, frailty, vulnerability and risk of developing disabilities.

Currently carrying out a study aimed at validating a **"virtual metabolic clinic"** to offer specific support services to infectious disease clinics in Italy.

https://hivoutcomes.eu/case_study/italy-ageing-clinics/

Advocating for policy change at European level

HIV Outcomes Policy Asks: Enhancing long-term health and well-being among people living with HIV

This HIV Outcomes policy paper highlights four key areas where action is needed to improve health and well-being among people with HIV:

- Comorbidity prevention, treatment and management
- Ageing with HIV
- Measurement of person-reported outcomes (PROs) and monitoring of HRQoL
- Combatting stigma and discrimination

1 Comorbidity prevention, treatment and management

HIV CLINICS / CARE PROVIDERS

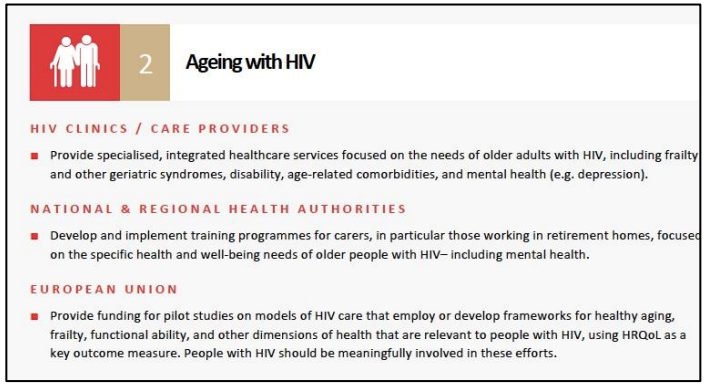
- Implement routine screening for all relevant comorbidities based on individual characteristics and needs, in line with national and international guidelines, using short, easy to administer, validated screening instruments.
  - Capture individual data on comorbidities using electronic health records as a tool to support integrated, personalised care.
  - Involve peers or community members to support with prevention, screening, treatment and management of comorbidities.

NATIONAL & REGIONAL HEALTH AUTHORITIES

- Develop/update a monitoring and evaluation framework for HIV care, incorporating indicators on comorbidities, leading causes of mortality and hospitalisation, and PROs including HRQoL.
  - Integrate the framework into the national HIV strategy and ensure funding for its implementation.

EUROPEAN UNION

- Expand the mandate of the Steering Group on Health Promotion, Disease Prevention, and Non-Communicable Diseases(NCDs) management to initiate work programmes on communicable diseases, such as HIV, including prevention, diagnosis and coordinated management of comorbidities.



2 Ageing with HIV

HIV CLINICS / CARE PROVIDERS

- Provide specialised, integrated healthcare services focused on the needs of older adults with HIV, including frailty and other geriatric syndromes, disability, age-related comorbidities, and mental health (e.g. depression).

NATIONAL & REGIONAL HEALTH AUTHORITIES

- Develop and implement training programmes for carers, in particular those working in retirement homes, focused on the specific health and well-being needs of older people with HIV– including mental health.

EUROPEAN UNION

- Provide funding for pilot studies on models of HIV care that employ or develop frameworks for healthy aging, frailty, functional ability, and other dimensions of health that are relevant to people with HIV, using HRQoL as a key outcome measure. People with HIV should be meaningfully involved in these efforts.

https://hivoutcomes.eu/update/hiv-outcomes-policy-asks/

The role of European cohorts of OALWH: POPPY, AGE$_h$IV, GEPPO, COBRA and FUNCFRAIL

- Existing aging HIV cohorts are pointing out **unmet medical needs of OALWH**
- No studies designed to detect best ART strategies in this population and various outcomes beyond viral suppresson: **frailty, geriatric syndromes, physical function, disability, quality of life and healthy aging** are still not routinely part of aging cohorts

Results from aging cohorts with outcomes that go beyond viral suppression can pave the way to health care providers to encounter unmet needs of OALWH.

https://doi.org/10.1007/s41999-019-00170-8

Albertina Nyatsi

Founding Director, Positive Women Together in Action

Eswatini

POSITIVE WOMEN TOGETHER IN ACTION

Empowering Positive Women

What aging with HIV is like in Eswatini

Aging with HIV is not easy, life is deteriorating and you feel neglected at home, community and health centre. No value.

What aging with HIV means

- Less opportunities as most are for 18-35 years old
- High catastrophic costs to care for several diseases in one body
- Core infections, NCDs, osteoporosis, eye problems, joints etc.
- Disability due to the NCDs and weak immune system due to aging
- Mental health problems (speaking loudly, isolating self)

What aging means in Eswatini

Being judged for sexual choices :

- Why get into relationship yet you are old and positive
- You now want to kill yourself you know you are sick and old
- You want to kill him
- You are sick because you have sex yet you are positive and to think sex at your age

Initiatives in place

- 3 months dispensing of NCD medication like ART
- Regular testing for NCDs
- Availability of gel but one has to ask for it
- Psychosocial support and therapy in hospitals

Priority interventions for those aging with HIV in Eswatini

- Ensure availability of HIV aging SRH affirming services
- Prevention of stock outs as sometimes for NCDs people have to buy at the chemist
- Provision of food parcels for old people living with HIV
- National regulations and guidelines for inclusive care of older people living with HIV
- Update of care protocols to meet the needs of those aging with HIV

Thank you

Ngiyabonga

Kate Murzin

National Program Manager, Realize

Canada

realize

FOSTERING
POSITIVE CHANGE
FOR PEOPLE LIVING
WITH HIV AND OTHER
EPISODIC DISABILITIES

What does it mean to age with HIV in Canada?

- We don’t have a complete picture
- 24% of new HIV diagnoses are in people age 50+ (2020); there are few inclusive, sex positive sexual health resources
- Challenging long-held definitions to avoid erasure
  - aging ≠ old, elderly, senior
  - living with HIV long-term ≠ old chronological age
- Generativity and resilience
  - Volunteerism, community-based research
- Uncertainty
  - Availability of practical and caregiving support
  - Financial instability
  - Physical, functional and cognitive changes

Public Health Agency of Canada, 2022
The Pan-Canadian Research Agenda on HIV, Aging and Older Adulthood, 2022
PANACHE Ontario Community Report, 2021

What are a few key issues facing older people living with HIV in Canada?

- Government of Canada does not disaggregate HIV prevalence data by age
- Inequitable access to services based on province/territory of residence
- Limited access to rehabilitation services (e.g., physiotherapy), vision/hearing/dental care, mental health support despite “universal” healthcare system
- Low income and food and housing insecurity; reliance on government benefits
- Intersecting forms of stigma (HIV-related, ageism, racism, homophobia, transphobia, misogyny, ableism) can limit support

Murzin et al. 2022
Furlotte 2009
Sok et al 2018

What initiatives are in place in your region, if any, to address these issues?

Research

- Pan-Canadian Research Agenda on HIV, Aging and Older Adulthood (Realize)
- CTN HIV & Aging Research Development Team
- CHANGE HIV (Walmsley), Canadian HIV & Aging Cohort Study (Durand), PANACHE (Murzin & Walmsley)

Education

- Workshops on caring for clients with HIV for staff in aging sector (e.g., long-term care, home care)
- Training for pre-entry-to-practice healthcare professionals

4th Canadian HIV & Aging Symposium

Policy

- Situational analysis of ageism in Canada's HIV, hepatitis C, STBBI response
- Some provinces now publishing prevalence data by age

Practice

- HIV & Aging specialty clinics (CHAI initiative, McGill)
- Research into social work interventions for people with HIV experiencing cognitive impairment (Eaton)
- Peer support programs for older people living with HIV in community-based HIV organizations

Eaton et al 2022
Canadian HIV and Aging Cohort Study (Durand)
CIHR Canadian HIV Trials Network - https://www.hivnet.ubc.ca/

Realize – www.realizecanada.org
CHANGE HIV: Correlates of Healthy Aging iN GEriatric HIV Study (Walmsley)

iCOPe HIV Proposed Vision, Objectives and Activities

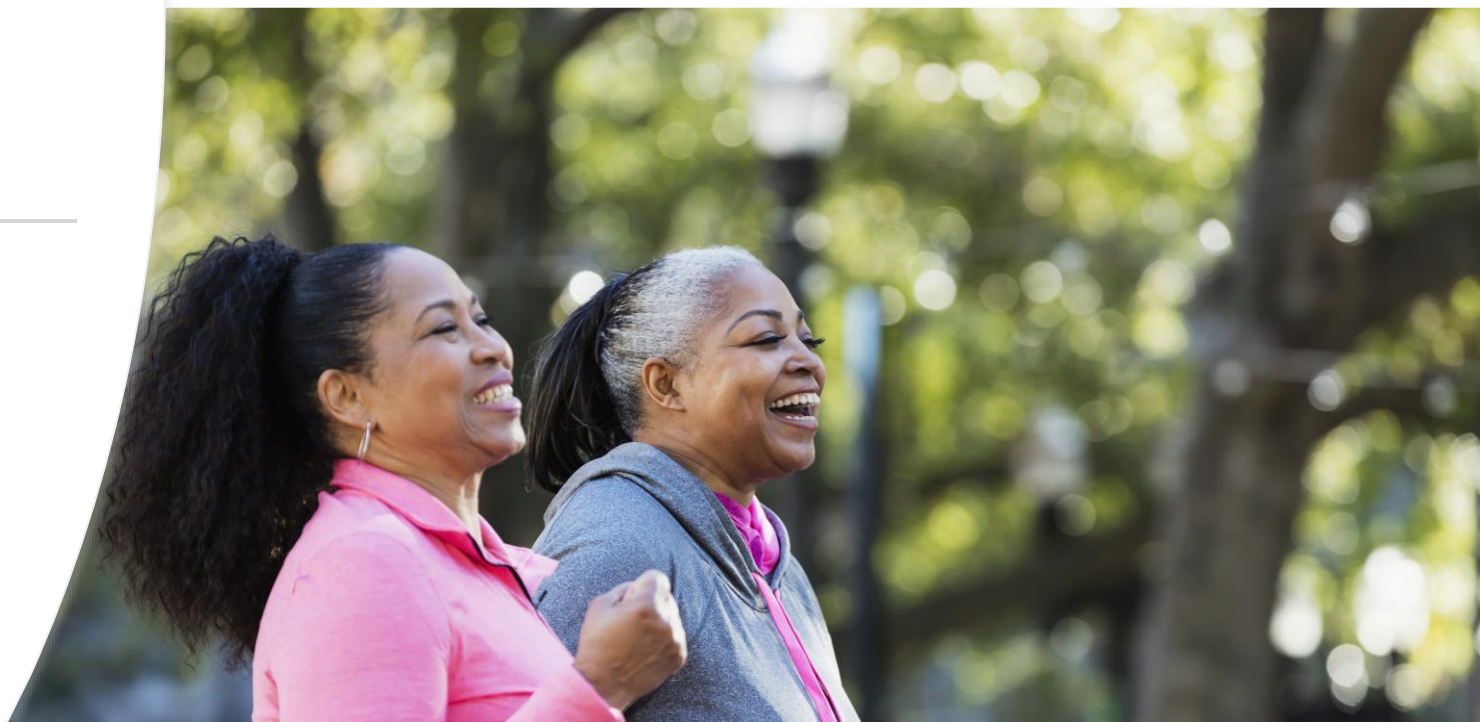
Vision

iCOPe HIV's vision is improved care, optimal quality of life, and empowerment for ageing and elderly people living with HIV around the world.

iCOPe HIV Draft Logic Model

Glasgow Manifesto	CARE Calls to Action 1-4	QUALITY OF LIFE Calls to Action 5-8	EMPOWERMENT Calls to Action 9-10	ESTABLISHING iCOPe HIV
Objective	Increase the capacity of decision-makers to implement models of care for older people with HIV based on best (and promising) practices globally.	Document priority issues affecting quality of life of older people with HIV around the world and initiatives in place to respond to these issues.	Increase knowledge among older people with HIV of age-related health conditions, geriatric syndromes and prevention and management strategies.	To increase the organizational capacity of iCOPe HIV to respond to issues related to HIV, aging and older adults.
Proposed Activities	Environmental scan to identify innovative models of care Literature review and interviews to document best (and promising) practices Produce an advocacy resource to guide decision-making	Conduct a global survey with organizations serving older people with HIV Produce survey report documenting key findings and recommendations	Identify priority topics for webinars with iCOPe member orgs Engage HIV, aging, health and quality of life experts as presenters Plan, promote, conduct and evaluate educational webinars	Recruit Steering Committee members, emphasis on inclusion Draft Terms of Reference Communications Create GM Infographic Seek funding

We want to hear from you!



Polling Questions

Which of the proposed iCOPe HIV objectives would you give the highest priority?

- Objective 1: Increasing the capacity of decision-makers to implement comprehensive models of care for older people living with HIV based on best (and promising) practices.
- Objective 2: Documenting priority issues affecting quality of life of older people living with HIV globally and initiatives that are responding to these issues.
- Objective 3: Increasing knowledge of aging-related health conditions, geriatric syndromes and prevention/management strategies among older people living with HIV.

(Multiple choice)

Feedback, ideas & discussion

Next Steps

- Additional webinar(s) focused on engagement
- Stakeholder survey
- Email communications

Thank you!

Organizations that endorsed the Glasgow Manifesto

Webinar Guest Presenters

- Dr. Luciana Spadaccini
- Brent Allan
- Shiba Phurailatpam
- Albertina Nyatsi

Realize staff for Tech Support

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