



Enhancing Quality of Life: Building Capacity to Serve People Aging with HIV and Long-Term Survivors

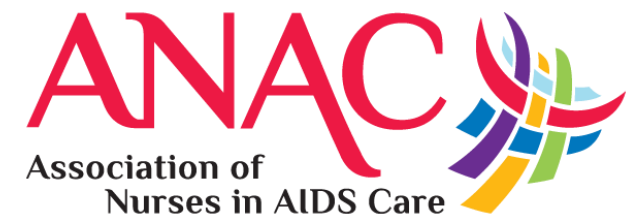
Harold J. Phillips, MRP

Paula A. Basta, M.Div

Waheedah Shabazz-El

Moderator: Ronald Johnson

June 27, 2022



Association of Nurses in AIDS Care (ANAC)

Mission

ANAC fosters the professional development of nurses and others involved in the delivery of health care for persons at risk for, living with, and/or affected by the human immunodeficiency virus (HIV) and its comorbidities. ANAC promotes the health, welfare and rights of people living with HIV around the world.

Housekeeping

- Please keep lines muted unless speaking
- Please type questions and comments in the Question or Chat area
- There will be a Q & A session at the end of the webinar, if time allows



Nursing Continuing Professional Development (NCPD)

ANAC will provide 1 contact hour of NCPD on completion of this activity.

To receive a certificate of completion, attendees must:

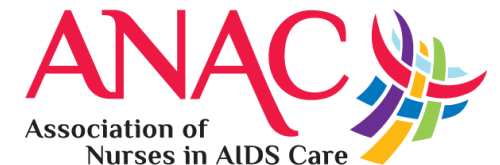
- Be registered to attend;
- View today's webinar presentation; and
- Complete the online, post-activity evaluation. You will receive a link to the evaluation by email.

The deadline to claim contact hours is 6/26/23.



ANAC is accredited as a provider of nursing continuing professional development by the American Nurses Credentialing Center's Commission on Accreditation.

NCPD questions? Email Julie@anacnet.org





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***Enhancing Quality of Life: Building Capacity to
serve People Aging with HIV and Long-Term
Survivors***

June , 2022

Harold J. Phillips, MRP

Director

White House Office of National AIDS Policy

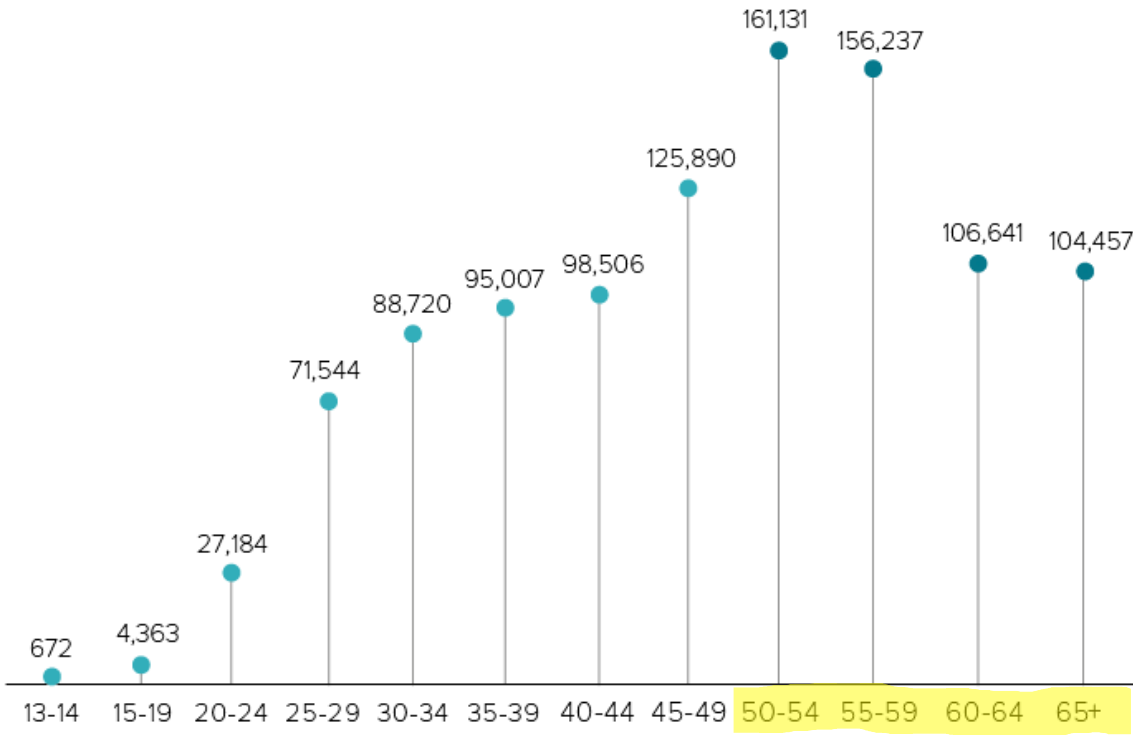


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HIV and Older Adults: The Numbers

Adults and Adolescents with Diagnosed HIV in the US and Dependent Areas by Age, 2018

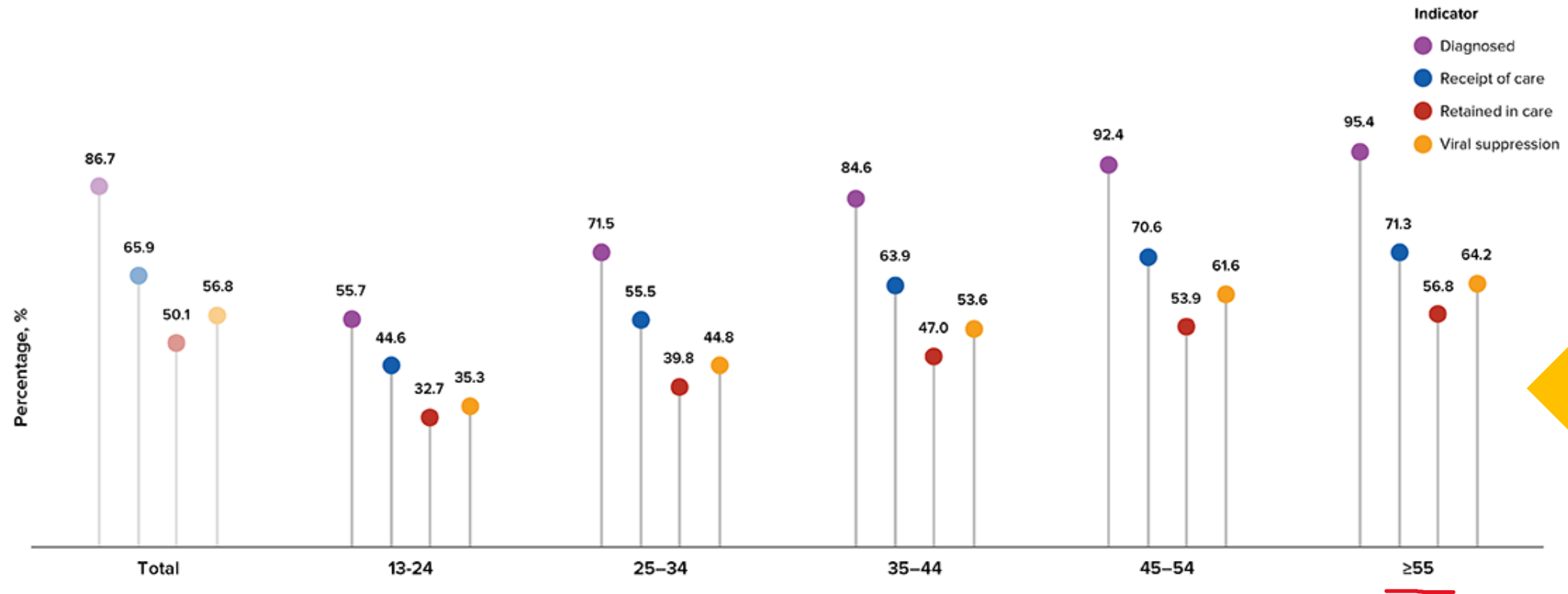
Over half of people with diagnosed HIV were aged 50 and older.



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



Figure 17. Prevalence-based HIV Care Continuum for Persons Aged ≥ 13 Years Living with HIV Infection (Diagnosed or Undiagnosed) at Year-end 2019, by Age —United States

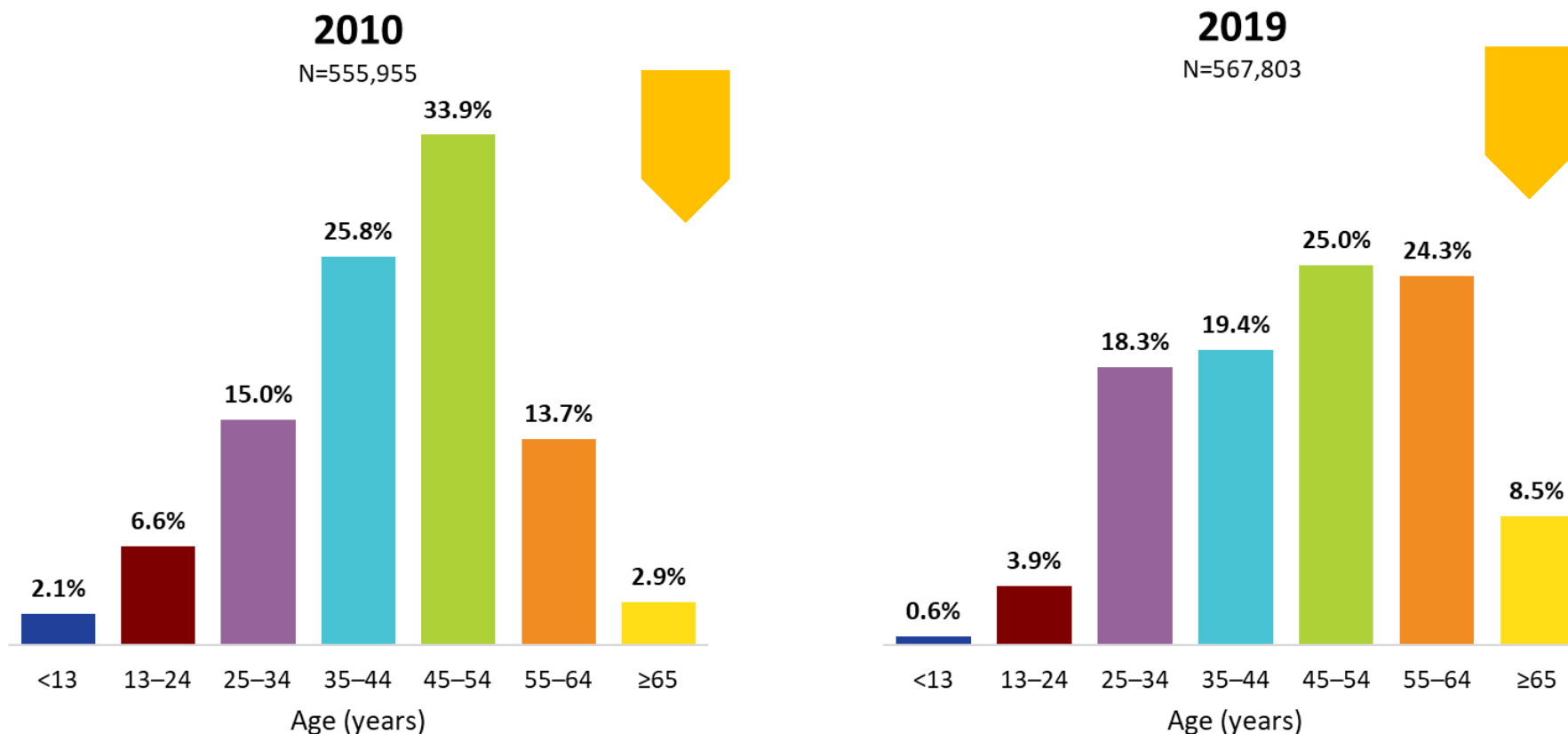


Note. See Guide to Acronyms and Initialisms, Data Tables, and Technical Notes for more information on Definitions and Data Specifications.

CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2019. *HIV Surveillance Supplemental Report* 2021;26(No.2). <http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html>. Published May 2021.



Ryan White HIV/AIDS Program Clients, by Age Group, 2010 and 2019—United States and 3 Territories

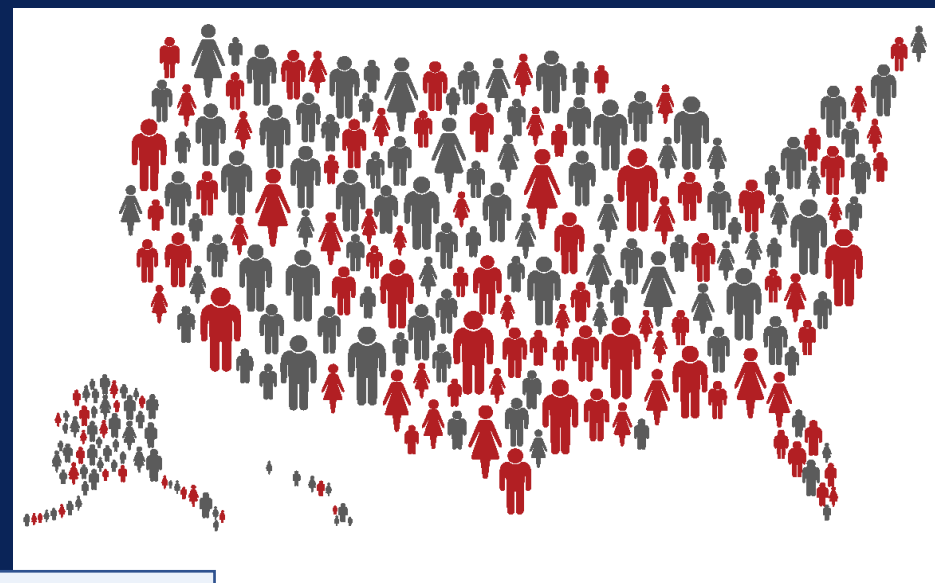


^a Guam, Puerto Rico, and the U.S. Virgin Islands.



In 2020, the RWHAP served more than half a million people in the United States and 3 territories^a

SERVED **561,416** clients in **2020**
MORE THAN 50% of people with **diagnosed HIV in the United States**



73.6%
were racial/
ethnic minorities

47.9%
were aged 50
years and older

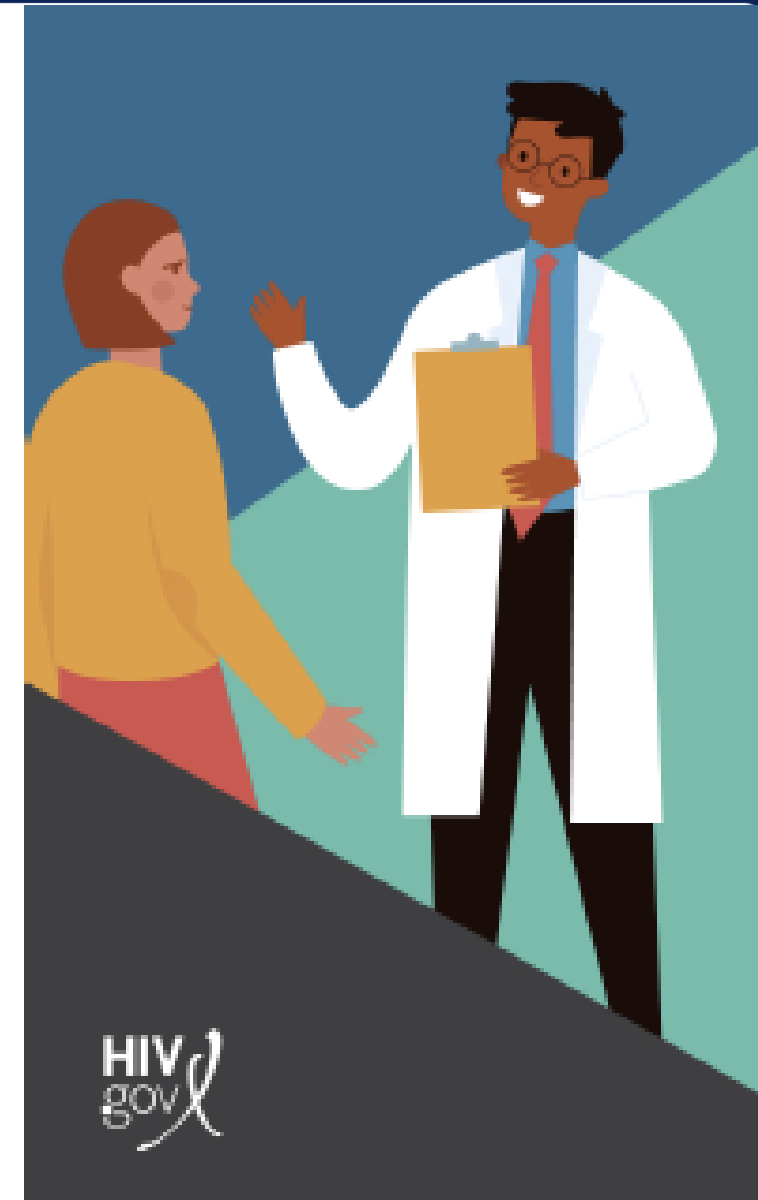
4.8%
had unstable
housing

60.9%
were living at or
below 100% of
the **Federal
Poverty Level**

^a Guam, Puerto Rico, and the U.S. Virgin Islands.

Challenges & Concerns

- Although they visit their doctors more frequently, older people and their providers are less likely to discuss sexual or drug use behaviors.
- Estimated 18,800 people >50 years old with undiagnosed HIV
- Older people in the United States are more likely than younger people to have late-stage HIV infection at the time of diagnosis.
- Stigma
- Special challenges for preventing other diseases



RWHAP HIV and Aging Initiative

- *Initiative* will strengthen the evidence base for clinical and psychosocial services that improve the lives and health outcomes of people with HIV who are aging.
- \$4,500,000 per year for three years from August 1, 2022, through July 31, 2025 (years)
- Initiative has three components:
 - Capacity-building provider – one recipient
 - Demonstration sites – 10 recipients
 - Evaluation provider – one recipient

Each demonstration site will involve people aging with HIV in the implementation, refinement, evaluation, and dissemination of the emerging strategies.

Initiative Activities:

- Implement emerging strategies that comprehensively screen and manage comorbidities, geriatric conditions, behavioral health, and psychosocial needs of people 50 years and older with HIV;
- Evaluate the impact of the emerging strategies; and
- Document and disseminate the emerging strategies.

Applications were due January 25, 2022!

HIV and Aging Resources

- **Two Reference Guides: Optimizing HIV Care for People Aging With HIV**
 - Incorporating New Elements of Care
 - Putting Together the Best Healthcare Team

<https://hab.hrsa.gov/clinical-quality-management/clinical-care-guidelines-and-resources>
- **HIV and Aging Technical Expert Panel (November 2020)**

<https://hab.hrsa.gov/sites/default/files/hab/Publications/factsheets/hrsa-aging-tep-summary.pdf>
- **HIV and Aging Manuscript (November 2020)**

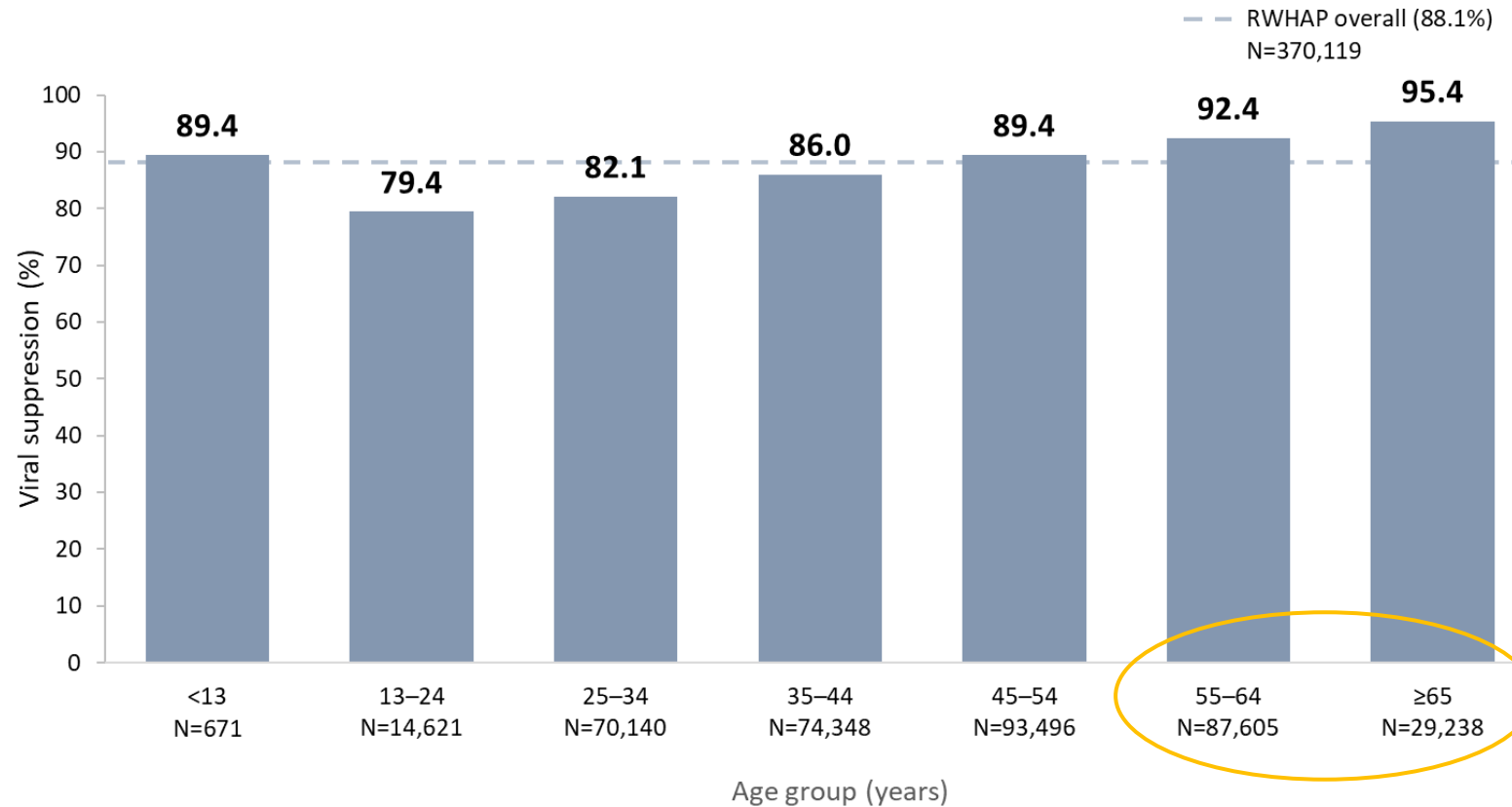
<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0241833>
- **National HIV Curriculum HIV including Older Adults Module** www.hiv.uw.edu
- **Aging and HIV National Webcasts: March & June 2020:** <https://targethiv.org/calendar/healthcare-needs-adults-hiv-who-are-aging-rwhap> and <https://targethiv.org/calendar/psychosocial-and-support-needs-people-hiv-who-are-aging-ryan-white-hivaids-program>
- **Access, Care, and Engagement Technical Assistance (ACE TA) Center** <https://targethiv.org/ace>



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Federal Activities on HIV and Aging

Viral Suppression among Clients Served by the Ryan White HIV/AIDS Program, by Age Group, 2019—United States and 3 Territories^a



N represents the total number of clients in the specific population.

Viral suppression: ≥1 OAHS visit during the calendar year and ≥1 viral load reported, with the last viral load result <200 copies/mL.

^a Guam, Puerto Rico, and the U.S. Virgin Islands.



Technical Expert Panel

Considerations for Providing HIV Medical, Psychosocial, and Support Services to People Aging with HIV

- Diversity among people aging with HIV
 - Age-related differences (50s vs. 60s vs. 70s)
 - Long-term survivors
 - Newly diagnosed
- Isolation, Loneliness, and Lack of a Social Support Network
- Workforce
- Geriatric Multidisciplinary Approach to Health Care

[Optimizing HIV Care for People Aging with HIV: Incorporating New Elements of Care](#)

[Optimizing HIV Care for People Aging with HIV: Putting Together the Best Health Care Team](#)



Addressing the Health Care and Social Support Needs of People Aging with HIV

Technical Expert Panel Executive Summary

- This Technical Expert Panel (TEP) Executive Summary includes the following sections:
- Considerations for providing HIV medical, psychosocial, and support services to people aging with HIV;
 - Opportunities for improving health care services and social support for people aging with HIV;
 - How RWHP recipients can improve services for people aging with HIV; and
 - Workforce issues.

The Ryan White HIV/AIDS Program: Serving People Aging with HIV

- In 2019, almost half (46.8 percent) of RWHP clients were aged 50 and older, the majority of these clients were aged 50–59 years, 28.5 percent of all RWHP clients. Nearly 10.0 percent of RWHP clients were aged 60–64, and 8.5 percent were aged 65 and older.
- The majority of older RWHP clients are male, approximately 71.0 percent of clients aged 50 years and older.
- Almost 70.0 percent of these clients are from racial and ethnic minority populations, the vast majority being Black/African American.

Considerations for Providing HIV Medical, Psychosocial, and Support Services to People Aging with HIV

Panelists identified issues that relate to aging in general, aging issues specific to people with HIV, and the provision of services to people aging with HIV.

HIV-Related and Age-Related Stigma. Almost 40 years into the HIV/AIDS epidemic, HIV-related stigma is still a barrier to care for people with HIV. Stigma toward people who are older, also known as ageism, on the part of the general public and service providers can influence a person's willingness to access and remain in care. Negative preconceptions exist about older adults in terms of their ability to carry out the activities of daily life and their ability to make decisions related to their care and life.

Perceptions and Realities About Aging. Panelists discussed that to effectively serve older individuals, whether they are HIV positive or not, clinicians must first understand each individual's attitude toward aging. Some people, no matter their age, resist accessing services for older patients. Their perception is that they do not feel old and do not want to be viewed as old. Clinicians and other service providers need to take into consideration patients' attitudes toward aging, as well as their physical and mental health and social support needs, and not base assessments strictly on age.

Increasing Demands for Care as the United States' Population Ages. Panelists emphasized that the United States lacks the capacity to meet the health and social service needs of an aging population. Most significantly, there is a shortage of geriatricians. Primary care physicians lack the skills and time to address the needs of aging patients and do not routinely conduct the necessary screenings for this population. Panelists discussed that although some RWHP clients do see a geriatrician, HIV and geriatric care may not be well coordinated. Also, people aging with HIV need access to additional specialists (e.g., cardiologists, endocrinologists, rheumatologists).

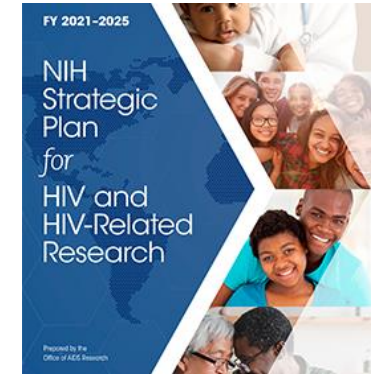


The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau (HAB), which oversees the Ryan White HIV/AIDS Program (RWHP), convened a Technical Expert Panel in November 2020. It explored the health care and social support needs of RWHP's aging population, with a focus on the barriers to and strategies for providing services. Twenty panelists representing people with lived experience, federal partners, state and local health departments, health care providers, researchers, and peer support organizations took part in the discussions.

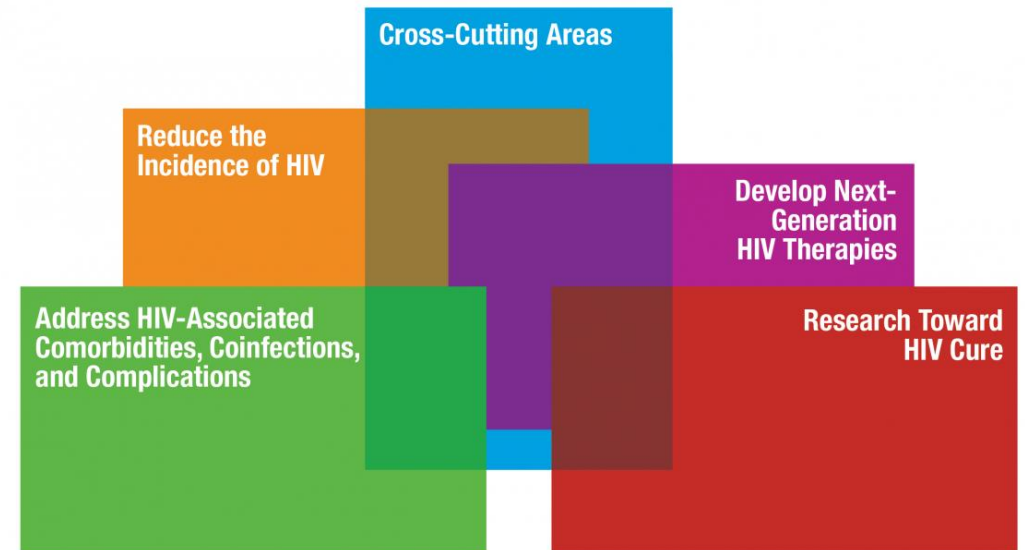


NIH

Priorities NIH's Strategic Plan for HIV Research



- Reduce incidence of HIV
- Develop next-generation HIV treatments
- Conduct research toward an HIV cure
- Address HIV-associated comorbidities, coinfections, and complications
- Cross-cutting areas



Veterans Affairs

Serving Large Number of Veterans, Research Informing All

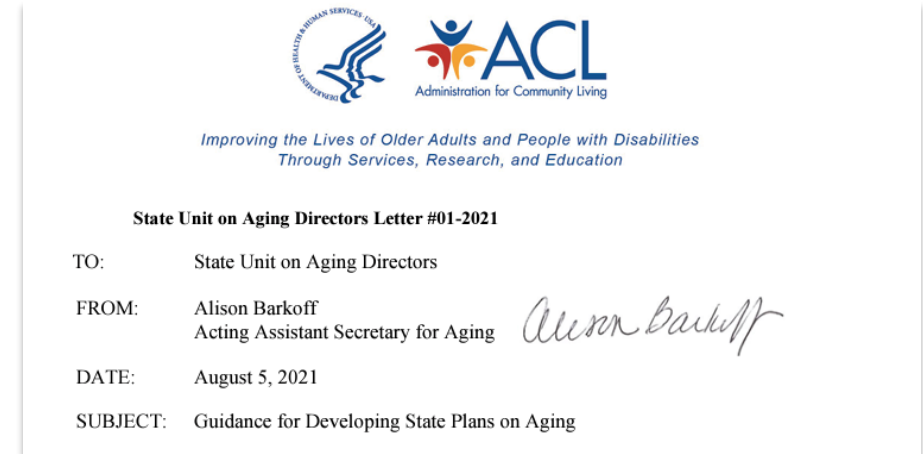
- Largest single system provider of HIV care in the country
- High viral suppression rates among veterans with HIV in care
- Veterans Aging Cohort Study (VACS)
 - Started in 1997
 - >40,000 HIV+ veterans in observational cohort
 - Objective: to understand the role of comorbid medical and psychiatric disease in determining clinical outcomes in HIV infection



New Guidance for State Aging Plans

- Older adults in greatest social need includes LGBTQ+
 - AoA supports technical assistance via [National Resource Center on LGBT Aging](#)
- Include plans and measures the state will use to demonstrate its progress towards serving older adults living with HIV/AIDS

[https://acl.gov/sites/default/files/about-acl/2021-08/State%20Plan%20Guidance Plans%20Due%20Oct%202022%20-%20ACL%20SUA%20Directors%20Letter%20%2301-2021.pdf](https://acl.gov/sites/default/files/about-acl/2021-08/State%20Plan%20Guidance%20Plans%20Due%20Oct%202022%20-%20ACL%20SUA%20Directors%20Letter%20%2301-2021.pdf)





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Implementing the National HIV/AIDS Strategy: Aging with HIV

NHAS QoL Indicator Listening Session

National HIV/AIDS Strategy (2022-2025)

Reflects President Biden's commitment to re-energize and strengthen a whole-of-society response to the epidemic while supporting people with HIV and reducing HIV-associated morbidity and mortality.



Elements of the National HIV/AIDS Strategy

- 1 vision
- 4 goals
 - 21 objectives
 - 78 strategies
- 8 priority populations
- Indicators of progress
 - 9 core indicators
 - 8 disparity indicators
 - **1 developmental indicator**

NATIONAL HIV/AIDS STRATEGY



for the **United States**
2022–2025



Goal 2: Improve Health Outcomes for People with HIV

Objective 2.5

Expand Capacity to provide whole-person care to older adults with HIV and long-term survivors

1. Identify, implement and evaluate models of care that address aging-related issues
2. Identify and implement best practices to address Behavioral health and psycho-social needs
3. Increase capabilities of providers of social services used by older adults such as senior services, housing services, and disability services to support older people with HIV
4. Promote research into aging-related conditions in people with HIV of all ages
5. Encourage multi-agency, multi-sector collaborations to support the ability to age with HIV



NHAS Federal Implementation Plan – Agency Action Items to Implement Strategies

The NHAS details 21 objectives and 78 strategies for federal and nonfederal stakeholders to implement to achieve the Strategy’s goals.

National HIV/AIDS Strategy	Federal Implementation Plan
<p>Goals: Broad aspirations that enable a plan’s vision to be realized</p> <p>Objectives: Changes, outcomes, and impact a plan is trying to achieve</p> <p>Strategies: Choices about how best to accomplish objectives</p>	<p>Action Steps: Specific activities that will be performed to implement the strategies and achieve the goals of the plan</p> <p>Progress Reports: Reports on progress, successes, and challenges</p>

NHAS Federal Implementation Plan will detail the action steps that Federal Departments and agencies will take to implement the strategies and achieve the goals of the NHAS.



Quality of Life Indicator Work Group

Developmental Indicator:

“[Q]uality of life for people with HIV was designated as the subject for a developmental indicator, meaning that data sources, measures, and targets will be identified and progress monitored thereafter.”

ONAP convened a work group to lead development of the indicator

- Co-chairs:
 - Kate Buchacz, PhD, Acting Team Lead for Treatment Research Team, HIV Research Branch, Division of HIV Prevention, CDC
 - Norma Harris, PhD, MSPH, Associate Director for the Office of Performance Improvement (Acting), Division of HIV Prevention, CDC
 - Marlene Matosky, MPH, RN, Chief, Clinical and Quality Branch, Division of Policy and Data, HIV/AIDS Bureau, HRSA
- Members represent 8 federal agencies: ACL, CDC, HRSA, 3 NIH institutes/offices, SAMHSA, and DOJ



Charges to the QoL Indicator Work Group

1. Develop the NHAS indicator on quality of life (QoL) among people with HIV using existing data sources
 - a. Consider various approaches to this
 - b. Assess available data options and select best source(s)
2. Engage HIV community members in developing the QoL indicator
3. Ensure there is a connection between the indicator and the ability of agency programs to help move the QoL indicator in the right direction (discussion with the full NHAS Federal Implementation Workgroup so that they can consider agency actions as they implement the Strategy)
4. Recommend to ONAP/FIW other aspects/dimensions of QoL that could be addressed through other federal action items and/or complementary sources of data



Summary of the process to date

- In February 2022, ONAP convened the QoL FIW
 - The agencies represented on the QoL FIW include HRSA , SAMHSA, ACL, NIH, DOJ, and CDC
- On February 23, 2022, ONAP hosted a community engagement meeting
 - Community members expressed a strong desire for ONAP to consider including other factors that influence quality of life, including social determinants of health (e.g., unemployment, food insecurity, housing instability) and not solely focus on HRQOL for the NHAS quality of life indicator work.
- The QoL FIW has met 2-4 times each month since community meeting to review, discuss and prioritize candidate measures for QOL-related indicators across multiple domains (physical, mental/emotional, social and structural/subsistence)
- In addition to data from the MMP, data from a NIH cohort (CNICS) of PWH are also being considered.

Quality of Life – domains and concepts

Physical

e.g., mobility, physical pain

Mental/Emotional

e.g., cognition, mood disorders

Social

e.g., social support, isolation

- **Cross-cutting components and into broader QOL:** e.g., life satisfaction, fatigue, vitality, sexual health and partner intimacy, SES/financial security, independence, religious/spiritual satisfaction
- **For persons with HIV – early in the epidemic thru today – specifically:**
 - physical limitations/impairments with immunodeficiency or AIDS
 - access to and impact of HIV medical care
 - benefits and complications of ART
 - comorbidities with aging
 - HIV-related stigma
 - provider trust

Note: 3 Blue boxes represent key domains of Health-Related Quality of Life



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Whole-person Care For Older Adults Living With HIV & Long-term HIV Survivors.

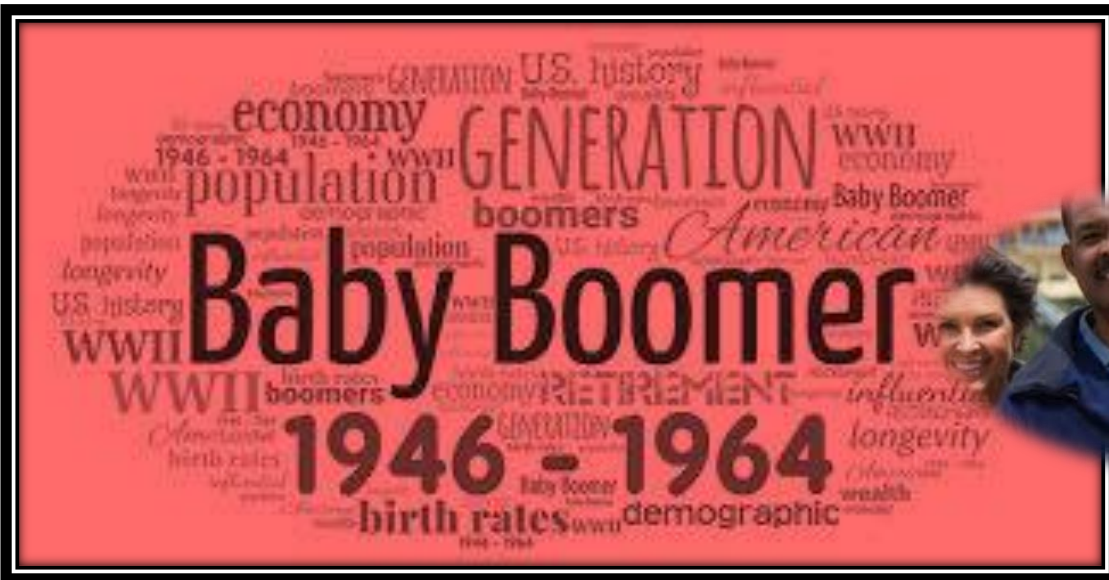
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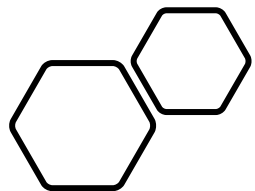


The first cases of what would later become known as AIDS were reported in the United States (U.S.) in June of 1981. Today, there are more than 1.2 million people living with HIV in the U.S. and there are more than 35,000 new infections each year. Jun 7, 2021

41 calendar years later, here we are:



HIV, AIDS

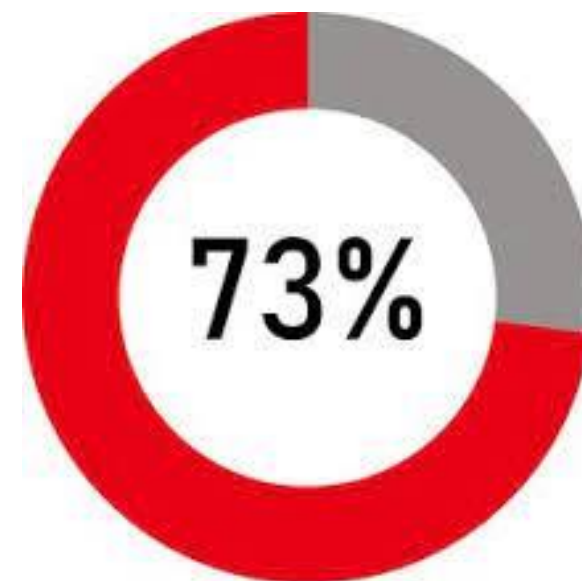


According to Gilead –HIV- Age –Positively Report

<https://www.gilead.com/-/media/files/pdfs/other/GILEAD-HIV-Age-Positively-Report.pdf>



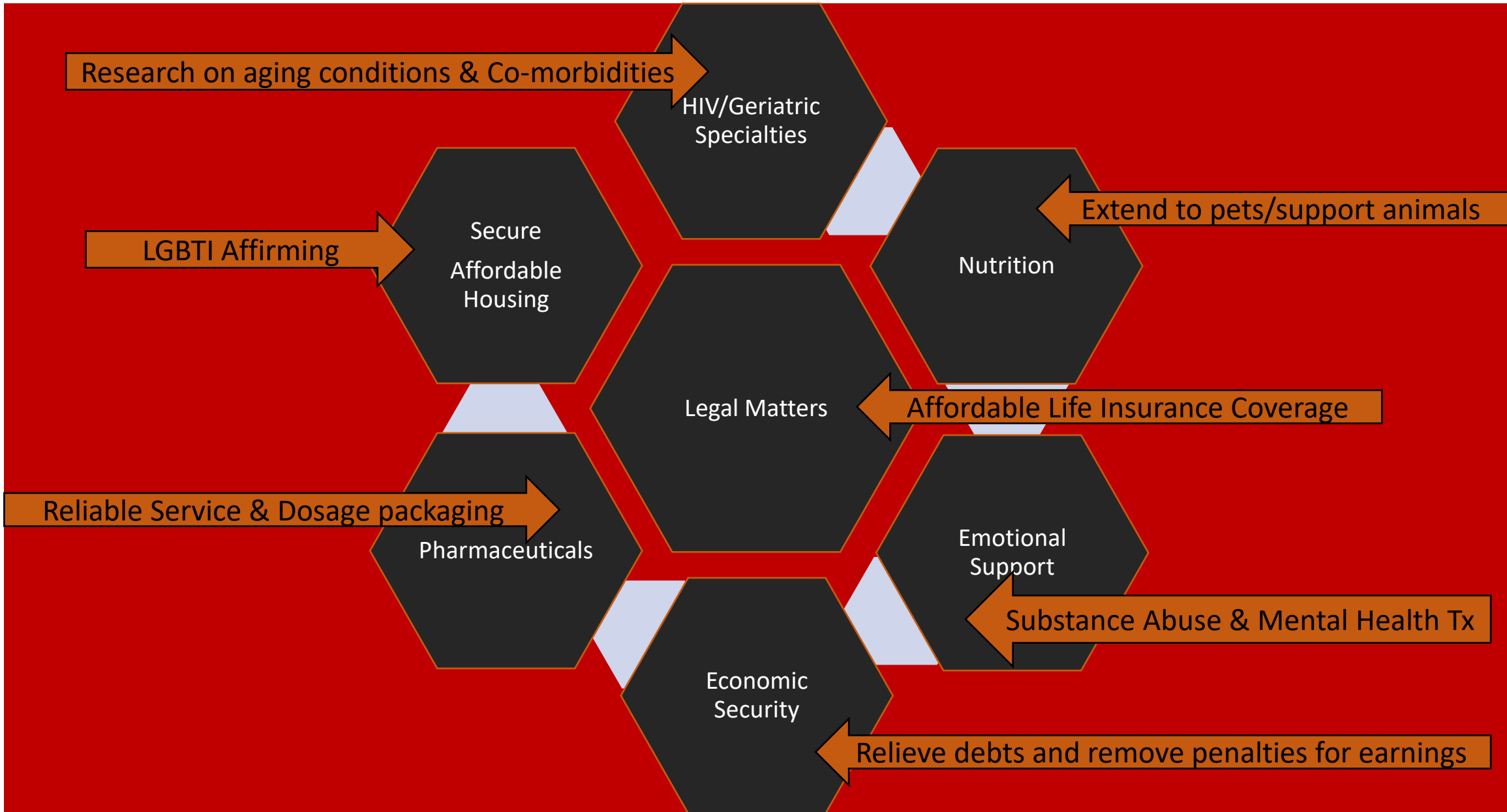
- Over 60% of people living with HIV in 2020 were over the age of 50.
- By 2030, at least 73% of people living with HIV will be over the age of 50.



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- “We are **more** than our diagnosis; we need to be seen in our entire humanity
- While good blood work may be an indicator of effective treatment, it is not an accurate indicator of our quality of life.”

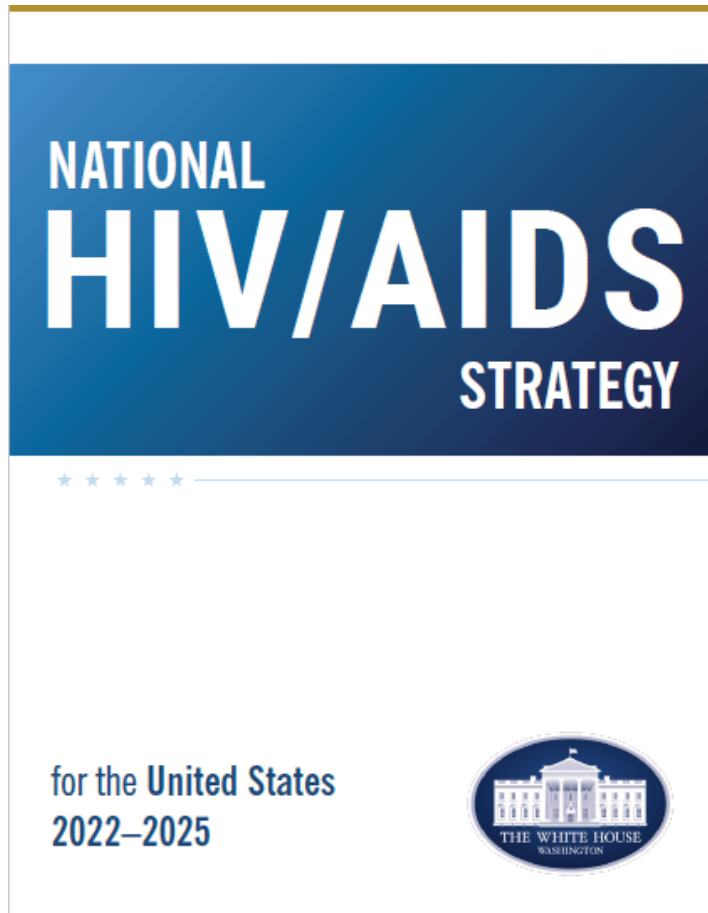






Too much *Red Tape*...
Sadly, many die waiting.

Goal 2: Improve HIV-Related Health Outcomes of People with HIV



- Objective 2.5, “Expanding the capacity to provide whole-person care to older adults with HIV and long-term survivors.”
- 2.5.2) Identify and implement best practices related to addressing psychosocial and behavioral health needs of older people with HIV and long-term survivors including substance use treatment, mental health treatment, and programs designed to decrease social isolation.

NATIONAL
HIV/AIDS

STRATEGY

Address Frailty

- Optimize collaborative multi-agency and multi-sectoral approaches and strategies to **support healthy aging with HIV.**

for the **United States**



Recommendations:

- **Regulatory Life Insurance:**

- Feeling death was eminent, many sold their life insurance policies in the early days.
- HIV, has since been classified as a “chronic manageable condition” PLHIV, older adults living with HIV and long-term HIV survivors should have access to affordable- meaningful policies.

- **Economic Justice -tangible relief**

- Debt relief/forgiveness
- End threats to benefits- should a person attempt to return to the work-force.

- **HOPWA**

- Advance from perpetual rental assistance to implement homeowner initiatives/opportunities for older adults living with HIV and long-term HIV survivors.

Thank you

<https://www.hivcaucus.org/>

<https://www.reunionproject.net/>



waheedahtheLegend@gmail.com

Link to Claim Contact Hours for Today's Webinar

<https://www.classmarker.com/online-test/start/?quiz=eth62a7497257e0a>