HIV HEALTH EQUITY

MEETING OUR OBLIGATION TO CARE FOR PERSONS AGING WITH HIV

For the Aging and HIV Working Group of the Federal AIDS Policy Partnership (FAPP)

SEPTEMBER 2025

PREPARED BY

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Federal AIDS Policy Partnership
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Acknowledgements

The FAPP Aging Working Group acknowledges with gratitude the work put into developing this policy brief by the following individuals: Tom J. Villa, Jules Levin, Jeff Berry, Jeff Taylor and Ronald Johnson. We also appreciate the document revision and approval from the members of the Aging Working Group.

Background

During the forty-plus years since the start of the HIV pandemic, major advances in science and medicine have transformed HIV into a manageable chronic disease for many PWH, at least for persons with access to anti-retroviral therapy (ART) and the necessary healthcare and support services. Despite very early ART there is persistent low-grade inflammation (29), and persistent inflammation can be linked to increased risk for premature multimorbidity and premature death (30).

But many in the now aging and elderly HIV population are suffering as they did in the early days of the HIV epidemic; except this time it's due to accelerated or accentuated aging, immunosensencence (premature aging of the immune system) and higher rates and earlier onset of often disabling comorbidities, severely reduced quality-of-life (QOL) for many — worse than in the uninfected general population, as well as premature disability and death (24, 31) for many. In this section we review the health and care challenges that older, elderly, and aging PWH and long-term survivors are facing currently and future projected worsening of this unaddressed crisis — which includes NOT getting good and adequate care in HIV and Ryan White Clinics. In the following section is our plan for a response from federal HIV authorities we require to meet this problem.

In this section we review the health and care challenges that older, elderly, and aging PWH, long-term survivors are facing currently and future projected worsening of this unaddressed crisis – which includes NOT getting good and adequate care in HIV and Ryan White Clinics.

As part of the required solution, we request a federal "HIV Aging Czar" and a Task Force that includes the affected PWH community working directly with an HIV Aging Czar and able to forge solutions across the various hetetofore fiefdoms of agencies and institutes. The federal response to the HIV aging crisis has been undermined by the siloing of NIH institutes and agencies, and not working collaboratively. Indeed there is evidence that improved focus on timely aging screening and care can in fact improve outcomes, as MAC-WIHS sees reduced impairments in their aging cohort populations, due to the full implementation of screening for cognitive impairment and additional aging screenings. This approach could be duplicated and integrated into the Ryan White and HIV clinics system.

Plus, implementation research can be integrated into both care and ACTG research, but only if we break down the siloing between agencies and institutes, and allow for collaboration, which could be facilitated by an "Aging CZAR", and a task force that includes the PWH community.

Neurocognitive impairment (NCI) is another major complication of HIV and is associated with depressive symptoms, decreased daily functioning, and poorer quality of life; from an NIH funded study (34). Depression and cognitive impairment are prevalent conditions among PWH with 41% of PWH study participants meeting criteria for global NCI, and rates of domain-specific NCI ranged from **38.6% (learning) to 25.0% (processing speed).** With respect to depression, 56.6% met criteria for lifetime major depression disorder (MDD, 8.1% met criteria for current MDD. **38.6% (learning) to 25.0% (processing speed).** With respect to depression, 56.6% met criteria for lifetime MDD, 8.1% met criteria for current MDD. Depression and NCI are a prevalent pair of comorbidities among PWH, likely attributable to several common factors, including common neurobiological pathways (e.g., dopaminergic changes, neuroinflammation); common psychosocial determinants (e.g., poverty, stress, discrimination, childhood trauma); and (3) common behavioral symptoms (e.g., substance use, ART nonadherence, sleep disturbance, poor nutrition). Depression remains a common and serious comorbidity in PWH. The prevalence of depression among PWH is two-fold to four-fold higher compared to the general population. (10–13) Studies estimating the national prevalence of depression in PWH indicate that approximately one-quarter of PWH have symptoms of current depression and 42% have a diagnosis of lifetime depression, with higher rates among men who have sex with men living with HIV(19) and women with HIV.

The aging/HIV population is half the HIV population and soon will be the majority of the HIV population in the USA, yet many of us are suffering poor QOL, premature disability and death, and a social disconnectedness called social isolation and loneliness. There is a large need to implement programs to address social isolation and loneliness among the aging HIV population. We know these conditions increase the risk for heart disease, cognitive impairment, and physical impairment. Our HIV healthcare system is not addressing these needs and essentially ignoring the scope and largeness of the very serious problem. **Social Determinants of Health** are important determinants of long-term conditions and multimorbidity in the general population and for PWH. The intersecting relationship between SDH and multimorbidity in people with HIV remains poorly studied. **Blacks and Latinos, and women of color** suffer accelerated aging (weathering) due to care system structural barriers, material hardship, and systemic racism in marginalized ethnic groups.

Social isolation (which elderly PWH are at higher risk for), discrimination, and financial, and food insecurity are associated with multimorbidity. Chronic inflammation and immune activation can occur in the setting of controlled viraemia under optimal ART (25, 26, 28). African-American women and MSM suffer high discrimination-related interpersonal trauma (27). In the general population, among men, Blacks and Hispanics had a two-fold increase in age-adjusted relative risk of stroke as compared with whites. Among women, Blacks and Hispanics were also found to have at least twice the incidence rates of stroke as whites (relative risk (RR) = 2.8 and 2.1, respectively) (36).

In the United States today, approximately 11% of persons living with HIV (PLWH) are elderly[1], defined as age 65 or older, and 54% are considered older persons living with HIV (OPLWH) age 50+.[1] In New York City 36% of PWH are > 60 years old (b), and in San Francisco 73% are over 50 (c). These numbers are increasing; in a publication from Hopkins researchers and NIH funded (32): a 6-fold increase in PWH > 75 is projected; 31% of PWH by 2030 will have 1 or more mental and physical comorbidities; 64% will have 1 or more mental disability; 45% will have 2 or more physical comorbidities (heart disease, kidney disease, etc.), by 2030 80% of PWH > 70 will have 2 or more comorbidities; 50% of PWH 50-59 will have 2 or more comorbidities; of note 13% of **PWH < 30** and 19% **of PWH 30- 39** will have 2 or more comorbidities — this paper's authors say we need to "allocate appropriate resources to see healthcare needs."

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It's also projected that by 2030 75% of PWH in the USA will be over 50. It's projected the prevalence of comorbidities will increase significantly among aging PWH over the next 10 years in all groups across gender, racial and sexual background lines. Despite major advances in HIV prevention and treatment, *HIV care services* have not kept pace with the increased and increasingly-complex needs common to aging with HIV.[2,3] We feel the aging problem in HIV has not received anywhere near the attention and gravity it deserves and needs. The ongoing all-of-government approach to end the HIV epidemic (EHE) focuses almost exclusively on biomedical prevention and treatment[4], a public health response appropriate to reduce new diagnoses but has not addressed the complex care needs

of persons aging with HIV. You cannot End the Epidemic without including in the discussion and addressing the aging and HV problem, and the needs of older and elderly PWH.

Despite claims by some HIV government officials that PWH have almost a normal lifespan, research published by Julia Marcus and Kaiser Permanente report 9 years reduced survival for PWH compared to uninfected, and in that study they report earlier onset by age for comorbidities for PWH by 8-15 years, and 6 years reduced survival for those starting ART with 500 CD4 (a). These outcomes of course depend on many factors. But multimorbidity and comorbidity, and lack of adequate care for older PWH are key factors for whom mortality is reduced.

Longer life for PWH is now within reach for OPLWH but comes at steep cost in the form of greatly increased rates of age-associated HIV comorbidities, frailty and resulting poverty. Moreover, the impact of aging with HIV and the need for a comprehensive response were both predictable and predicted, having been the focus of clinical research and public discussion for more than the past decade.[5] The challenges of aging with HIV are not unique but rather quite similar to those reported among survivors of cancer[6,7] serious chronic illness[8] or traumatic injury[9] and among military veterans.[10] Together, we and other survivors of complex chronic conditions share a common need for a comprehensive system of integrated health and social services to enable and support our return to the best possible health and function so that we may remain independent, engaged and productive members of our communities and thrive as we age with dignity.[11,12]

Photo: Disabled and Here

It is clearly recognized by NIAID, OAR and HIV aging researchers that **many PWH experience higher rates of key comorbidities and earlier onset** of these including osteoporosis and fractures (x), chronic kidney disease (y), cardiovascular disease (z, 21), cognitive impairment (1a, 2a), physical impairment and frailty (high rate, 3a) associated with a reduced capacity to perform independent normal living activities that results in disability. As well, mental health for PWH is essentially ignored. PWH often suffer with mood disorders, depression, PSTD (22), cognitive decline, internalized stigma and external stigma. These concerns affect long term outcomes and are factors in developing comorbidities. Indeed social determinants of health, and disparities in care are a well-recognized cornerstone of poor aging with HIV. Indeed African Americans, Latinos and women of color suffer disproportionately from comorbidities, often receive worse healthcare, and have worse outcomes. In addressing the needs around aging and forging a solution special attention

must be paid to the needs of these marginalized populations, they need special programs designated to support their care such as heart disease and diabetes support and prevention programs. Two studies in Medicare among PWH find African Americans and Latinos face 2.4 to 7 times higher rates of certain comorbidities (n, o).

Researchers at Kaiser Permanente reported in 2022 in a study of PWH over 50, 36% had mild cognitive impairment, 6% dementia, and 58% normal cognitive functioning, with 5% to 20% reporting difficulty in each of these independent activities of daily living (housekeeping, working, laundry, finances, groceries, managing medications). 40% of those with dementia or cognitive impairment were Black, authors said "possible elevated risk among Black PWH" (d).

Many Aging and elderly PLWH face very **poor quality of life due to multiple comorbidities** and face the specter of **earlier onset disability and premature death** due to the "accelerated or accentuated" aging they experience, or the physical and mental/cognitive impairment they experience. Despite these clear and obvious problems the HIV healthcare system and the Ryan White Care system are failing to provide the screenings and care our older and elderly PWH need. Indeed unmet needs for this population is getting worse in RW Clinics. There is little to no screenings for osteoporosis, cognitive impairment and frailty despite that several key HIV Guidelines and HRSA recommend these screenings for PWH >50 (s,z,1). In NYC, despite that older and elderly PWH with multiple comorbidities need attention and care, care in RW clinics is getting worse for these individuals. The medical visits with HIV clinicians and doctors are 20 minutes, this is an impossible time within which to be able to address all the unmet needs around aging; all too often HIV doctors are not knowledgeable enough to address aging and comorbidities and mental health; there is essentially little to no access to mental health services and care; referrals to specialists can make PWH wait 4-6 months for an actual appointment; the patient portals are often useless as doctors do not respond adequtely to patient inquiries; the "telephone tree" is where you cannot anymore reach a live person in your RW doctor office clinic, its simply a series of recordings and messaging. These problems are NOT unique to NYC but are reported by PWH from all over the USA.

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Young adolescents and young adults who are lifetime survivors are as well often suffering premature onset and greater numbers of comorbidities that include bone disease, impaired cognitive function, hyperlipidemia and premature signs of heart disease. **Young adults who aquired HIV perinatally had a high incidence of type 2 diabetes, abnormal lipids, hypertension, and chronic kidney disease (CKD), according to analysis of 375 people in the North American NA-ACCORD cohort. Rates of these comorbidities exceeded rates in the general population (by age 30)** and sometimes outran rates in older people with HIV infection. 1 in 5 young adults (19%) with perinatally acquired HIV had type 2 diabetes; 40% had high cholesterol; 50% high triglycerides; 22% hypertension; 25% chronic kidney disease; authors suggested: clinicians "may consider early screening and treatment for these comorbidities at younger ages for people with perinatally acquired HIV" (35).

Photo: Vice

Photo: BHOC

Long-term survivors (LTS) who may be living with HIV for 20 years or more but may not yet be 50 years old often also suffer these conditions described above for earlier onset of comorbidities. I would differentiate these groups from the older and elderly. Older and elderly are in general at greater risk for premature death and at higher risk for the more severe affects of these comorbidities like fractures, heart attacks, physical impairment and cognitive decline. Nonetheless, these younger groups are suffering the affects as well of "accelerated or accentuated aging". They need proper screening and care.

Older and elderly PWH need and many indeed call for **"patient centered care, integrated care",** often said today to describe the much broader needs for care in this population beyond viral suppression (4a, 5a). Today HIV doctors all too often place all their focus on

viral suppression and no attention or inadequate attention to the many other needs of the aging HIV population. The medical literature reports successful development of a number of effective new **models of geriatric HIV care** by leading academic medical centers and HIV clinics in the United States and European Union (See Appendix A: Emergent Models of Care). And President Biden has committed to meaningful action: "The National HIV/AIDS Strategy 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." The need is clear and compelling.

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Effective interventions are now at hand. The time to act is now. A number of so- called "Aging/HIV clinics have sprung up around the USA in very recent years, for example in NYC, in SF, in Baltimore. The HRSA SPNS project established 10 clinics nationally. In NYC 3 aging/HIV clinics for African Americans, Latinos and women of color started 2 years ago. NYS funded 10 throughout the state. This falls way short of meeting the needs of the large and growing aging HIV population. It falls way short of meeting our needs. We do not have 7-10 years to wait for outcomes of these "demonstration projects". There are 200,000+ PWH over 60 right now in the USA. Most PWH in NYC over 60 are NOT getting their care needs met and it is the same throughout the USA. In fact, we do not know the best model to provide good care for the aging and elderly PWH, these new aging clinics may not indeed be the best way to provide care to all aging and elderly PWH. And what is the best model to provide good care for LTS and young adults and adolescents who acquired HIV by perinatal transmission. These questions are ignored by federal HIV leaders.

Improving care for the aging requires a close look at the needs around home health care and nursing homes, assisted living. Attention for this has been ignored and is long overdue. One model for consideration for elderly PWH is for RW clinics to implement home visits. The needs for PWH in nursing homes have been ignored, in fact PWH often receive very poor care in nursing home facilities (p, q, r, t).

HOW DO WE INTEGRATE ELEMENTS OF GERIATRIC CARE INTO RW HIV CLINICAL CARE?

"Many PWH have expressed concerns relating to **cognition**, access to community services, daily function and gait, management of complex comorbidities, and healthy aging.

Compounding the complex care of older adults living with HIV is a shortage of infectious disease providers, especially HIV specialists, and geriatricians. In 2019, 20.7% of infectious disease positions were unfilled in the U.S.(6) With limited resources and a growing population of older adults living with HIV, new models of care may be needed. Such models may include referrals to geriatricians outside of the HIV clinic, geriatricians embedded within HIV clinics, and referral to internists or family medicine providers for co-management. In these three models of geriatric consultation for older PWH, there is a demonstrated commitment to enhance patient goals and outcomes by focusing on the geriatric 5Ms: what matters most to patients, mobility, mind, medications, and multicomplexity. A patient-centered approach was a strength across all these models, as was the utilization of expertise across disciplines. Similar challenges arose, regardless of geographic location or institution type. They included: 1) Logistical barriers: The ideal location for PWH to access geriatric care services (within or outside of the facility) is variable. 2) Referral criteria and role clarity of the geriatric specialist. Obtaining sufficient and sustainable funding sources is a challenge for many clinics. Patient involvement is essential to ensure that these models of care reflect what PWH seek in their care. Over the short term, it may be beneficial for HIV providers seeking geriatric consultation to utilize telehealth" (g).

Recently reported at CROI 2024 was **prefrailty+ frailty** of 58% in CNICS Cohort in the USA (h); "multiple pathways of inflammation were associated with higher frailty scores in in virally suppressed PWH engaged in care" including sleep disorders which has been often reported as a problem for PWH and is associated with a higher risk for developing comorbidities including cognitive impairment.

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As well at CROI 2024 CFAR reported that for PWH with frailty they had a 24% reduction in quality of life (u).

Many older PWH had **low nadir CD4 and poor recovery of CD4** and inability to normalize CD4/CD8 ratio, all 3 of which situations are associated with an increased risk for earlier onset for non-AIDS comorbidities at a younger age. High rates of geriatric syndromes in PLWH have been often reported. There is an increased risk for premature frailty at all ages among PWH. Frailty is associated with an increased risk for cognitive decline. Multi-morbidity leads to polypharmacy with PWH often taking 16 medications a day and often leads to high muscle relaxants, and polypharmacy is associated with frailty and recurrent falls (23). Modifiable risk factors are associated with these affects such as physical exercise and activity, poor diet, smoking cigarettes and alcohol use, yet we do not have programs providing education and support around these for PWH. We need to incorporate them into preventative care for aging for PWH. Resilience can be reinforced but we do not have support programs for that for PWH. The authors say "assess functional status and adopt rehabilitation interventions to limit impairments; assess and manage comorbidity risks proactively to avoid muti-morbidity" (i).

In a very sobering analysis at the International Aging and HIV Workshop in 2016 Giovanni Guaraldi reported on a model projecting from his aging clinic in Italy that by 2030 30% of PWH will have geriatric syndromes and 34% will be disabled; frailty and prefrailty will approach 50% (j). At the European AIDS Conference (EACS) and the Aging Workshop Guardaldi reported on "cognitive frailty" (CF), with 6.5% of PWH, higher than in the general aging population in his aging cohort having cognitive frailty and there was strong association between CF and the trajectory of physical function decay, suggesting that physical functioning may represent a rehabilitation intervention to revert frailty and CF (k, l).

Latinos face many challenges. There is quite a lot of cultural and linguistic diversity. Their capacity to navigate the healthcare system is often challenging for them. They need special support and education. Studies report they often appear to suffer higher rates of cognitive impairment and certain comorbidities like diabetes and heart disease. **African Americans** as well suffer disproportionately with greater numbers of comorbidities and worse mortality, They also need special support care and services. The feeling of displacement is felt keenly by many Latinos.

The **Older Americans Act** needs to include PWH so we can have equal access to community aging resources. PWH need special linkages and support to access these services due to having worse physical and cognitive impairment than people without HIV at earlier ages.

Women face significant disproportionate challenges around aging. Women have high rates of comorbidities, worse cognitive and physical function (e, f) with HIV+ women in WIHS experiencing lower income, higher body mass index, and a history of tobacco and crack cocaine, injection drug use, and that "interventions are needed that target modifiable risk factors – concluding "the overall burden of aging-related comorbidities was higher in women vs men. Comorbidity screening and prevention strategies tailored by HIV serostatus and sex or gender may be needed." HIV+ women suffer effects of menopause making aging more accelerated for them, with earlier onset of menopause and menopause-related symptoms, an association with earlier or accelerated aging and onset for comorbidities and physical function decline. Yet the issues of care around menopause often receives no or little attention by HIV clinicians.

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Ageism is a part of our HIV system, It has become part of the HIV system of research and care and has such impaired PWH from receiving good care and the attention needed. In this Position Paper, we use experience of people with HIV and clinicians taking care of them to explore these issues in high-income countries. The intersectionality of multiple -isms, which affect the lives of older people living with HIV, and ageism enhance several HIV-related issues, including self-inflicted stigma, and loneliness. The model of care for older people living with HIV needs to go beyond virological success by adopting a geriatric mindset, which is attentive to the challenge of ageism and is proactive in promoting a comprehensive approach for the aging population. All stakeholders and the community should work together to co-create institutional strategies and educational programmes and enable respectful intergenerational dialogue to foster a stigma-free future for older people living with HIV (m).

Our Objective

Our goal is for the federal government, HHS and other key agencies to **in earnest** begin a process that guides and accelerates implementation of a comprehensive, all-of-government approach to address the complex whole-person needs of persons living and aging with HIV, with urgent attention to identify, stabilize and care for the most vulnerable group, specifically, which is the elderly PWH over 65. But also to address this problem of aging for PWH over 50, and for long-term survivors living with HIV for many years, 10+ to 25 years who may not yet be 50, and those young adults who acquired HIV by perinatal transmission.

For a number of years now we have been repeatedly approaching federal HIV leadership to address this problem, but we are not getting our needs met, we have not had an adequate response; as mentioned above there are 200,000+ PWH over 60 now in the USA the vast majority of whom do not receive the care they need, plus younger PWH over 50 are not screened for key aging-related conditions including osteoporosis (bone mineral density test), frailty, cognitive function and other testing. We want federal leadership to bringing together key agencies what are tied to the solution, which would include CMS, HHS, HRSA, ONAP, NIAID, to forge a solution. The RW Care system needs to be reconfigured to meet the needs of these affected and aging populations, Indeed the aging/HIV population is over 50% of the HIV population in the USA and its projected that by 2030 75% will be over 50, yet our problems outlined here are not addressed, despite that we are the majority of PWH in the USA. In NYC 80% will be over 50 by 2030.

To facilitate and coordinate this process we want a **National HIV and Aging Czar** appointed, who would work closely with the Director of the White House Office of National AIDS Policy (ONAP) and with HHS, HRSA and CMS and all relevant agencies, which might also include HUD and NIAID, whose sole focus is on HIV and Aging. Working with this "Aging Czar" would be a select committee of PWH well versed in the needs for this population.

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The Plan

We request an urgent meeting with key federal policymakers to discuss the following priority needs, issues and proposed solutions. Our objectives for this initial meeting are:

- To catalyze a comprehensive, all-of-government approach to implement models of care for persons aging with HIV and long-term survivors and assign this initiative the highest priority;
- To form a multi-agency Steering Committee to guide this priority project;
- To set an aggressive timeline to implement and refine solutions;
- To set firm dates for subsequent meetings.

Implementation of this community-informed proposal will help address the urgent needs of persons aging with HIV and long-term survivors and aligns with the National HIV/AIDS Strategy (2022-2025) and the supporting Federal Implementation Plan (NHAS 2022-2025).

We request an urgent meeting with key federal policymakers to discuss the following priority needs, issues and proposed solutions.

04 | PRIORITY NEEDS OF PERSONS AGING WITH HIV

Priority Needs of Persons Aging with HIV

The priority needs of persons aging with HIV include:

- Urgent assessment and stabilization of HIV Long-term Survivors and elderly PLWH
- Implement models of care to provide comprehensive, coordinated, multidisciplinary, whole-person care for all OPLWH
- Reconfigure the Ryan White Care system to one that meets the needs of the aging and elderly PWH as well as LTSs and young adults and adolescents who acquired HV by perinatal transmission.
- Prevention and wellness services to enhance outcomes; implementation research to support care and services;
- Policy interventions to address social determinants of health for OPLWH, and disparities as mentioned above

Photo: BHOC

- Research program to support implementation and further refinement of this plan and its various components
- Include aging concerns, improving clinical care, research solutions in the EHE objectives, and NHAS as well.

Each of these priority needs of persons aging with HIV is described below in descending order of priority, with the highest priority needs requiring the most urgent action listed first.

1. Identify, Assess and Stabilize the Most Vulnerable Elderly PLWH and Long-term Survivors

Utilize a whole-of-government approach led by federal agencies to identify and locate each and every elderly PWH and HIV long-term survivor (LTS), and assess their whole-

person health needs. Take immediate action to stabilize the health and well-being of individuals determined to be at risk.

a. The highest priority "target population" for this *initial assessment* includes the frail elderly, specifically all PLWH first diagnosed prior to the availability of comprehensive anti-retroviral therapy (cART) in 1996[13] *plus* all persons living with HIV (PLWH) age 65+.

b. Assessments include physical, mental and functional health; cognition; social engagement and support systems; housing, food and financial stability, etc.[11,12,13,14,15,16,17,18,19]

c. Individuals may be identified readily via EHR and insurance claims data

d. To be completed within six months and no later than September 2024.

2. Implement Emergent Models of Care for OPLWH

The vast majority of OPLWH are beneficiaries of public health plans such as Medicare, Medicaid, the Ryan White HIV/AIDS Program (RWHAP), and the Veterans Health Administration (VHA), placing primary responsibility for their health and welfare on the federal agencies that oversee these programs. This leadership role for the federal government enables prompt and decisive action, specifically, forging prompt implementation of emergent models of care (Appendix A) across the national network of provider agencies serving persons aging with HIV, and reconfiguring the RW Care System to integrate aging care into the RW clinics. Through this initiative, the federal government will encourage, fund, facilitate and support implementation of such models of care.

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a. Encourage, fund, facilitate and support experimentation with different comprehensive care models by large academic medical centers with capacity for such initiatives;

b. Work through the Ryan White HIV/AIDS program, Medicare and Medicaid to underwrite demonstration projects for smaller sites to identify best practices to provide screening assessments, leverage local resources, identify and address "what matters most" to the patients they serve.

c. For specific actions required, see Appendix B: Implement comprehensive, coordinated, multidisciplinary, whole-person care for OPLWH.

3. Leverage Prevention and Wellness Services to Enhance Outcomes

Frailty assessments, physical functional assessments, cognitive assessments, and bone disease (osteoporosis-bone mineral density testing [BMD]) are typically performed for older adults (age 65+) who present with symptoms.

Photo: BHOC

Indeed currently several Guidelines recommend these tests for PH >50, but these recommendations are NOT implemented in the clinic . However, OPLWH experience increased risk of accelerated and/or accentuated aging. Mitigating such risk requires assessments be performed proactively and at much earlier ages (starting age ~50) to enable early detection and treatment of these aging- associated HIV comorbidities.[17] We want a research program developed and specifically focused on identifying key causes of accelerated, accentuated (immunosensence aging in PWH, and to search for interventions, both pharmacological and wholistic, such as designing exercise and diet programs, mental health support programs, heart disease and diabetes support programs to be implemented in clinics as part of an overall solution. All programs must be culturally suitable for Latinos, Blacks-African-Americans and women of color.

a. Provide evidence-based assessments, prevention and wellness services to persons aging with HIV as defined by HHS (age 50+) and extend access to such services based on the evidence to at-risk groups at younger ages, e.g., to women with HIV starting in their mid-30s due to their demonstrated increased risk of cardio-vascular disease, etc.

b. For details, see Appendix C: Prevention and Wellness Services for OPLWH.

4. Policy Interventions to Address Social Determinants of Health

The data discussed above provide persuasive rationale for agencies and organizations to dedicate significant resources to the development and implementation of novel HIV-specific tools for addressing sociodemographic disparity, modifiable lifestyle factors, and comorbidity screening and prevention to improve overall and comorbidity-free outcomes for individuals with HIV."[2]

a. Access to Aging Services: Ensure access to the full range of aging services for older persons living with HIV (OPLWH) and LGBT+ elders by designating both groups as "populations of greatest social need" under the Older Americans Act (OAA). This

will be accomplished at the federal level during the next reauthorization of the OAA in 2024. Work to facilitate similar actions by each state/territory that has not already enacted such legislation (55 of 59);

b. Enhance Financial Stability of OPLWH:

   i. Facilitate smooth transitions for OPLWH from SSDI (disability benefits) onto SS retirement benefits and Medicare (Note: Impending income crash for LTS who have been on disability for decades and who will fall off when they transition onto Social Security, which they might not have paid much into)

   ii. Support work for those willing and able by encouraging, facilitating and supporting employers (public and private) to offer flexible work arrangements to OPLWH such as job sharing, flex- time, part-time and contract work; recognition of lived experience toward job requirements, virtual/ telework, etc.

[...] understand and address the whole-person health challenges faced by persons aging with HIV, now a growing majority of the U.S. population of persons with HIV and projected to reach 75% by the year 2030.

c. Expand Access to Housing Assistance for OPLWH.

   i. Q: Are we using all available housing assistance: HOPWA, HUD/HCV, PACE program, LITCH housing for seniors w/low income, etc.?

d. Expand access to transportation services, Provide better financial support related to healthcare transportation.

5. Research to Address the Priority Needs of Persons Aging with HIV

Expand and rebalance federal research activities (NIA, NIAID, ACTG, other institutes) to reflect the changed nature of the HIV epidemic with significantly increased focus to understand and address the whole-person health challenges faced by persons aging with HIV, now a growing majority of the U.S. population of persons with HIV and projected to reach 75% by the year 2030. Activate and focus the combined expertise and resources of all relevant federal agencies together with the federal research enterprise to address the priority needs of OPLWH. Form a cross-agency collaboration to design a research approach that focuses on improving the care in the clinic for aging and elderly PWH and LTSs, as well as those who acquired HIV by perinatal transmission. Form a select community ad board to work with this collaboration.

a. Implementation Science and Research**:** The most pressing need is to identify how best to implement the models and elements of geriatric HIV care to support optimal health for persons aging with HIV. To this end:

i. Fund and coordinate an all-of-government Implementation Science and research initiative to support effective and efficient implementation of emergent models of care for HIV and aging across each of the various health programs: Medicare, Medicaid, RWHAP, commercial health plans, etc. To support reconfiguring the RW Care system to provide integrated personalized care in the clinics that includes elements of geriatric care into RW clinics.

ii. The initiative would be similar in scope and scale to those recently conducted by HHS to support implementation of HIV prevention and treatment.[4,24]

iii. For details, see Appendix D: Implementation Science and Research

Policy, Focus and Funding: Designate HIV and Aging as a federal research priority with leadership and coordination provided by HHS and dedicated funding streams commensurate with the prevalence of aging and aging-associated HIV comorbidities within the U.S. population of PLWH. Appoint a National HIV and Aging "Czar", who works closely with the Director of the White House Office of National AIDS Policy, whose sole focus is on HIV and Aging.

iv. For details, see Appendix E: Policy, Focus and Funding for HIV and Aging.

a. **Translational and Clinical Research**: Designate HIV and Aging as a national research priority with dedicated funding streams commensurate with the prevalence of aging and aging-associated HIV comorbidities within the U.S. population of PLWH.

v. For details, see Appendix F: Translational and Clinical Research for HIV and Aging.

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Appendix A: Emergent Models of Care for Persons Aging with HIV

Objective

To identify for consideration by health plans, health systems, policymakers and providers the range of evidence-based emergent models of care to provide comprehensive, coordinated, multidisciplinary, whole-person care for older persons living with HIV (OPLWH) age 50+ as recommended in the global Consensus Statement.[1]

Emergent Models of Care for OPLWH

For a clear, concise and accessible introduction to geriatric care models[2] and the application of geriatric principles to HIV care, see Singh, et al (2017),[3] Erlandson and Karris (2019),[4] Siegler, et al (2020)[5], and Guaraldi, et al (2021).[6]

The literature describes a number of emergent models of care, each informed by specific local conditions: existing HIV care services delivery systems, the needs of the local population of OPLWH, resource availability, etc. These models of care are listed below along with the names of HIV clinics that have adopted each model.

1. **Outpatient referral/consultation:**[7]
   - *Aging with HIV Program*, New York-Presbyterian Hospital/Weill-Cornell Medical Center[8]
   - University of Colorado, Aurora, CO[7]
   - The John G. Bartlett Specialty Practice, Johns Hopkins Medicine, Baltimore, MD

2. **Combined HIV-geriatric multidisciplinary clinic:**[7]
   - *Aging with HIV Program*, New York-Presbyterian Hospital/Weill-Cornell Medical Center[7,8]
   - *Golden Compass* Program, San Francisco General Hospital[7,9,10,11]
   - McGill University Health Center (MUHC), Montreal, Canada[7]
   - Modena HIV Metabolic Clinic (MHMC), Department of Surgical, Medical, Dental and Morphological Sciences. University of Modena and Reggio Emilia, Italy[6]
   - *PLUS50* Clinic, Chelsea and Westminster Hospital, London, UK[7,12]
   - *Sage Clinic* at the Ian Charleson Day Centre, Royal Free Hospital, London, UK[13]
   - *Silver Clinic12*, Brighton, UK[7,14]

- *The Silver Project* and HIV and Aging program at UCSF 360, San Francisco, CA
- *The THRIVE* Program, University of Maryland Medical System-Baltimore[7]

3. Dually-trained providers within one setting:[7]

- *Age Positively* Program at Massachusetts Hospital[7]
- Health Resources and Services Administration (HRSA) Geriatrics Workforce Enhancement Programs
- University of Pennsylvania Medical Center[7]

4. Expanded Care Coordination and Case Management services:

- *Be into Health* program, Family Health Centers at NYU Langone[15]
- Community Support Services, New York State Department of Health-AIDS Institute
- HIV Care Directions®, McDowell Healthcare Center, AZ[16]
- HIVE (HIV-Elders) program of APLA Health and Wellness, Los Angeles, CA
- National Resource Center for Care Coordination and *Pozitively Aging with HIV*
- People Aging with HIV pilot program, New York State Department of Health-AIDS Institute
- Project Prosper, NYC Department of Health and Mental Hygiene[17]
- SagePositive-New York

5. "Geriatric Champion" model: One or more members of the clinical staff (primary care physician, HIV specialist physician, nurse, etc.) develop proficiency in geriatric principles and facilitate or "champion" their introduction into clinical practice and clinic workflow.[18]

Model comparisons: Several review articles provide experience-based comparisons of the various models of care.[1,6,7]

Transitioning to new models: Several articles examine issues related to transition from current models of care and suggest strategies for successful transition to the provider's chosen new model.[6,19,20,21,22]

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Appendix B: Implement comprehensive, coordinated, multidisciplinary, whole-person care for Older Persons Living with HIV (OPLWH)

The vast majority of OPLWH, defined as those age 50+, are beneficiaries of public health plans such as Medicare, Medicaid, the Ryan White HIV/AIDS Program (RWHAP), and the Veterans Health Administration (VHA), placing primary responsibility for their health and welfare on the federal agencies that oversee these programs. This leadership role for the federal government enables prompt and decisive action, including:

1. **Publication of specific directives** within one year (i.e., by January 30, 2024) to facilitate implementation of emergent models of care (Appendix A) across each of the public health programs;
2. **Provide specific guidance and training** for ways to redirect existing funds and resources to implement and sustain HIV geriatric models of care.[1,2]
3. **Provide urgent supplemental funding** to health plans, health systems, community health centers and HIV clinics currently contracted with HRSA, the RWHAP and/or CMS to facilitate implementation of their chosen emergent model(s) of care for HIV aging. Funding needs are estimated to range between $1M/clinic[3] and $3M/clinic.[4]
4. **Inform and train HIV services providers** on the emergent models of care and relevant funding streams: RWHAP providers, state and local health departments, federally- qualified health centers (FQHCs), academic medical centers, AIDS services organizations (ASOs)/HIV clinics, Medicaid Special Needs Plans, Medicare Advantage health plans, commercial health plans, etc.
5. **Facilitate reimbursement:** Convene and coordinate a public-private initiative to facilitate reimbursement for HIV geriatric services by all insurers and health plans, public and private.
6. **Require data collection, reporting and analysis**: Require all federally-funded healthcare services, programs and providers to track, analyze and report indicators of clinical care and outcomes specifically for persons aging with HIV as a standard component of program reporting:
    a. Establish standards for data collection and reporting by clinically relevant priority groups, e.g., OPLWH (age 50-64), elderly PLWH (age 65+), and HIV LTS (HIV diagnosis prior to HAART/1996), etc.
    b. Assess performance of the emergent models of care implemented for the priority populations with regard to demonstrated capacity to enhance clinical outcomes, patient-reported outcomes/Quality of Life, and cost of care across the individual's lifespan.
    c. Utilize these data to inform care services enhancements, guide policy and funding decisions aimed to increasing engagement in care, decreasing disparities and

enhancing HIV and aging Quality of Life indicators included in the National HIV/AIDS Strategy and Federal Implementation Plan.

d. Applies to all CDC-funded HIV data collection and reporting, especially the Medical Monitoring Project; HRSA's RWHAP; all CMS programs and services (all Medicaid and Medicare programs, health plans and services); etc.

7. **Create an open-access public repository of effective models of care for OPLWH**: Identify for consideration by health plans, health systems, policymakers and providers the full range of evidence-based emergent models of care to provide comprehensive, coordinated, multidisciplinary, whole-person care for older persons living with HIV (OPLWH) as recommended in the global Consensus Statement.[5] Create a public repository of these best practices; actively disseminate such information to and through all public health plans; encourage and support similar dissemination through employer sponsored and commercial health plans and health systems. Designate a lead agency within the Department of Health and Human Services responsible to create, update, maintain and disseminate such information nationwide.

8. **Adapt federal healthcare programs to meet the long-term care needs of OPLWH**:

   a. Programs include Medicare, Ryan White HIV/AIDS program, etc.

   b. Who is going to pay for home attendant services? How are we going to keep people in the community? How are we going to make nursing homes safe spaces?

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Appendix C: Prevention and Wellness Services for OPLWH

Frailty assessments, functional assessments, and cognitive assessments are typically indicated and performed for *older adults (age 65+) who present with symptoms*. However, OPLWH experience increased risk of accelerated and/or accentuated aging. A recent study found age-related comorbidities occurred 9.5-16 years earlier among individuals with HIV infection than among HIV-uninfected individuals depending on when ART was initiated, among other factors. <Collins, 2022> Mitigating such risk requires assessments be performed proactively and at earlier ages to enable early detection and treatment of these aging-associated comorbidities. Evidence-based means to identify persons who might benefit from further comprehensive geriatric assessment include observed and/or self-reported symptoms, the VACS index, < Hernández-Ruiz, 2022 > and/or a CD4+/CD8+ ratio of <1.< Ruiz-Manriquez, 2022 >

Prevention and wellness services will be provided *at minimum* to persons aging with HIV as defined by HHS (age 50+) and extended *based on the evidence* to at-risk groups at younger ages, e.g., increased risk of cardio-vascular disease for women with HIV starting in their mid-30s, etc.

1. **Assessments**: Clinical practices need help figuring out how to incorporate these services into their workflow (appointment time, staffing, physical space, etc.) Solutions may differ by practice type, i.e., a small medical group of PCPs or HIV specialists does not have similar resources to an HIV clinic or academic medical center. Few medical practices are trained and equipped to perform these assessments. This applies to both primary care and specialist practices. Geriatric specialists are prepared to conduct these assessments, but the longstanding national shortage of geriatric specialists means that many older persons lack access.

    a. Identify screening assessments whose findings are actionable and most effective to enhance outcomes. Develop methodology to assist providers to prioritize assessments for the population(s) served. Provide robust funding similar to the HRSA-NCI initiative: Accelerating Cancer Screening awards (2022).

    b. Provide urgent supplemental funding as needed to health plans, health systems, community health centers and HIV clinics currently contracted with HRSA, the RWHAP and/or CMS to facilitate implementation of such assessments.

    c. Facilitate reimbursement: Convene and coordinate a public-private initiative to facilitate reimbursement for evidence-based HIV geriatric assessments by all insurers and health plans, public and private. Inform and train HIV services providers on the relevant funding streams and reimbursement processes.

    d. Implement evidence-based screening/early detection for HIV-associated comorbidities for OPLWH [4,5,6,7,8,9,10,11,12] thru all public health plans by January 30, 2024.

2. **Support services:** Fund and require provision of evidence-based support services such as health and social services navigation, peer support and buddy programs to reduce social isolation and loneliness and enhance health outcomes.

   e. Identify best methods to ensure seamless transition of program beneficiaries to Medicare: Policy and benefits alignment, care coordination systems and processes, service navigators with expertise in the unique needs of the vulnerable population of older PLWH.

3. **HIV Self-management Programs:** Fund development and provision of evidence-based services to augment/extend/support an HIV services provider system that is chronically short-staffed and underfunded. Services to include health education, self-care and chronic disease self-management programs *tailored specifically for persons aging with HIV*, with an eye to include technology-enabled, multi-channel communications options to meet disparate learning styles, literacy levels, preferences for engagement, etc.

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Appendix D: Implementation Science and Research Needs for HIV and Aging

While persons aging with HIV now represent a growing majority of the US population with HIV, and federal research agencies conduct a considerable amount of implementation science (IS) research, little of it to date (~3% for the years 2017-2021) has been aimed at addressing issues associated with aging with HIV.< FAPP; Bansal > Addressing these needs will involve designing, funding and coordinating an all-of-government Implementation Science and research initiative for interdisciplinary management of multimorbidity associated with HIV aging< Collins, 2022 > similar in scope and scale to those recently conducted by HHS to support implementation of HIV prevention and treatment,< Purcell, 2022; Mustanski, 2022 > to include:

1. **Emergent Models of Care:** Identify best practices for effective, efficient and prompt implementation of emergent models of care for HIV and aging with consideration for:
    a. Health plan type: Publicly-insured (Medicaid, Medicare, VHA); commercially- insured (ACA, individual and employer-sponsored); uninsured/underinsured (Ryan White HAP, out-of-care), etc.
    b. Geography: Urban areas with access to academic medical centers/tertiary care v. rural areas where most HIV care is provided by primary care providers.
    c. Individual demographics: Groups with disparate impact such as by age (LTS and elderly PLWH age 65+ v. OPLWH age 50-64), by sex (e.g., increased risk for CVD among WLWH starting in mid-30s), by gender identity/expression (Transgender and non-binary), by race/ethnicity, etc.

2. **Expanding access to care beyond big cities, academic medical centers and the RWHAP provider network:** Many OPLWH live outside the service areas of the big-city academic medical centers piloting new models of care. *What strategies, models of care, and/or resources have been used successfully (or might be used) to care for them? What does the evidence show for the following?*
    a. CMS Network Access/Adequacy Standards: The Centers for Medicare and Medicaid Services has long set adequacy standards for provider networks that participate in the Medicaid program. Such standards set minimum coverage levels for specialist providers for a given population, e.g., *x* number of gastroenterologists per 100,000 health plan members (covered lives). *How might such network adequacy standards be modernized to ensure appropriate access to HIV geriatric care services for OPLWH? To behavioral and mental health services tailored to the needs of those aging with HIV and by providers experienced/competent in caring for OPLWH?*

b. Community-based Services: Alternative methodologies, staffing and/or settings to expand access to clinically-appropriate comprehensive geriatric assessments and other assessments via in-home services (for example by a specially-trained nurse) or within the primary care team/practice;< Singh, et al, 2017 > monthly clinics sponsored at local senior centers, in retail pharmacies and/or urgent care centers, etc. Also needed are opportunities for enhanced social engagement and social supports to mitigate the impacts of isolation and loneliness.[5,6,7,8,9,10,11,12]

c. Community health centers/FQHCs: A number of FQHCs/community health centers have a long history caring for members of the LGBT+ community and PLWH. *What approaches are they adopting to care for persons aging with HIV and what has been their experience?* See: Callen Lorde (New York City), Fenway Health (Boston), Howard Brown Health (Chicago), Whitman-Walker Health (Washington, DC), etc.

d. Group Health Model: These commercial health plans have decades of experience managing insurance risk and providing comprehensive, coordinated multi-disciplinary care to enrolled members thru multidisciplinary clinics staffed by employed physicians, nurses and ancillary providers. *What has been their experience providing person-centered, geriatric HIV care, and what lessons might be useful to other provider groups or health plans?* See for example: Kaiser-Permanente Health Plan (National); Geisinger Health System (PA); Group Health Cooperative of Puget Sound (WA), etc.

e. Health and HIV Service Navigation and Care Coordination:

   i. Identify best practices to use service navigation and care coordination to enhance engagement and retention in care, clinical and cost-of-care outcomes, and Health-related Quality of Life (HRQoL) for OPLWH.

   ii. Identify best practices to support smooth transition to Medicare and continuity of care for OPLWH. Pay special attention to the unique needs of RWHAP beneficiaries, many of whom may lack experience selecting health insurance/ health plans, Medicare-Medicaid "dual-eligibles," and other groups facing socio-economic disadvantage.

   iii. Determine effective means to provide service navigation and care coordination to OPLWH who reside in areas not served by HIV specialty clinics or ASOs.

f. Special-Needs Health Plans (SNPs): A small number of SNPs serve Medicaid and/ or Medicare-Medicaid "dual eligible" beneficiaries living with HIV. *What models of care do they employ, and what have been their outcomes (clinical and cost)? Are other markets amenable to SNPs?* See for example: Positive Healthcare (AIDS Healthcare Foundation); VNS Health; CareMore Health; Medicare SNPs; Medicaid HIV SNPs, etc.

g. Telehealth: *How might successful HIV telehealth services models[13] be utilized/ adapted to expand access to HIV geriatric specialist and other consults to address the needs of OPLWH in underserved areas? What actions, policies and/or supports would facilitate implementation by states of a hub-and-spoke service model in*

which state-designated HIV Geriatric Center(s) of Excellence utilize telehealth and other strategies to ensure access to services throughout the entire state?

h. Veterans Health Administration (VHA): The VHA is the largest health system in the United States and among the largest providers of HIV care services. *What model(s) of care have been adopted or considered by the VHA for persons aging with HIV?*

3. **Financing:** Identify and assess methods to finance emergent models of care for HIV aging across each of the various public health plans;

4. **Assess Outcomes**: Assess performance of these emergent models of care for the priority populations and in the various settings for demonstrated capacity to enhance clinical outcomes, patient-reported outcomes/Quality of Life, and cost of care across the individual's lifespan.

5. **Prevention/early detection and treatment of comorbidities of HIV aging**: How rapidly to implement into clinical practice screening/early detection and rapid-start treatment of the co-morbidities and complications associated with aging with HIV. Screening guidelines and interventions to be based upon the latest research findings and updated at regular intervals as the science advances.

   a. Identify/develop comorbidity screening assessments specifically tailored to persons aging with HIV and whose findings are actionable and most effective to enhance outcomes. Tailor assessments and interventions to groups at increased risk, e.g., women, non-Hispanic Blacks, and those with public insurance.< Palella, 2019> Develop methodology to assist providers to prioritize assessments for the population(s) served.

   b. Assess performance of prevention/early detection and treatment protocols to enhance outcomes

   c. "[I]ncreasing comorbidity burden among individuals with HIV infection is associated with higher resource utilization and direct medical costs (ie, $300-$5000 more per patient-month for individuals with HIV infection who have comorbidities than for those who do not)."< Lerner, 2020 > Identify best practices for use of prevention/early detection and treatment of HIV aging-associated protocols to enhance health outcomes and reduce future healthcare spend by Medicare. See for example Medicaid Waiver program used by Maryland to test and treat HCV among Medicaid beneficiaries to reduce future cost burden to Medicare.< Rand, 2017>

6. **HIV Self-management:** Identify efficacious and effective methods to implement at scale various HIV self-management/chronic disease self-management programs, training and/or "tools" to enhance access to services, health outcomes, health equity, and/or cost of care:

a. Leverage the existing infrastructure and expertise of the AETCs, ASOs, community health centers, and FQHCs.

b. Lived Experience: Assess efficacy and identify best practices to employ persons with lived experience to deliver HIV self-management training and services;

c. *Positive Self-management Program (HIV)* is an award-winning Chronic Disease Self-management (CDSM) program from Stanford Medicine (funded by the U.S. Administration for Community Living/ACL) provided primarily via in-person workshops by local health system staff trained as facilitators. A companion handbook, *Living a Healthy Life with HIV*, and supplemental online material also are available.

i. Results to date: xx participants; $yy/participant; etc.

ii. *What is needed to facilitate development of additional new content tailored to the needs of persons aging with HIV with specific attention tounique needs of pre-HAART Long-term Survivors, elderly PLWH (age 65+), OPLWH (age 50-64, women, men, trans and gender-diverse), and verticals (those born with HIV or who acquired it at a young age)?*

iii. *Which new/additional/alternative learning modalities might help reach a greater proportion of OPLWH, particularly those living in rural and other underserved areas?*

iv. *What role(s) might exist for cohort-based virtual workshops designed to facilitate supportive peer relationships among participants to enhance program outcomes, social engagement and health outcomes? How might these be scaled nationally?*

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Appendix E: Research Policy, Focus and Funding

During the early years of the HIV pandemic, co-infections and co-morbidities impacting PLWH were primarily other infectious diseases. The NIAID and ACTG were well suited to plan and conduct research to address these issues. Today, effective HIV therapies enable PLWH to live long and healthy lives, and the health conditions of most impact are primarily non-infectious chronic diseases/conditions associated with aging. OPLWH face increased risk of such aging- associated comorbidities, with many impacted by accelerated and/or accentuated aging. To design and conduct needed research into these issues may require expertise and resources from external Institutes, Centers and federal agencies in addition to those traditionally involved.

1. **Objectives for HIV and Aging Research Policy, Focus and Funding**:

   Facilitate collaboration among and within HHS, OAR, ACTG, NIA, other agencies as needed to agree upon a common set of such research questions to form a shared research agenda. Use the steering committee and infrastructure created during the above for long-term oversight and coordination of such research

2. **Meaningful Participation of People with HIV/AIDS (MIPA)**: Ensure appropriate representation and meaningful involvement in all decision-making spaces and all stages of HIV clinical research:

   a. **OPLWH,** especially pre-HAART HIV Long-term Survivors (LTS), those living with HIV since birth/childhood ("verticals"), and other under- represented groups;

   b. **Members of groups disproportionately impacted by HIV:** women, sexual and gender minorities, racial and ethnic minorities, etc.

   c. **All stages of research:** Includes NIH process through which research priorities are set and funds awarded; Institutional Review Boards (IRBs); community advisory boards (CABs), etc. How do the attitudes, perceptions, needs and values of PLWH and other stakeholders inform each step of the research process? How do you involve PLWH in your research?

   d. **Community engagement:** Stakeholders, esp. clinical trials participants, need to be kept informed of the progress, results, and publications derived from the studies in which they participate;

   e. **Implementation:** Apply MIPA principles to all taxpayer-funded research (NIH); for inclusion into FDA requirements for approval of new therapeutic drugs and devices for HIV; and advocate for integration as best practices into industry-sponsored research;

3. **Identify/define scientific questions and research priorities**. Negotiate stakeholder consensus for balance within the HIV and Aging research portfolio:
   - Biomedical research: xx%
   - Behavioral and social sciences research: xx%
   - HIV Cure research: xx%

4. **Clarify "ownership" of HIV and aging research within the federal government**: Identify appropriate federal department, Institute/Center, or agency to address each question (some may fall outside NIH to other departments/agencies). Clarify "ownership" of HIV and aging research within HHS and NIH:
   a. Specific point of contact and process to propose HIV aging research projects
   b. How fund such research?
   c. By whom and how are such proposals coordinated across ICs and shepherded thru the review and approval process?
   d. Modernize network governance (ACTG) to provide meaningful involvement of community (PLWH) with sufficient voting rights/power to influence research priorities, plans, and projects.

5. **Increase funding for research of HIV aging**: Treatment advances over the past several decades now enable PLWH to live longer, healthier lives than previously possible. Today more than half (52%) of PLWH in the US are age 50+ *<CDC, HIV Surveillance Report, 2019>*, a proportion projected to reach 70% by 2030. Unfortunately, federal investment in HIV and aging research does not reflect this progress with less than 3% of HIV research funds directed to HIV and aging research.[1,2] An OAR working group identified HIV and aging as a "unique model of multi-morbidity" that provides researchers the opportunity to gain insights applicable to many populations and that benefit the wider field of healthcare. *< Brennan-Ing, et al, 2021 >*
   a. Ensure funding levels appropriate to the proportion of the population of PLWH who are age 50+ (currently 50% and rising to 70% by 2030, CDC) and appropriate also to this unique opportunity to advance scientific understanding of aging.
   b. Increase research of Translational and Implementation Science: Expedite efforts to turn new scientific findings into treatments/interventions to enhance quality of life for PLWH. Focus on services that are accessible, affordable, culturally appropriate and acceptable to target audience(s), and feasible with resources available.
   c. Create clear pathway(s) in the federally-funded research ecosystem and the AIDS Clinical Trials Group (ACTG) for proposal, funding and sponsorship of HIV and aging clinical trials:

6. **Community Needs Assessment: *Monitoring the State of Aging with HIV in the US:*** Select/create a standardized survey instrument for long-term, longitudinal assessment of the health status and needs of OPLWH across the US to inform development and future enhancement of HIV care services, programs and policies for persons aging with HIV. Implement assessments thru the existing HIV services infrastructure of community health centers, FQHCs, ASOs, local health departments, etc.

7. **Enhance diversity of participants** in clinical trials to reflect the community of persons living with/affected by HIV:

   a. Inclusion of older PLWH**:** Older adults in general are the primary consumers of medications and non-pharmaceutical therapies. Half of all PLWH in the US are age 50 or older, a proportion expected to grow to 70% by the year 2030.<CDC, 2018 >Many older PLWH have multiple chronic conditions, are often excluded from clinical trial participation, and may accrue less benefits and/or greater potential harm from the interventions being investigated.

      i. Use functional inclusion criteria in place of arbitrary age limits.< NIH, 2017; NCI, 2018 >

      ii. Adopt use of standardized age sub-groups for research involving older adults <FDA, 2012>:<65, 65-74, 75-84, 85+

      iii. Consider adding to protocols that include PLWH a sub-group for age 50-64 years to account for accelerated/accentuated aging associated with HIV.

      iv. Require justification for exclusion of any sub-group from protocol.

      v. Enhance accessibility to clinical trials thru policies, processes and resources that support expansion of community-based research.

      vi. Granting federal agencies increased authority to incentivize and require research that includes older adults

   b. Require representative inclusion in HIV research of all stakeholder groups affected by HIV, especially groups that have been underrepresented historically such as African American and Latino MSM, cisgender women, transgender and gender-nonconforming individuals, etc. (Common Rule principle of justice):

      i. Require justification for exclusion of any sub-group from protocol

      ii. Require affirmative plan for follow-on studies to assess safety and efficacy in any groups excluded from initial trials

   c. Adopt policy of "Presumed Eligibility" of PLWH to participate in clinical research: As longevity for PLWH approaches that of the general population there is increasing need to adopt an affirmative policy/presumption of inclusion rather than exclusion of PLWH in trials of new treatment interventions, especially in emerging fields such as geroscience. <NIH Workshop

on HIV-Associated Comorbidities, Coinfections, and Complications: Summary and Recommendation for Future Research, 2019>

Establish a scientific consensus re. clinical definition of "immunocompromise" (or better yet its inverse, "immune competence) for the purpose of clinical trials participation of PLWH.< Villa, 2021 >

d. Implementation and Reporting:

i. Create and maintain a reference database of disease demographics for HIV and relevant comorbidities, coinfections and complications to guide trial design.

ii. Facilitate multidisciplinary and cross-institute collaboration and sharing of best practices. What might be learned/borrowed from the National Institute on Aging and its networks?

iii. Require application of the above guidelines to all taxpayer-funded research (NIH) and into FDA requirements for approval of new therapeutic drugs and devices. Advocate for integration as best practices into industry-sponsored research;

iv. Create tools and training to support implementation of these requirements, appropriate diversity/inclusion of participants, community engagement at all stages

v. Include data on adherence in the Tracking Accountability in Government Grants System (TAGGS); publish adherence data by protocol, investigator and institution

vi. Condition federal award-funding on adherence to these principles.

8. Data collection: The quality and applicability of research findings depend upon the data collected. Advocate for enhanced data collection across all federal agencies and federally-funded programs and services, a true all-of-government approach.

a. Collection of "SOGI" data (Gender identity, gender expression, and sexual orientation) is necessary "to address health disparities and for providing person-centered care and services to the US population as a whole."<(Baker, Streed and Durson, 2021), (Fenway Institute, 2020) >

b. SOGI data collection recommended as standard practice for population surveys, clinical research, public health surveillance, and Electronic Health Records.< NASEM, 2020 >

c. Advocate for the Office of Management and Budget (OMB) to use its existing authority "to promulgate flexible standards to guide collection of demographic data throughout the federal statistical system."< Baker, Streed and Durson, 2021 >

d. Advocate for the Interagency Working Group on Equitable Data to work with the U.S. Domestic Policy Council to identify deficiencies in data collection across all federal agencies and propose solutions.< Aggarwal, 2021 >

i. Enabling this data collection may require federal changes to Health Level 7

(HL7) data collection processes and systems;

ii. See for evidence-based recommendations on which data elements to collect and guidance on meaningful use: Federal Committee on Statistical Methods; the Sexual and Gender Minority Research Office at the National Institutes of Health (NIH); the NIH PhenX Toolkit for biomedical research;

a. For PLWH, collect also in healthcare settings:

i. HIV serostatus, year of diagnosis, nadir CD4 T-cell count;

ii. Require of public health agencies, HIV care services providers, health plans and health insurers, clinical researchers, etc.

9. **HIV cure research:** In many ways, HIV may be viewed as the ultimate viral foe - - mutating rapidly, hiding in parts of the body beyond the reach of treatments, able to lay dormant for many years only to resume infection if treatment is halted. Considered in the present context of a global respiratory virus pandemic, research to develop the knowledge, strategies and tools to overcome the challenges presented by HIV should be seen as valuable preparation to prevent and/or defeat future threats from currently-unknown viruses. Cure-directed HIV research therefore should be continued and expanded:

a. Develop the conceptual framework to fit HIV cure strategies into the Continuum of Care (CoC) for PLWH including clinical practice; acceptance by PLWH, HIV providers, and payors; and accessibility (cost of treatment; infrastructure required, etc.)

b. Develop the framework to fit HIV cure research into the federal Plan to End the HIV Epidemic and the NHAS.

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Appendix F: Clinical and Translational Sciences Research for HIV and Aging

< Intro >

1. **HIV and Aging Scientific Questions:** OPLWH co-morbidities are a component of HIV aging. Are they all?
   a. Which co-morbidities are the most impactful to address/treat?
   b. If we addressed all co-morbidities, would we see premature aging slow/stop?
   c. What implications of cumulative treatment of all a patient's comorbidities - - could they handle it? DDIs?

2. **Socio-behavioral Sciences Research Agenda**:
   a. Mental Health
   b. Substance Use
   c. Social isolation and loneliness: Effective methods to prevent/mitigate/treat social isolation and loneliness (and the many serious adverse effects they cause) among OPLWH. Note: Similar issues of isolation and loneliness apply to the entire population of older adults, so this research might be a subset of a larger research effort. Findings may also generalize to other populations.
   d. Clinical Care and interventions, including lifestyle interventions, such as diet and exercise
   e. Support services-model programs
   f. Social Health: Identify effective approaches to integrate social risk factors (isolation, poverty, lack of support network) into models of care for specific populations and under what circumstances:
      i. Assess objective and relative efficacy to prevent/treat loneliness in older PLWH:
      ii. Cognitive Behavioral Therapy (CBT), social interactions/supports, psycho-educational support groups, other interventions
      iii. Efficacy of telehealth services, e.g., CBT provided in-person v. CBT by telehealth
      iv. Support Services for older PLWH: Identify optimal combination of support services to enable PLWH/LTS to thrive as we grow older:
      v. Identify unique needs of HIV aging, "gaps" in general aging services (unmet needs)

vi. What might we learn/borrow/adapt from survivorship programs developed for cancer survivors, trauma and/or other chronic health conditions?

vii. Efficacy of Peer-to-Peer Support services to enable older community- dwelling PLWH to age successfully in place (at home).

g. Platform for LT longitudinal BSSR to help understand facilitators and barriers to healthy aging with HIV, develop and assess behavioral and psycho-social interventions. (See: PRIDE study; *All of Us* research program.)

h. Clinical research participant satisfaction: Enhance recruitment and retention of research participants, especially those from priorities groups historically underrepresented. Develop and implement standardized tool(s) to survey participants regarding their experience as a participant in clinical research. Implement for each publicly-funded research project/clinical trial involving human subjects. Encourage/provide incentives/require data collection and analysis at various levels: individual investigator, institution, clinical trials network, etc. Discuss with ACTG and other HIV research networks.

3. **Biomedical Scientific Agenda**: improved understanding of risk factors and pathophysiologic factors associated with comorbidity burden among individuals with HIV, innovative and HIV-specific tools for early comorbidity detection and prevention.<Collins, 2022 >

a. Premature aging and frailty

b. Biology of aging with HIV and biomedical interventions to mitigate/reverse such accelerated and/or accentuated aging (e.g., senolyitcs)

c. HIV-related cancers, screening and treatment

d. Metabolic disorders

e. Neurocognition

f. HIV Long-term Survivors: Enhance understanding of AIDS Survivor Syndrome/ complex PTSD;< Anderson, 2016 > identify best practices to mitigate and manage the comorbidities and unique needs of (pre-HAART) Long-term Survivors (LTS);

g. Long-term effects of hormone therapy among persons aging with HIV and taking cARTs:

i. Transgender women taking estrogen (gender-affirming hormone therapy)

ii. Transgender men taking testosterone (gender-affirming hormone therapy)

iii. Cisgender men with HIV taking testosterone due to hypogonadism (hormone replacement therapy/HRT)

iv. Cisgender women with HIV taking estrogen HRT at menopause.

h. Vaccinations:

i. Develop and publish evidence-based guidelines re. safety and efficacy for PLWH of the various vaccine platforms, e.g., mRNA, viral vector, etc.

ii. HIV and "immune amnesia," the gradual loss of immunity induced by childhood vaccinations.< Thomas, et al, 2020 > The growing number of PLWH above age 50 makes it vital for us to understand this issue and assess the potential need for revaccination due to HIV-mediated immune system amnesia/immune-senescence.

i. HIV cure research: Balance within the HIV cure research portfolio to ensure full and fair exploration and development of cure strategies for both long-term/chronic infection, acute/early-treated infection, and verticals.

4. **Community-engaged research:** Provide greater support for use of community-informed, community-engaged, and community-based participatory research methodologies.

References

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06 | ACRONYMS AND ABBREVIATIONS

Acronyms and Abbreviations

Last updated: January 24, 2023 by Thomas J. Villa

ACA	The Affordable Care Act (formally, the Patient Protection and Affordable Care Act)
ACTG	AIDS Clinical Trials Group
AETC	HRSA's AIDS Education and Training Center program
ARC	AIDS Research Centers program of the National Institute of Mental Health
ART/cART	Anti-retroviral therapy / combination ART
ASO	AIDS services organization
CBO	Community-based organization
CFAR	Centers for AIDS Research
CVD	Cardio-vascular disease
EHE	*Ending HIV in the US* initiative
EHR	Electronic health record
FQHC	Federally-qualified health center
HCV	Housing Choice Voucher (Section 8)
HHS	US Department of Health and Human Services
HIV	Human immunodeficiency virus
HOPWA	Housing for Persons with AIDS program
HRQoL	Health-related Quality of Life
HRSA	US Health Resources and Services Administration
HUD	US Department of Housing and Urban Development
LGBT+	Inclusive terms for persons who identify as lesbian, gay, bisexual, transgender, gender non-binary, or other
LTS	Long-term survivor / HIV long-term survivor
MIPA	Meaningful Participation of People with HIV/AIDS
NHAS	National HIV/AIDS Strategy (2022-2025)
NIH	US National Institutes of Health
NIMH	National Institutes of Mental Health
PACE	Program of All-inclusive Care for the Elderly

ACRONYMS AND ABBREVIATIONS

PLWH/PWH	Person(s) living with HIV
OPLWH	Older person(s) living with HIV
OAR	Office of AIDS Research of the US National Institutes of Health
RWHAP	Ryan White HIV/AIDS Program
SDOH	Social determinants of health
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
SNP	Special Needs Plan
VA	US Department of Veterans Affairs
VHA	Veterans Health Administration
WLWH	Women Living with HIV

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