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Women's Research Initiative on HIV/AIDS (WRI) 2026

WRI

Summary of WRI Webinars on Lifetime Survivors

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Together, we can change the course of the HIV epidemic…one woman at a time.

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Introduction

- Summary from three WRI 2026 webinars:
  - *Living with and Treating HIV for a Lifetime* (May 19)
  - *Sexual and Reproductive Health* (June 18)
  - *Accelerated Aging and Comorbidities* (July 21)
- Top-line points across clinical care, psychosocial issues, lived experience, and health care delivery.
- Shared throughlines across all three:
  - "Life does not pause for HIV"
  - Lifetime survivors remain underrepresented in research and care models built around other populations.

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Webinar 1: Living With and Treating HIV for a Lifetime

Presented by Allison Agwu, MD, Ezer Kang, PhD, and Tia Morgan-Revere, MS

- Traced the history of pediatric/perinatal HIV--from the first identified U.S. infant case (1982) to today's roughly 12,800 lifetime survivors.
- Framed survivorship simultaneously as a medical story (treatment evolution), a social/historical story (shifting stigma narratives), and a personal story (lived experience).







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Living With and Treating HIV for a Lifetime: Clinical Points (1)

Longer Lives, but a Persistent "Healthspan Gap"

- Life expectancy with HIV has improved dramatically, but **comorbidity-free years remain far fewer for people with HIV** than without — roughly 11–15 comorbidity-free years versus 27–31 for peers without HIV.
- Lifetime survivors are estimated to **lose roughly 9–16 healthy years** compared to peers without HIV, even under modern treatment.
- By age 30, young adult lifetime survivors show **markedly higher cumulative rates of type 2 diabetes, high cholesterol, high triglycerides, hypertension, and chronic kidney disease** than the general population.
- **Multimorbidity, cardiovascular disease, and neuropsychiatric conditions are all more common** among people living with HIV than among those without.

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Living With and Treating HIV for a Lifetime: Clinical Points (2)

Decades of Treatment Evolution Leave a Toxicity Legacy

- Antiretroviral therapy (ART) evolved from toxic, complex multi-drug regimens in the 1980s–90s (e.g., stavudine, didanosine) to well-tolerated single-tablet regimens today — so **a lifetime survivor's birth cohort determines which drugs shaped their body**.
- Earlier, **more complex regimens carry lasting effects** across nearly every organ system: central nervous system (neuropathy), bone (osteoporosis/osteopenia), liver, kidney, heart, and body composition (lipodystrophy).
- Lifetime survivors face a **distinctive mix of treatment fatigue, drug resistance carried over from earlier suboptimal regimens, and an ongoing "quest to be normal"** while managing a lifelong, highly visible medical regimen.

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Living With and Treating HIV for a Lifetime: Psychosocial Points

Historical Stigma Narratives Shape Mental Health

- Adult lifetime survivors have **lived through roughly four developmental periods and three decades of shifting HIV narratives** — the public story changed even as they grew up inside it.
- Framing has shifted along three axes**: innocence → culpability; crisis → chronicity; self-protection → public safeguarding** each with real consequences for how survivors were seen and treated.
- In the 1990s, people with AIDS were sorted into "carriers" versus "victims"; **children were viewed most sympathetically but held essentially no power** to shape their own narrative.
- These shifting narratives have contributed to both "flourishing and languishing" mental health among adult lifetime survivors; **internalized stigma carries cumulative, long-term psychological effects**.

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Living With and Treating HIV for a Lifetime: Lived Experience Points

"More Than a Diagnosis"

- Beating the odds and **surviving and thriving** (including post-graduate degrees, marriage, motherhood).
- Invisible **weight of survivorship**: stigma carried through daily life, exhaustion from constant health vigilance, and survivor's guilt from losing friends and community members along the way.
- Pediatric-to-adult **care transition** is a distinct challenge — learning independence in health management and finding one's own voice in medical decisions.
- Healing may come through **community and advocacy** --"We are no longer just surviving — we are building lives."

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Living With and Treating HIV for a Lifetime: Health Care Delivery Points

A High-Risk Transition and a Thin Evidence Base

- **Care needs shift by decade of life** — from pediatric/adolescent care and simple regimens in the second decade, to full self-management and rising comorbidities from the third decade onward.
- The transition from familiar pediatric teams to adult health systems is a **vulnerable, destabilizing juncture** requiring deliberate relationship-building and skill transfer.
- Current evidence relies on a patchwork of case reports and single- or multi-site cohorts (e.g., Johns Hopkins, PHACS, IeDEA, NA-ACCORD), each with real limitations — **no purpose-built research infrastructure** yet exists to address health care delivery for lifetime survivors specifically.

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Webinar 2: Sexual & Reproductive Health

Presented by Amelia Stanton, PhD; Kimberly Canady, BS, and Kathleen M. Powis, MD, MPH, MBA

- Sexual and reproductive health (SRH) is a **fundamental human right** and a life-course issue — spanning sex education, family planning, maternal and newborn care, STI prevention, menopause, and reproductive cancers.
- Both research and lived experience argue that SRH care for lifetime survivors must **go beyond risk reduction to address pleasure, intimacy, and autonomy.**







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Sexual & Reproductive Health: Clinical Points (1)

Two Federally Funded Studies Help Build the Evidence Base

- HOPE Study: 14-site U.S. longitudinal cohort of 856 women with HIV, ages 18–45, **tracking health outcomes** across the reproductive years.
  - 30% are lifetime survivors
- UPLIFT Study: examines **infant-feeding decisions** among women with HIV.
  - evidence shows likelihood of HIV transmission during breastfeeding is under 1%
  - with sustained viral suppression, shifting guidance from "can women breastfeed?" to "how do we best support women who choose to breastfeed?"
- Both studies model **shared decision-making** between women and their care teams rather than one-size-fits-all clinical directives.

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Sexual & Reproductive Health: Clinical Points (2)

Lifetime Survivors Are Not a Monolithic Population

- **Birth cohort and treatment era shape SRH experience**: women who survived childhood before combination ART was available were more likely to face prolonged uncontrolled viremia and exposure to older, more toxic regimens.
- Women diagnosed and treated more recently benefited from **earlier viral suppression and better-tolerated regimens** — producing meaningfully different reproductive, psychosocial, and aging trajectories.
- Implication for research and care alike: **findings from one cohort of lifetime survivors should not be assumed to generalize** to all lifetime survivors.

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Sexual & Reproductive Health: Psychosocial & Lived Experience Points

Reclaiming Pleasure, Intimacy, and Narrative

- Women living with HIV **want to reclaim their stories** beyond risk, transmission, and disease management:
  - A digital storytelling project found narratives centered on pleasure, dating, disclosure, motherhood, self-love, and resilience, and participants described the **process itself as validating and healing**.
  - Direct message to clinicians and researchers: "Healing isn't only about surviving HIV. It's about learning that a woman's **needs, desires, boundaries, and pleasure mattered too**."
  - A community input exercise asked directly: "What do you wish people asked you about in terms of sex, relationships, and having children?" — underscoring that **clinical encounters often omit these topics** entirely.

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Sexual & Reproductive Health: Health Care Delivery Points

Toward Integrative, Pleasure-Inclusive SRH Care

- SRH services should be **fully integrated** with holistic HIV care, designed to be inclusive, nonjudgmental, accessible, and evidence-based.
- Sex education and counseling should **explicitly address pleasure and satisfaction**, not only risk reduction and prevention.
- Care models should be **responsive to needs** that lifetime survivors themselves have voiced — not only needs assumed by providers or researchers.

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Webinar 3: Accelerated Aging & Comorbidities

Presented by Alora Gale, Sahera Dirajlal-Fargo, DO, Christina Psaros, PhD, and Leah Rubin, PhD

- Lifetime survivors are "the **quintessential long-term survivors**," who are nonetheless often left out of aging-and-HIV conversations designed around people diagnosed in adulthood.
- Aging is **shaped by an evolving social context** (stigma, discrimination), cumulative loss of family, friends, and community, treatment uncertainty across shifting eras, and intersecting forms of discrimination (ageism, racism) — producing chronic stress and, for some, trauma layered on top of ordinary aging.






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Accelerating Aging & Comorbidities: Clinical Points

Accelerated Biological Aging and Cardiovascular Risk

- HIV is associated with roughly **9–16 fewer comorbidity-free years** even as overall lifespan has improved; ART slows the accelerated biological aging trajectory but does not fully reverse it.
- Young adults and lifetime survivors show **elevated rates of HIV-related cardiovascular comorbidities** — cardiomyopathy, subclinical vascular disease, endothelial dysfunction, and cardiac fibrosis/inflammation — yet few cardiovascular prevention trials enroll participants under age 40.
- The REPRIEVE trial (statin) demonstrated **cardiovascular benefit for adults with HIV ages 40–75**, leaving open whether and when younger lifetime survivors should begin preventive therapy.
- HIV and aging produce **overlapping, compounding comorbidity profiles** (heart, kidney, liver, bone, metabolic, and cognitive), with medication toxicity adding a further layer of risk.

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Accelerating Aging & Comorbidities: Brain Health Points

Cognitive Trajectories Are Not One-Size-Fits-All

- Brain health reflects the **cumulative effects** of biological, physical, psychosocial, and structural factors across the entire life course — not just current HIV status.
- A decade of research on women aging with HIV shows **distinct cognitive trajectories**: decline in one cognitive domain does not necessarily predict decline in others.
- Patterns of cognitive impairment **differ by s**ex — brain health in women aging with HIV does not simply mirror findings in men, underscoring the **need for sex-specific research**.
- **Structural and environmental factors** — food deserts, walkability, housing quality, green space, neighborhood safety — shape the health behaviors that could otherwise help mitigate cognitive risk.

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Accelerating Aging & Comorbidities: Psychosocial Points

Chronic Stress, Trauma, and Resilience in Aging

- **Chronic stress and complex trauma** (from loss, uncertainty, stigma, and intersecting discrimination) manifest as anxiety, hypervigilance, grief and guilt, avoidance, and sometimes health-compromising coping such as substance use.
- Despite this, many lifetime survivors show **real resilience** — through acceptance and meaning-making, strong relationships, and active self-management of their health.
- A review of the evidence found **psychosocial interventions** produce meaningful, if modest, improvements in depression, coping, and quality of life — but scalable, age- and sex-specific programs remain scarce.

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Accelerating Aging & Comorbidities: Health Care Delivery Points

A Geriatric, Trauma-Informed Care Model

- **Structured geriatric-style framework applied early** — even though lifetime survivors can be any age — using a "5 Ms" approach (Mind, Mobility, Medications, Multimorbidity, Matters Most) plus a proposed sixth "M": Modifiable.
- **Embedded mental health and trauma-informed ca**re that addresses survivor guilt, depression, and anxiety as distinct from general geriatric mental health needs.
- **Team-based staffing** beyond infectious disease/primary care — incorporating social workers, chaplains, mental health specialists, and rehabilitation therapists.
- **Structural and social determinants** — housing instability, poverty, transportation barriers — treated as **core clinical priorities**, not optional add-ons.
- **Providers:** assess structural barriers, mental health, social connectedness, stigma, sexual satisfaction, and adherence; acknowledge survivors' own expertise; and offer trauma-informed, evidence-based interventions that help solve real barriers to wellness.

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Cross-Cutting Points from All Three Webinars

- A **life-course lens** is essential.
- There are clear **medical/clinical and psychosocial differences** between lifetime survivors and others living with and not living with HIV.
- Lifetime survivors are **not one population**-- be cautious of generalizing.
  - **Birth cohort** is important.
- **Stigma's psychological effects compound** across life domains—they don't just sit in one mental health arena.
- While there is evidence of hardship and difficulty for lifetime survivors, there also is **evidence of resilience and self-advocacy**.
- Health care (broadly defined) must **center the voice of lifetime s**urvivors directly and **build integrated, team-based, whole-person, affirming care** rather than siloed, disease-specific and deficit-driven models.

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Core Research Gaps Identified Across The Webinars

- Very little research treats lifetime survivors as a **distinct population**.
  - Most data comes from mixed cohorts combining lifetime survivors with people diagnosed or aging with HIV later in life — and even fewer studies focus specifically on women lifetime survivors.
- The **evidence base is fragmented** across case reports, single- and multi-site cohorts, and modeling studies, each with real limits:
  - Relevant findings are sometimes "tucked into" adjacent research topics (e.g., HPV studies), making them hard to locate, synthesize, or act on.
- **Birth-cohort and treatment-era heterogeneity** is rarely built into study design, despite clear evidence that survivors' experiences differ substantially depending on when they were born and initiated treatment.

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Sample Open Research Questions Identified Across The Webinars

- Clinical:
  - Should younger lifetime survivors receive preventive cardiovascular therapies before current age-based risk thresholds apply?
  - Can "biological age" under modern ART be reversed, not just slowed (geroprotector research)?
  - What does optimal, operational infant-feeding support look like in practice?
- Psychosocial / Brain health:
  - How do distinct cognitive trajectories intersect with reproductive milestones (e.g., menopause) and cumulative psychosocial stress over decades?
  - What are the long-term effects of shifting historical stigma narratives on mental health across the lifespan?
- Structural:
  - How can resilience-building and trauma-informed interventions be scaled and tailored by age and sex, rather than adapted wholesale from general geriatric or general-HIV models?

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Key Research Opportunities Identified Across The Webinars

- Build lifetime-survivor-specific, women-centered longitudinal research infrastructure (expanding HOPE-like models).
- Center lifetime survivor voices directly in research design.
- Improve dissemination so findings don't stay buried inside adjacent literatures.

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Thank You!









