

The Pan-Canadian Research Agenda on HIV, Aging & Older Adulthood

Preamble

Population aging significantly influences governmental and organizational decision-making in Canada. Setting priorities for aging research requires close attention to health equity since new knowledge can be mobilized to shape policies and practices that affect the well-being of diverse aging and older adults. Research on new and emerging populations of aging and older adults – for example, people living with HIV - is critical as it may challenge dominant narratives about common trajectories of aging and homogenous aging-related needs.

We lack national-level data on the proportion of people living with HIV in Canada who are aging (age 50-59) and older adults (age 60+), but modelling suggests that between 40-50% of the 62,050 people living with HIV in Canada are within these age groups.^{1,2} That equates to between 25,000-31,000 aging and older adults living with HIV in Canada. This population continues to grow as the life expectancy of people living with HIV approaches that of the general population and people aged 50 and older account for a significant proportion of new HIV diagnoses.

Research in the field of HIV and aging has burgeoned over the last decade, but many gaps remain in our collective knowledge and resultant implementation of evidence-based responses. The needs and preferences for support of the *first cohort* of people to reach older adulthood (age 60+) with HIV need to be clearly understood, articulated, and translated into action, and soon, if we are to achieve parity in objective health outcomes and subjective determinations of ‘aging well’ among older adults, regardless of HIV status.

The Pan-Canadian Research Agenda on HIV, Aging and Older Adulthood represents a clear, community-informed plan to optimize the impact of research focused on HIV, aging and older adults in Canada over the next five years. The recommendations herein will ensure that the efforts of knowledge keepers, mobilizers, and users in the previously siloed fields of HIV and gerontology are synergistic, centre the living expertise of aging and older people living with and affected by HIV, and lead to the development of effective, equitable HIV- and aging-related policies, practices, and programs.

¹ Smit M, Brinkman K, Geerlings S, Smit C, Thyagarajan K, Sighem Av, de Wolf F, Hallett TB; ATHENA observational cohort. Future challenges for clinical care of an ageing population infected with HIV: a modelling study. *Lancet Infect Dis*. 2015 Jul;15(7):810-8.

² Autenrieth, C. S., Beck, E. J., Stelzle, D., Mallouris, C., Mahy, M., & Ghys, P. (2018). Global and regional trends of people living with HIV aged 50 and over: Estimates and projections for 2000-2020. *PloS one*, 13(11), e0207005.

Sources of Evidence

The recommendations in The Pan-Canadian Research Agenda on HIV, Aging and Older Adulthood are supported by evidence collected through:

- Think Tank discussions held with 51 HIV and aging research stakeholders (aging and older adults living with HIV, community-based researchers, social science and programmatic researchers, researchers studying aging in related populations, clinical researchers) in March 2021
- The *Environmental Scan of In-Process Research Activities on Health, HIV and Aging* conducted in June-September 2021
- Consultations with members of the National Coordinating Committee on HIV and Aging's Research Working Group (NCC)

Interested Parties

The Pan-Canadian Research Agenda on HIV, Aging and Older Adulthood is a tool to guide decision-making by four interested parties:

- 1) Research Funders and Grant Review Committees
- 2) Principal Investigators and Research Team Members
- 3) Policy Makers and Policy Change Advocates
- 4) Institutions, Residential Care Settings and Community-Based Organizations

The recommendations are relevant to stakeholders engaged in most types of HIV- and aging-related research and evidence production, including epidemiological studies, community-based research projects, biomedical and clinical trials, implementation science initiatives and program evaluation. There are two notable exceptions. The NCC does not have the expertise to make recommendations regarding priorities for basic science research and drug development.

The Pan-Canadian Research Agenda on HIV, Aging and Older Adulthood includes recommendations organized around five themes:



Complexity & Connectedness



Phase & Phrase



What's Working



Diverse Viewpoints



Making Connections for Change

Complexity & Connectedness

Aging and older people living with HIV are *whole* persons living within communities and society. According to the 2021 *Environmental Scan of In-Process Research Activities in Canada Related to Health, HIV and Aging*, almost half of the research currently being done on HIV and aging in Canada focuses on physical health, including a significant proportion that examines age-related comorbidities. There is a heavy bias towards biomedical research, both in terms of financial investment and total number of studies. An assessment of the comprehensive physical, social, emotional, sexual, cognitive and resource needs of aging and older adults living with HIV in Canada has not been conducted to-date. A lot of uncertainty exists among people living with HIV, their clinicians and service providers regarding the long-term impact of combined antiretroviral therapy, access to non-judgmental aging-related care and support, and the availability of informal carers.

Recommendations:

- 1.1 Broaden the scope of inquiry beyond physical health and illness to include the mental/emotional well-being of people getting older with HIV (e.g., trauma, loss, survivors' guilt, loneliness) and the social context of aging with HIV (e.g., intimacy, caregiving relationships, intersecting forms of stigma, social isolation).
- 1.2 Investigate attitudes and beliefs among care providers and society at large that perpetuate HIV-stigma, ageism and intersecting forms of stigma and discrimination, negatively affecting the well-being of aging and older people living with HIV.
- 1.3 Measure and describe the impact of social and structural determinants on the health of aging and older adults living with HIV (e.g., housing, income, benefits, food security, employment, etc.).
- 1.4 Conduct formal program evaluations to assess the impact, accessibility, and acceptability of existing aging-focused programming to people living with HIV.
- 1.5 Prioritize research on the impact of disability on aging and older adults living with HIV and potential rehabilitative strategies. Community members are calling for research on:
 - Pain management
 - Cognitive impairment
 - Fatigue
 - Sensory changes (e.g., vision, hearing)
 - Sexuality
- 1.6 Track the short- and long-term effects of antiretroviral therapy (ART) and the impact of polypharmacy on aging and older adults living with HIV.
- 1.7 Seek out aging and older adults living with HIV who have lived in, or currently live in, residential and institutional care (e.g., hospitals, hospice/palliative care, long-term care, supportive housing) to ask how HIV-related stigma and its intersection with other forms of stigma, impact the care they receive and how current staff and volunteer training could be improved.

- 1.8 Characterize models of care and institutional policies that support aging and older adults, including people living with HIV, to maintain their identity, community, and autonomy in these settings to reduce uncertainty and anxiety, especially for communities who face intersecting forms of stigma (e.g., HIV-related stigma, homophobia, transphobia, racism, etc.).
- 1.9 Assess the comprehensive service and support needs of older adults living with HIV. Analyses should consider differences in access to services and care among sub-populations of older adults living with HIV (e.g., women, diverse ethno-cultural communities, urban and rural dwellers, etc.).
- 1.10 Prioritize exploratory qualitative research on aging with HIV, particularly to address current gaps in research on the experiences of communities affected by intersecting forms of stigma and use qualitative data to help make sense of quantitative data being amassed.
- 1.11 Optimize the use of existing data to reduce the burden of research participation on aging and older adults living with HIV. Health administrative data can be used to quantify and describe service use across care delivery settings, and chart reviews can be used to assess multiple health domains.

Phase & Phrase

All people living with HIV in Canada are *getting older*, some are *aging* (age 50-59), and some are already *older adults* (age 60+) but too often research funding calls and proposals use these *phrases* interchangeably, effectively erasing important distinctions between age cohorts. People of different chronological ages may have distinct care needs, access to resources, and lived experiences. *Phase* of life also requires consideration in research on HIV, aging and older adulthood as many of the factors that shape a person's wellbeing – social roles, sources of income, a sense of purpose – change across the life course, and not necessarily in concert with chronological age. Finally, the *age* of a person's HIV – in other words, the length of time they have lived with HIV and the historical context in which they were diagnosed – is a separate, but often overlapping determinant of health. In HIV-focused research, clear distinctions must be made between aging, older adulthood, and long-term survivorship. Moreover, it is important to define the chosen terms as concepts such as aging have historically been used differently in the HIV community than in gerontology or policymaking.

On the agenda:

- 2.1 Engage participants of diverse chronological ages and different life stages (e.g., pre- and post-retirement; before and after eligibility for Old Age Security) in HIV and aging research.
- 2.2 Pursue longitudinal research that follows people living with HIV from the time of diagnosis, through older age, until end-of-life.
- 2.3 Re-examine the late life and end-of-life experiences and care needs of aging and older adults living with HIV (e.g., perspectives on medical assistance in dying, access to/use of hospice and palliative care, etc.) in the era of effective ART.
- 2.4 Differentiate between projects that address the needs and experiences of three populations with distinct, but often overlapping, needs in funding calls and research proposals:
 - “older adults living with HIV”³
 - “people living long-term with HIV” and
 - “people aging with HIV”.
- 2.5 Employ implementation science to design effective models of care and programming that address the needs of the oldest people living with HIV in Canada who may already need services and supports for seniors.
- 2.6 Study how ageism, along with other relevant, intersecting systems of oppression, impact the lives of aging and older people living with HIV.

³ “Older persons” are defined by the United Nations as people age 60 years or older. See United Nations Development Program. (2017). Ageing, Older Persons and the 2030 Agenda for Sustainable Development. Accessible from: https://www.un.org/development/desa/dspd/wp-content/uploads/sites/22/2017/08/Ageing-Older-Persons-and-2030-Agenda_Issues-Brief-low-resolution-.pdf

What's Working

To create the social and structural conditions needed to foster optimal wellbeing among aging and older people living with HIV in the context of an underfunded community-based HIV response and an aging Canadian population, evidence is needed. We need to illustrate what aging well with HIV 'looks like' and how it compares to aging without HIV; develop clinical and research tools to measure gaps between an individual's current and desired states of well-being; and evaluate responses that claim to effectively maintain or improve individual and community health. The *Environmental Scan* identified few in-process research projects in which assessment tools and/or models of care relevant to the needs of aging and older adults living with HIV were being developed or evaluated.

On the agenda:

- 3.1 Validate an assessment tool to clarify personal expectations of aging well for individual people living with HIV based on individual goals and self-determined criteria for 'success'.
- 3.2 Conduct comparative research into the experience of getting older with and without HIV, using appropriately matched comparator groups, to tease out the contribution of HIV to the overall experience of aging and the resultant implications for older people living with HIV.
- 3.3 Establish community consensus about what is needed to ensure optimal aging with HIV so that public and organizational policy and care practices can be measured against this benchmark.
- 3.4 Evaluate existing HIV and aging care models to assess whether they are holistic (e.g., addressing physical, mental, emotional, sexual, financial, and other domains of well-being) and fully integrate preventive health strategies.
- 3.5 Evaluate patient satisfaction with clinical care among aging and older adults living with HIV.
- 3.6 Assess gaps in knowledge related to HIV and aging among health and social care providers across diverse settings, provider types, and specialities (e.g., HIV care, aging care, home and community care, long-term care, social work, nursing, medicine, rehabilitation, etc.).
- 3.7 Evaluate the effectiveness and acceptability of chronic disease management programming for aging and older people living with HIV, especially as they support managing chronic pain.
- 3.8 Assess the availability and acceptability of educational resources on sexuality and pleasure for aging and older adults living with HIV.

Diverse Viewpoints

Inclusivity is key to impactful research on HIV, aging and older adulthood. There are very few projects currently underway that focus on the needs of women, non-binary and trans-identifying people aging with HIV, or the experience of racialized older adults living with HIV. Bias is introduced into the research process and findings when aging and older adults living with HIV who are faring less well physically, mentally, financially, or otherwise experience barriers to engagement, both as potential research team members and research participants. Low-barrier research methods and multi-pronged approaches to research team building are needed.

On the agenda:

- 4.1 Increase meaningful participation by aging and older adults living with HIV across the research process from conceptualization of the study to translating knowledge into practice. It's imperative that community members be involved in interpreting the findings, no matter the type of data or analysis used.
- 4.2 Design research sampling strategies that engage diverse communities of aging and older adults, both as members of the research team, and as research participants. Be attentive to intersectionality.
- 4.3 Build and strengthen community partnerships to engage aging and older adults whose perspectives are not well-represented in HIV and aging research, including:
 - Racialized communities
 - Indigenous communities
 - Women, non-binary, two-spirit, and trans- people
 - Men who identify as heterosexual
 - People living in residential care
 - People aged 70+
 - People who are not associated with a community-based HIV organization
 - People newly diagnosed with HIV
 - People who use drugs
 - People who are vulnerable to HIV
- 4.3 Consider multifaceted approaches to research team member engagement and data collection that facilitate participation in research by aging and older adults living with HIV who are home-bound, constrained for time, living outside urban centres, reliant on caregivers, experiencing mobility issues or lack technological skills.

Making Connections for Change



Think Tank participants unanimously agreed that research evidence on HIV, aging and older adulthood often ends up being shelved instead of being translated into programs or practice or mobilized to change policy. Research and practice are largely funded independently leading to great demonstration projects never being scaled up. As some people living with HIV are already in their 60s, 70s and 80s, this pipeline needs to be streamlined if we hope to make changes that improve their well-being in aging. Strategic partnerships designed to leverage the expertise of, and disseminate findings among, diverse actors in the HIV/STBBI and aging sectors, including aging and older adults living with HIV, community-based service providers, clinicians, researchers, and policy makers, need to be built. Active forms of knowledge mobilization beyond simple information sharing should be prioritized.

On the agenda:

- 5.1 Ask research questions that address urgent, unmet needs for information among aging and older people living with HIV; fill existing knowledge gaps among those who provide support and care to aging and older adults living with HIV; or generate findings with the potential to influence significant changes in policy to better the health and well-being of aging and older adults with HIV.
- 5.2 Plan for and produce accessible outputs that communicate research findings in plain language (e.g., storytelling, social media content, mobile apps, fact sheets, self-assessment tools, referral lists, infographics, webinars, media interviews, non-academic articles, health guides, etc.) and identify channels for dissemination that get these tools into the hands of aging and older people living with HIV, community-based service providers, and primary care physicians.
- 5.3 Engage policy experts, political actors, and other knowledge users across the research process, especially in developing research questions about HIV, aging and older adulthood. Engage research team members from both the HIV and aging sectors.
- 5.4 Conduct stakeholder analysis of HIV and STBBI policies to determine how older adults living with HIV perceive policy goals (e.g., “ending the AIDS epidemic”).

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