

# Gauging Gaps and Gaining Ground: A Pan-Canadian Perspective on HIV and Aging Research and Setting Research Priorities

**2021 Think Tank Report**

**March 2021**



**Realize** is the leading national, charitable organization working to improve the health and well-being of people living with HIV and other episodic disabilities, across the lifespan, through integrated research, education, policy and practice. **Realize** members come from across Canada, as well as internationally, and include people living with HIV and other chronic conditions, members of community-based HIV and disability organizations, national associations of health professionals, government agencies, private businesses, universities, and the employment sector.

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## Acknowledgements

We respectfully acknowledge that the **Realize** office sits on the traditional territory of the Wendat, the Anishnaabeg, Haudenosaunee, Métis, and the Mississaugas of the Credit First Nation.

Think Tank Participants:

Our sincerest thanks to the 50+ people from across Canada who participated in our Think Tank discussions. We appreciate your willingness to share your time, experience, and ideas.

Think Tank Planning Committee:

**Realize** would also like to recognize and thank those whose input shaped the form and content of the event, including **Realize** staff and students, and members of the National Coordinating Committee on HIV and Aging (NCC), Research Working Group:

*Puja Ahluwalia*

*Charles Furlotte*

*Hannah Kia*

*Jacob Mathew*

*Kate Murzin*

*Celeste Pang*

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Think Tank Co-Facilitator:

The Think Tank sessions flowed smoothly and elicited rich dialogue thanks to skillful co-facilitation by *Alphonso King Jr.*, also known as *Jade Elektra*, an out HIV activist, founder of POZ-TO and POZPLANET Magazine, actor, DJ Relentless, recording artist and community leader.

Think Tank Funders:

This project was made possible by grants and sponsorship from the following organizations:

A grant from the Public Health Agency of Canada

A grant from Gilead Sciences Canada, Inc.

Think Tank Report Authorship:

**Realize** would like to thank *Sunny Wang* for her swift and thorough analysis of the information and ideas shared across the Think Tank discussions and primary authorship of this report.

## About the Think Tank

### Background

The average age of people living with HIV in Canada has been on the rise since the introduction of combination antiretroviral therapy (cART) 25 years ago. Many individuals have reached a point where their aging-related healthcare and broader support needs are more pressing than their HIV-related needs. Still, the experience of living with HIV, and that of being an older person, remain inextricably intertwined. The well-being of each older adult living with HIV today is impacted by their cumulative lived experiences, their chronological age, and the trajectory of their HIV diagnosis, treatment and care. High levels of complexity impact how they understand and cope with the experience of aging and their ability to navigate services to optimize well-being.

As this is the first cohort to experience the intersectional identity of ‘older adult living with HIV’, there remain many unanswered questions about their information and support needs and preferences. Some of these are currently being explored by research teams, and in conversation among community members, across Canada. Other questions of significant interest to older people living with HIV and those who support them still need to be asked and answered.

### Purpose

*“A think tank is defined as a process for in-depth consideration of issues and challenges whose relevance reaches beyond the individual person or program and the immediate time frame.”*  
(Caliva & Scheier, 1992)

The purpose of the Think Tank was to identify shared and divergent perspectives, key themes, and emerging issues across diverse stakeholder groups to inform the development of a national research agenda on HIV, aging and older adulthood in Canada.

We felt it was time to systematically review current research efforts in the field of HIV, aging and older adults to identify areas of strength and potential gaps. Future research priorities will emerge from this analysis and should centre the issues of greatest importance to older adults living with HIV in Canada. Research evidence can be a powerful tool for influencing policy and practice to make change that improves the lives of this burgeoning population.

### Format

**Realize’s** 2021 Think Tank was held virtually, with invited participants joining one of six small-group facilitated discussions held between March 8-17, 2021. Each session was co-facilitated by Kate Murzin, **Realize’s** National Program Manager and program lead on HIV and aging initiatives, and Alphonso King Jr., either as himself or as beloved drag persona and recording

artist Jade Elektra. Information and ideas shared during the sessions were captured by two note-takers.

## Summary Description of Think Tank Participants

In total, 51 unique participants attended six Think Tank sessions. Each session was attended by at least one member of the National Coordinating Committee on HIV and Aging, Research Working Group. The stakeholder perspectives represented in each meeting are listed below:

Session 1 - March 8<sup>th</sup>: Community perspectives (Older Adults Living with HIV)

Session 1a: 9 participants

Session 1b: 10 participants

Session 2 - March 10<sup>th</sup>: Community-based researchers (10 participants)

Session 3 - March 11<sup>th</sup>: Social science and programmatic researchers (9 participants)

Session 4 - March 15<sup>th</sup>: Researchers studying aging in related populations (7 participants)

Session 5 - March 17<sup>th</sup>: Clinical researchers (7 participants)

## Key Issues and Emerging Themes

### 3A. Summary of Key Issues By Stakeholder Group

Across all five stakeholder groups, the following topics emerged as common themes:

1. Long-term care: transitioning and maintaining autonomy
2. Stigma in systems and institutions
3. HIV and aging: putting research into practice
4. Priorities for research: expansion, engagement and expertise
5. HIV and aging in the post-COVID-19 era

Within these five overarching topic areas, each stakeholder group prioritized different research questions related to HIV, aging and older adulthood.

Community perspectives from Older Adults Living with HIV (OALWHIV) focused on:

1. How aging with HIV impacts the physical body
2. Sexual intimacy, function, and expression
3. Equity, diversity and inclusion in research and care settings
4. Addressing uncertainty in aging

Community-based researchers focused on:

1. Creating and maintaining spaces for wellness for OALWHIV in community and institutional settings (ex. long-term care facilities)
2. Reframing research by focusing on equity and practicing researcher reflexivity
3. Addressing long-term survivorship and research in the era of “ending HIV” and post-COVID-19

Social science and programmatic researchers focused on:

1. Building resilience through engaging community and healthy living
2. Involving racialized communities in research

Researchers studying aging in related populations focused on:

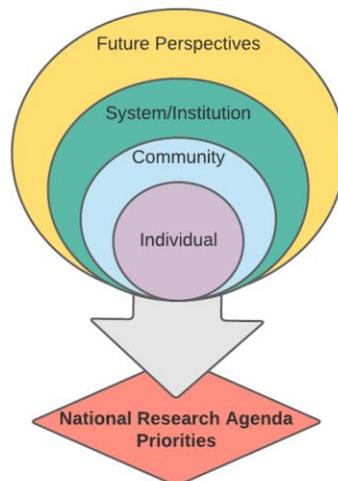
1. Tension between community structures and institutional structures
2. Long-term care and maintaining autonomy and identity
3. What it means to age well and strategies to manage the effects of aging

Clinical researchers focused on:

1. Developing a model of HIV and aging care focused on preventative and holistic care
2. Risk factors and disease burdens in HIV and aging
3. Knowledge translation and implementation
4. The need for longitudinal studies with long-term follow-up of OALWHIV

### **3B. “Nested” Diagram: 4 Levels of Research Priorities in HIV and Aging**

The diagram below categorizes topics raised by all stakeholder groups across the Think Tank sessions within 4 “nested” levels. It is important to note that all levels are dynamic and interact with one another despite the boundaries that separate them.



**The Individual:** At the core of the diagram is the individual who lives and ages with HIV. This level encompasses research topics that explore the implications of HIV and aging on the body, mind and spirit.

OALWHIV discussed experiencing pain, neuropathy, cognitive impairment, fatigue, cardiovascular and lung disease, and loss of eyesight/hearing. A priority for OALWHIV was understanding the risk factors for common comorbidities associated with aging with HIV (e.g., neurological disorders, cancer), namely: sexually transmitted and blood-borne infections (STBBI), obesity, tobacco and drug use. Short-term and long-term effects of antiretroviral (ARV) medication on sexual function and the aging body, as well as potential interactions with other medications, were of specific concern to OALWHIV.

The need to improve our collective understanding of mental health issues among OALWHIV was a common thread among all stakeholder groups. Specifically mentioned were trauma, loss, social isolation and managing “survivor’s guilt”.

As our understanding of interactions between aging, HIV, comorbidities and medication use improves, future research should focus on chronic disease management strategies. Preventative care and the use of substances to mitigate pain and neuropathy were topics of particular interest for both clinical researchers and OALWHIV.

**The Community:** At the community level lies the importance of addressing interpersonal relationships, intimacy, sexual pleasure, and social support in HIV and aging research.

For OALWHIV, it is important to explore strategies for managing loneliness, loss, and isolation; explore ways to build a support network with other OALWHIV; and negotiate intimacy and care with partners and loved ones. Understanding how relationships with friends or family members may change as they take on the role of caregiver to OALWHIV might be of interest.

A priority for OALWHIV was learning about how to improve sexual function and pleasure. Other stakeholder groups mentioned sexual expression as an important part of maintaining autonomy and identity, especially in institutions such as long-term care.

**The System/Institution:** At the level of systems and institutions lie important issues such as improving access to services, facilitating participation in research, expanding education, and addressing stigma.

OALWHIV talked about gaps in service provision (e.g., psychosocial support, assisted living and home care support) that made it hard to meet their unique needs. In addition to limited community-based services, discussions centred around HIV and palliative care being poorly integrated in the general healthcare system. It was noted that services that are inclusive of OALWHIV from diverse ethnic and cultural communities need to be expanded, including the provision of language services and culturally-specific accommodations. From a research perspective, these types of gaps and barriers indicate that comprehensive needs assessments

are warranted and analyses should take into account differences in access to services and care among sub-populations of OALWHIV (e.g., urban and rural dwellers).

Both OALWHIV and researchers agreed that institutional barriers prevent certain OALWHIV from participating in research studies. For example, researchers studying aging in related populations discussed how current research tends to represent older adults who are already well-connected socially and/or engaged in care, and have access to certain resources, such as time, mobility, and social supports that enable their participation. Designing low-barrier research for OALWHIV and taking steps to engage with communities that are interested but have limited resources to support their participation would enable a more accurate and diverse representation of OALWHIV in research.

Research into long-term care settings for OALWHIV was a priority for researchers studying aging in related populations. More research is needed to determine how best to maintain a sense of autonomy and social connection for residents in institutional settings such as hospice, palliative and long-term care. As well, addressing the tension between institutionalized care and maintaining a sense of agency and identity for OALWHIV should be explored. For example, how do OALWHIV express their sexuality in long-term care and negotiate intimate relationships? Other concerns in such settings include transphobia, isolation from community, and the impact of regulations that prioritize risk reduction over intimacy within long-term care settings.

Mandatory equity, diversity and inclusion (EDI) training was recommended for staff in all care settings by researchers who study aging in related populations. In the context of research, it is critical to investigate the experiences of OALWHIV in hospitals, care homes, or other health service settings to understand how stigma and discrimination affect their experience of care, and how current training programs can be improved upon. In addition, studies should investigate how engaging and supporting LGBTQ+ care providers in these settings could benefit people aging with HIV.

Both researchers and OALWHIV identified a need for physicians and health care providers to develop expertise related to HIV in older age (e.g., HIV could be a sub-specialty for geriatricians). Research priorities may include evaluating patient satisfaction with clinical care among OALWHIV and assessing gaps in provider knowledge on aging with HIV. Importantly, clinical researchers suggest that providers should focus on prevention in addition to treatment and HIV management for OALWHIV.

All stakeholders agreed that stigma against OALWHIV persists in society. Stakeholder groups identified the following factors as contributors to stigma: a lack of understanding of HIV and aging among the general public and care providers; discrimination and dismissal of older adults; misconceptions that older adults do not have and/or enjoy sex; and persistent misconceptions about HIV and people living with HIV from the early days of the epidemic. Research should investigate how these factors perpetuate stigma against OALWHIV and may affect their health and well-being.

Social and structural determinants of health that affect OALWHIV should be investigated. For example, housing, financial stability, social and structural supports, etc.

**Future Perspectives:** This level includes perspectives from all stakeholder groups that relate to actionable next steps to improve efforts in research and programming.

### The Holistic Perspective

Research on HIV needs to move beyond the traditional emphasis on biomedical data (e.g., CD4 count and viral load) to focus more on lived experience, including subjective feelings of health and well-being, and the impact of social determinants of health on OALWHIV. In the era of well-controlled HIV, laboratory measures are not necessarily relevant or necessary to answer HIV and aging-related research questions. Researchers may be able to use alternative sources of data (e.g., administrative databases, clinical charts) to reduce the burden of participating in research on OALWHIV while still filling gaps in our understanding of HIV and aging. Establishing new and ethical ways to use existing health data for research purposes may help to bolster HIV and aging research, especially if in-person engagement is becoming less common or less accessible (e.g., during the COVID-19 pandemic).

Age-, sex- and gender-specific analyses are important in the context of research on aging with HIV. Older adults may have different care needs, levels of access to resources, and lived experiences depending on their stage of life (e.g., people 50 – 60 years of age may still be engaged in paid work whereas those age 65+ often have access to public pensions). Women and men also experience aging with HIV differently based on their physiology and/or how their gender identity impacts their health and well-being. These differences need to be better understood.

### The Life Course Perspective

We need more longitudinal research that follows people living with HIV from diagnosis, through older age, until end-of-life. The impacts of long-term survivorship (e.g., loss, the stress of living long-term with a stigmatized illness) may occur anytime in one's life course and should be investigated as a health burden that may impact aging.

There has been a lot of messaging over the last several years around “ending the AIDS epidemic” a noble, and achievable goal thanks to a combination of biomedical advancements (e.g., HIV prevention strategies, antiretroviral therapy), sociobehavioural approaches, and good leadership. However, community-based researchers suggested that, for people already living and aging with HIV, there will be no “end”. HIV will impact them throughout their life course. Researchers need to unpack what “ending HIV” may mean for OALWHIV specifically.

Researchers should devote attention to understanding the late life needs of OALWHIV as they manage transitions into long-term and palliative care. Furthermore, addressing end-of-life

questions that arise in the context of HIV and aging should also be a priority (e.g., the rights of OALWHIV regarding decisions about care and treatment, perspectives on medical assistance in dying [MAiD], etc.).

### The Healthy Aging Perspective

There is lack of clarity about the similarities and differences between “aging in general” and “aging with HIV”, and comparative research may be used to tease out the contribution of HIV to the aging process and the resultant implications for OALWHIV. It may be relevant to explore HIV as a multiplier of the health-related burdens of aging and daily life. Importantly, defining healthy aging with HIV and lessening the uncertainty associated with this process should be a research priority (e.g., by evaluating supports for managing finances, accessing appropriate housing, maintaining quality of life, and preventing loss of autonomy).

The need for a deep dive into the experience of aging, differentiating between “getting older” and “being old”, and clarifying personal expectations of aging for individual OALWHIV were brought up as research priorities across all groups. Addressing ageism was mentioned as an important priority.

### The Community Engagement Perspective

A priority for future research should be engaging OALWHIV and valuing their expertise and lived experiences within the research sector. Increasing involvement of ethnoracial-, sexual- and gender-minority OALWHIV in research, whether community-based or academic, is paramount to producing representative and meaningful data. Think Tank stakeholders agreed that engaging the Black community, Indigenous community, and older straight men would greatly contribute to diversifying perspectives on HIV and aging beyond current research.

Before proposing a new study on HIV and aging, researchers should determine whether knowledge on the research topic has already reached the point of saturation. From the Think Tank discussions emerged questions about whether certain topics in HIV, or certain populations living with HIV, are being ‘over-researched’. In these instances, we risk investing resources when no new knowledge is being produced that truly contributes to advancing the field or leads to benefits for OALWHIV. Engaging with the end-users of research (e.g., OALWHIV, clinicians, service providers) from the point of study conception will help ensure that new research addresses an urgent, unmet need for information among OALWHIV, fills an existing knowledge gap among those who provide support and care to OALWHIV, or has the potential to influence significant changes in policy to better the health and well-being of OALWHIV.

Selection bias exists within research on OALWHIV as individuals who are faring less well physically, mentally, financially or otherwise experience barriers to participation. Researchers need to ‘enter the field’ and reach out to community members rather than expect them to access research opportunities, otherwise the data is predisposed to bias. Tools for engagement such as networking, social media, bringing in personal connections, and partnering with HIV

organizations may be useful to increase representation and numbers in research involving OALWHIV.

### Improving Knowledge Translation

A common thread across all stakeholder groups was gaps in translating recent research into programming and services for OALWHIV. Bringing research findings into care settings, addressing the disconnect between community and academia, and establishing an up-to-date, source of research findings for OALWHIV are priorities mentioned across all groups.

For OALWHIV, imparting knowledge and wisdom to the next generation was a topic of importance. It may be worthwhile to look into what this means for both older adults as well as individuals of middle and early age who are living with HIV, and to explore how this desire to pass on information could be better used to support the sharing of research findings within the community.

### The Future of HIV Research

New and adapted research methods implemented in response to COVID-19 and related public health restrictions may prove to be useful in future HIV and aging research. Limited access to in-person care, services and research opportunities has necessitated that we learn new ways of engaging key populations using technology and other remote communication tools. These tools may facilitate participation in future research by OALWHIV who find it difficult to engage in face-to-face research activities (e.g., those who live outside major urban centres, individuals who are home-bound or who experience mobility issues, etc.).

OALWHIV viewed the COVID-19 pandemic as a reminder of the need for research that increases our collective future preparedness (e.g., identifying effective systems-level responses, developing vaccines, etc.). With respect to research on HIV, aging and older adulthood, this idea may translate into the need to conduct intervention research *now* that helps us prepare to meet the aging-related needs of the oldest cohort of people living with HIV in Canada.

### Limitations

We wish to highlight several limitations to the Think Tank discussions and this report. First, we prioritized engagement by OALWHIV, community-based researchers, social scientists, and clinician-researchers as compared to basic scientists and epidemiologists. **Realize** does not have the expertise to make recommendations regarding priorities for laboratory research and drug development. We already advocate for further disaggregation of HIV epidemiological data for those age 50 years or older, and call for modelling HIV prevalence by age.

Second, participation in the Think Tank sessions was voluntary and by invitation only. Several invitees were unable to attend which meant that key perspectives were missing in some Think Tank discussions. In particular, Indigenous, Black, and Transgender communities could have

been better represented. We recognize that these communities face unique barriers to fulsome participation in HIV research.

### Conclusion & Next Steps

The primary goal of **Realize**'s 2021 Think Tank was to gather diverse perspectives to inform the development of a national research agenda on HIV, aging and older adulthood in Canada. This research agenda will provide a common direction for researchers, research funders, and community, enabling them to work together more easily to plan, implement and share the findings of research that improves the lives of OALWHIV in Canada.

This report summarizes the experiences and ideas shared by 51 participants from five different stakeholder groups. The “nested diagram” categorizes emerging research priorities according to their focus – the individual, the community, and the system/institutions. It also delineates future considerations for research related to HIV, aging and older adulthood.

To supplement what we learned through our Think Tank conversations, Realize will conduct an environmental scan of in-progress research on HIV, aging and older adulthood in Canada. It is critical that we understand the current research landscape (e.g., research questions being asked and answered, available funding, research designs) before making recommendations regarding future research priorities in this field of study.

Based on the key themes emerging from our Think Tank and the findings of the environmental scan, a draft research agenda on HIV, aging and older adulthood will be developed by **Realize** and other members of the National Coordinating Committee on HIV and Aging, Research Working Group. Draft research priorities will be shared with the HIV community - OALWHIV, service providers, clinicians, researchers, and research funders - at a virtual meeting in the spring of 2021 and stakeholders will have the opportunity to provide feedback before the research agenda is finalized.