



HIV and Chronic Pain in Canada

2022 Think Tank Report



Realize is a national charitable organization working to improve the quality of life of people living with HIV and related conditions through rehabilitation research, education, and cross-sector partnerships. **Realize** members are individuals and organizations that have an interest in HIV, disability and rehabilitation. These include: community-based HIV/AIDS, disability and rehabilitation organizations; national professional associations and individual clinicians; unions; private-sector companies; people living with HIV and other disabilities; health care, social care and human resources professionals; and other people who are interested in HIV, disability and rehabilitation.

For more information, please contact us at: 1240 Bay Street, Suite 600
Toronto, ON M5R 2A7
+1 416 513-0440 or at info@realizecanada.org
www.realizecanada.org

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Acknowledgements

Think Tank Participants:

Realize would like to thank the 27 people who participated in the *HIV and Chronic Pain in Canada* Think Tank on February 17th and 18th, 2022. We appreciate your willingness to share your time, expertise and ideas for moving this work forward together.

Think Tank 2022 Planning Committee:

Realize would like to recognize and thank Colleen Price, Francisco Ibanez-Carrasco, and Dr. Madeleine Durand who helped shape the form and content of the event.

Think Tank Facilitators:

We would like to particularly acknowledge, and thank Dr. Madeleine Durand, Adrian Betts and Lena Soje for facilitating the two Think Tank sessions.

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Introduction

Over the past 25 years, for people living with HIV who have access to combined antiretroviral therapy (cART), HIV has evolved from a progressive condition with a high fatality rate into a manageable chronic condition that many will live with into older age. Today, with early diagnosis and prompt treatment, people living with HIV can expect to live nearly as long as the general population, however, people living with HIV experience fewer comorbidity-free years, and many live with chronic pain (continuous or intermittent pain that has lasted for 3-6 months). 2,3

One in five people in Canada live with chronic pain and the prevalence is even higher among people over age 65.4 It's estimated that between 25-85% of people living with HIV experience chronic pain.5 The reasons for these high rates of chronic pain among people living with HIV are unknown but it is hypothesized that different pathways, including chronic inflammation, persistent immune activation, stigma, and other psychosocial factors, contribute to chronic pain in this community.6

The lack of treatment and support available for chronic pain worsens the experience. The most recent report from the Canadian Pain Task Force acknowledges that "chronic pain is largely invisible, and those affected often feel disbelieved and stigmatized." In accordance with this observation, people living with HIV often don't feel they receive the chronic pain management that they need. This can lead to decreased adherence to HIV treatment and poor retention in care which, in turn, may further stigma and discrimination and increase the risk of uncontrolled viral load.^{8,9}

¹ Marcus, J.L. (2020, March 8-11). Increased overall life expectancy but not comorbidity-free years for people with HIV. (Oral abstract). CROI 2020. Boston

² Merlin, J., Hamm, M., de Abril Cameron, F., Baker, V., Brown, D., & Cherry, C. et al. (2021). Special Issue HIV and Chronic Pain (The Global Task Force for Chronic Pain in People with HIV (PWH): Developing a research agenda in an emerging field). AIDS Care, 1-9. doi: 10.1080/09540121.2021.1902936

³ Canadian Pain Task Force. (2021). Canadian Pain Task Force Report: March 2021: An action plan for pain in Canada. https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2021.html#_Toc67582180

⁴ Canadian Pain Task Force. (2021). Canadian Pain Task Force Report: March 2021: An action plan for pain in Canada. https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2021.html# Toc67582180

⁵ Merlin, J., Hamm, M., de Abril Cameron, F., Baker, V., Brown, D., & Cherry, C. et al. (2021). Special Issue HIV and Chronic Pain (The Global Task Force for Chronic Pain in People with HIV (PWH): Developing a research agenda in an emerging field). AIDS Care, 1-9. doi: 10.1080/09540121.2021.1902936

⁶ Canadian Pain Task Force. (2021). Canadian Pain Task Force Report: March 2021: An action plan for pain in Canada. https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2021.html# Toc67582180

⁷ Canadian Pain Task Force. (2021). Canadian Pain Task Force Report: March 2021: An action plan for pain in Canada. https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2021.html#_Toc67582180

⁸ Merlin, J., Hamm, M., de Abril Cameron, F., Baker, V., Brown, D., & Cherry, C. et al. (2021). Special Issue HIV and Chronic Pain (The Global Task Force for Chronic Pain in People with HIV (PWH): Developing a research agenda in an emerging field). AIDS Care, 1-9. doi: 10.1080/09540121.2021.1902936

⁹ Canadian Pain Task Force. (2021). Canadian Pain Task Force Report: March 2021: An action plan for pain in Canada. https://www.canada.ca/en/health-canada/corporate/about-health-canada/public-engagement/external-advisory-bodies/canadian-pain-task-force/report-2021.html#_Toc67582180

Realize hosted a Think Tank in February 2022 to explore the strengths, gaps, and opportunities related to treatment, care and support for people living with HIV and chronic pain.

The Think Tank

The Think Tank was held virtually over Zoom. To facilitate participant engagement in small and large group discussions, invitees were divided into two groups and the event was held over two afternoons on February 17th and 18th, 2022, 1:00-3:00pm ET. Twelve people attended each day. Attendees included people with living experience of HIV and pain, researchers, clinicians, policy makers, educators and others whose contribution is central to a clearer understanding of the landscape of chronic pain and HIV in Canada. Each person had some connection to the topic of chronic pain, whether through lived experience, education and/or occupation.

Tammy Yates-Rajaduray, *Realize*'s Executive Director, and Paul Curwin, *Realize* Board Co-Chair, welcomed participants, acknowledged the Indigenous land upon which we met, described the history of *Realize* Think Tanks, and thanked Colleen Price, a community leader, for championing the need for this particular dialogue, all by pre-recorded video message. Tammy then passed the virtual microphone over to the co-facilitators; Dr. Madeleine Durand and Adrian Betts (Day 1) and Lena Soje (Day 2). The facilitators offered their own welcome, reviewed logistics and group norms, and outlined the importance of this addressing chronic pain among people living with HIV in Canada.

The Think Tank was structured around three discussions questions and participants were engaged through small group discussion in breakout rooms, large group dialogue, and polling questions (See Appendix A – Agenda). Realize staff and students were on hand to facilitate the breakout room discussions take notes throughout the sessions.

All participants were encouraged to complete the post-event evaluation (See Appendix B – Post-Event Evaluation). The response rate was 63%, with 17/27 participants completing the evaluation.

Discussion

"We need to start believing people about their experiences of pain" (Quote from Think Tank attendee)

Knowledge gathered from attendees in response to the Think Tank's three guiding questions is summarized below.

Question 1. Tell us a bit about how you or the people living with HIV that you work with have experienced pain over time.

During the discussion, pain was described as existing on a spectrum: encompassing physical pain such as neuropathy, mental pain associated with depression, emotional pain that is coupled with grief and loss, and spiritual pain, the living experience of being colonized and removed from one's ancestral lands for Indigenous peoples. Pain is multifaceted and can be both chronic and episodic, as well as being related specifically to one's HIV diagnosis, or something broader such as ageing.

Pain is, for the most part, invisible and its amorphous nature placed an extra burden on those experiencing it as they had to prove their level of suffering. This was described most often as being isolating and stigmatizing. One way isolation was experienced by participants was through exclusion from work, when their pain limited their ability to continue in their professional roles: "I tried full time work; it was an abysmal failure".

Participants described an undercurrent of ableism, suggesting that unless your prognosis is grave, the pain you feel isn't significant enough to warrant support: "Unless you're terminal, you're not really considered"; they were largely left on their own to manage their pain. Isolation was also felt in daily activities, and exclusion from family events and friendships when pain was not well managed. Intersecting stigma also has a significant impact on PLWH who are seeking help to manage pain. Participants often described the need to access pain medications as risky and they hesitated to bring up their experiences of pain with care providers; there is a tacit assumption of drug-seeking or that their HIV infection resulted from drug use, which then becomes the focus of the visit instead of their pain.

Participants described various coping strategies for dealing with their pain from "just getting up and going", to using marijuana (prescribed) as well as street drugs when prescription medications were inaccessible.

Question 2a. How are you asked about pain when you are seeking services?

Participants who were living with HIV shared that their HIV diagnosis impacted how they were treated when seeking services for their pain. Many reported that pain was viewed by practitioners as a lower priority than other health issues; health care providers made them feel that they should be grateful to be alive, and that pain is the 'cost' of that survival. The need for general practitioners to better understand pain, and to ask about pain was underscored. Participants emphasized the importance of

building a strong rapport with a physician before broaching the topic of pain and highlighted that new physicians often don't bring up pain or ask about coping with pain without prompting from the patient. Alternately, physiotherapists were praised as being proactive in discussions about pain; for many they played an important role in pain management.

Stigma was widely reported, especially in relation to substance use history. Many participants reported being apprehensive when seeking help for pain due to fear of being labelled as drug-seeking or being required to take a drug test before receiving pain treatment. Access to pain support was also limited by reliance on the emergency room or walk in clinics. Racism, specifically the idea that people of color experience less pain, was cited as a reason for avoiding medical care or follow up to care. The "siloed" nature of medicine was described as limiting support for pain and mental health care, as they are seen as separate specialties.

Question 2b. How do you ask about pain when someone is seeking care?

Participants who identified as physicians and clinicians described a need to build rapport with patients to limit assumptions about what someone in pain needs, or experiences. In addition, physicians described feeling disempowered to ask about pain in community settings, citing limited resources to support someone who reported pain to them; for example, referrals to rehabilitation are only worthwhile if a patient can afford to pay for such treatment. In contrast, they described being successfully able to support acute patients or post operative patients in managing their pain in hospital settings, where therapies and medications are included in the care plan. Physiotherapists and other health care practitioners described the need for unified language, to help reduce miscommunication between the individuals giving and receiving care for pain.

Participants with experience in harm reduction described a model to support people living with chronic pain that reframes drug use as part of coping with pain, instead of the more punitive idea of drugseeking. The need to interrogate how people are coping with their pain, and the extent to which pain interferes with their daily activities of living was suggested as an opening to a broader discussion about chronic pain. The experience of COVID-19 infection was described as increasing pain in those already living with chronic pain, though there is limited understanding as to how to support people in this situation.

Question 3. What else needs to be done in Canada related to chronic pain and HIV?

Four primary themes emerged for an action plan and next steps in the management of chronic pain in the context of HIV nationally: access to care, communication across disciplines, advocacy, and education.

Access to pain care, beyond primary care medicine, emerged as a key theme during the Think Tank. The need for universal access to physiotherapy was the most often cited requirement. Psychotherapy and mental health support, as well as the opportunity to use naturopathic and traditional medicine and Indigenous ways of knowing to treat pain, were also described as key needs to support a holistic

approach to chronic pain. Participants emphasized the need for a national drug plan, to balance inequitable access to pain medications across the country, and support for dental and oral care across the life course.

Communication: A gap in communication was identified between health care professionals across different specialities, and the need for a unified system of referrals for chronic pain management across disciplines was proposed. The burden of managing multiple treatments and care providers has too often fallen on those living with HIV and chronic pain. Participants suggested centralized case management and referrals, positioning primary care doctors as central to supporting access and referral to other therapies. This would also encourage a whole-person approach to treating pain and provide more proactive and comprehensive plan for living with chronic pain, including access to pain management interventions.

Advocacy: People living with HIV have advocated for access to relevant, responsive care each step of the way, and chronic pain is no different. There is an urgent need for advocacy to support a national framework for chronic pain, as well as to raise awareness of the impact of chronic pain across Canada. Advocacy is ongoing to dismantle the stigma associated with both HIV and chronic pain. Organizations such as Pain BC and the Canadian Pain Task Force continue to provide support for people who experience chronic pain and bring awareness to the issue nationally.

Education: The need for professional training and education about chronic pain and HIV across health disciplines was noted by participants. It is promising that an interprofessional pain curriculum has been implemented at the University of Toronto. Ongoing training in harm reduction and cultural competency was also discussed, as the experiences of people living with HIV and chronic pain are diverse and often require trauma informed care. While anecdotal evidence suggests that exercise may help those living with chronic pain, further research and education is required in this area.

Participant Evaluation Results

Total Attendees = 27 Total Evaluation Respondents = 17 Response rate = 63%

What sector do you primarily identify with in terms of your affiliation/your work?

HIV	8
Pain	1
Other chronic/episodic illness	0
(diabetes, arthritis etc.)	
Mental Health	0
Rehabilitation	3
Academic/University	3
Health Care (general)	1
Other (please specify)	1 (Pharma)
Total	17

Which best describes your role/position? (Please chose all that apply)

Person living with HIV	7
Person living with another	4
chronic/episodic illness	
Frontline worker/clinician	5
Educator/Academic	1
Manager/Executive Director	3
Researcher	7
Policy Maker	0
Program Planner/Developer	0
Funder - Research/Program	0
Other (please specify)	0
Total	27

What is the reach/scope of your work? If you are responding as a community member, what province or territory do you currently live in?

	T
My work is local/regional in	1
scope	
Alberta	
British Columbia	1
Manitoba	
Newfoundland and Labrador	
New Brunswick	
Northwest Territories	
Nova Scotia	1
Nunavut	
Ontario	6
Prince Edward Island	
Quebec	1
Saskatchewan	1
Yukon Territory	
My work is national in scope	5
I don't live or work in Canada	
Prefer not to answer	
Other (please specify)	1 - National & regional
Total	17

How would you rate your knowledge of the unmet needs of people living with HIV and chronic pain in Canada?

	Very	Low	Moderate	High	Very High	Total	Avg Score
Before the Think Tank	Low	2	9	4	лідіі 2	17	3.35
After the Think Tank	0	0	3	10	3	16	4.0

How would you rate your knowledge of the comprehensive impact of chronic pain on people living with HIV in Canada?

	Very	Low	Moderate	High	Very	Total	Avg
	Low				High		Score
Before the Think Tank	0	5	8	3	1	17	3.0
After the Think Tank	0	0	5	7	4	16	3.94

How would you rate your knowledge of programs and services that respond to the needs of people living with HIV and chronic pain?

	Very	Low	Moderate	High	Very	Total	Avg Score
	Low				High		
Before the Think	2	6	8	1	0	17	2.47
Tank							
After the Think Tank	0	3	7	5	1	16	3.25

In terms of today's discussion, what was the most relevant take-away for you?

- Chronic pain impacts the quality of life for many people living with HIV and other conditions. It is important to include discussions regarding pain when planning a rehabilitation program.
- People living with HIV and chronic pain are stigmatized
- It is important to develop a good network of support and learn what other organizations are doing to address HIV and Chronic Pain
- Indigenous needs
- That is an issue going on across Canada
- Learning more about the resources that are currently available for people living with chronic pain. Knowing that I am not the only one having the challenges was a relief and got me interested in wanting to learn more on what research is being done in this area and what interventions are also available to relieve the pain.
- I have learned about the impact of chronic pain on people's lives and the stigma experienced by PWA
- Not accepting pain as part of my survival journey.
- The limited scope of the biomedical view of pain was very clear from today's discussion but the participant's insights expanded my perspective substantially.
- The similarities in issues around chronic pain for PLHIV between where I am from (South Africa) and Canada. We can learn so much from each other
- I am not alone with the things I experience around pain, and I need more opportunities to explore that experience... like today
- Getting active will help reduce pain levels
- Thinking about ways to increase accessibility.
- Pain comes in many forms
- The intersecting factors of HIV x chronic pain and the unique role that stigma plays in the experience of living with both

Please indicate your level of agreement with each of the following statements about how you might apply the content from the Think Tank in your work and/or life:

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A	Total
I will talk to my doctor about pain at my next visit.	0	0	3	7	6	16
I will discuss the material covered in the session with a colleague or friend.	0	1	5	10	0	16
I will talk to someone about the content of this session and how it could influence my organization's policies, practices and/or services.	0	1	7	6	2	16
I will seek out more training and/or professional development on the topics covered in this session.	0	0	5	9	2	16
I will to reach out to a new partner (individual/organization/institution) to collaborate on a project on HIV and chronic pain.	0	1	9	5	1	16
This session sparked a new research idea in me.	0	1	8	4	2	15
I would like to use the material covered in this session, but I'm not sure how.	0	4	7	1	4	16
I have no plans to use the material covered in this session.	7	7	0	0	2	16

Overall, how would you rate the following aspects of the Think Tank:

	Not	Somewhat	Neutral	Satisfied	Very	Total
	Satisfied	Satisfied			Satisfied	
The relevance of the topic	0	0	0	6	9	15
The objectives of the day were	0	0	0	9	7	16
met						
Participant diversity in terms of	1	0	1	7	7	16
expertise, experience and ideas						
Quality of the facilitation	0	0	0	4	11	15
Opportunities to network and	0	0	1	6	9	16
connect with others						

Any recommendations to improve the Think Tank model of knowledge exchange?

- Looking forward to in-person think tanks some day. This was well done.
- I think we should have been given more time in the breakout rooms and more time to answer the questions
- Investigating chronic pain wholistically. Indigenous ways of knowing and doing.
- I think people living with HIV need to be a part of the conversations as a lot of us are aging and living with chronic pain and have lost hope of how to do effective pain management. To also learn about how to advocate for yourself in medical settings if HCPs dismiss your call of help.
- It was a very white cohort. Should be run with BIPOC only too.
- I would be pleased to participate again in discussions regarding this topic because it is an underserved area for PWH with very limited research.
- The larger groups made it more difficult to speak in the limited amount of time... a topic like this may need more time to fully get through content. Not knowing what was happening in the breakout groups left a good amount of the information lost to the group as a whole. Maybe a come back and discuss key point would have helped
- host more of these....
- include young people and more women
- A lot of the difficulties were largely due to the Zoom platform. Ideally Think Tank 2023 will be able to take place in person :)

Any additional comments?

- Thank you
- Indigenous knowledge
- Great job, looking forward to a HIV & Chronic Pain Symposium next.
- Thanks I really enjoyed taking part.
- Dr. Durand did a wonderful job of moderating the sessions!!
- Thanks you!
- I wanted to have a group of HIV+ folks here for this but could NOT forward any info sent to me....

Conclusion

The Think Tank brought together diverse stakeholders in rich discussion about HIV and chronic pain. Although the event is primarily aimed at generating dialogue and identifying potential strategies to address the theme, the evaluation results also show that this brief opportunity to dialogue with others had a positive impact on participants' self-reported knowledge levels. This Think Tank provided much-needed direction to *Realize* and our collaborators, current and future; we now have a clearer understanding of the comprehensive impact of chronic pain on people living with HIV in Canada, and a better sense of the policy, program and research priorities that might be used to mitigate this impact.

Appendices

Appendix A – Agenda







Réseau canadien pour les essais VIH des IRSC

THINK TANK HIV AND CHRONIC PAIN

FEBRUARY 17 or 18th, 2022 1:00 – 3:00PM ET

1:00pm ET	Welcome & Housekeeping	
	Welcome from <i>Realize</i>	Tammy Yates, Executive Director
		Paul Curwin, Co-Chair, Board of Directors
	Welcome from CIHR CTN	Dr. Madeleine Durand, Clinician Researcher, CHUM
1:15pm ET	Group Introductions	Think Tank Co-Facilitators:
		Adrian Betts, Executive Director, AIDS Committee of Durham Region (Day 1)
		Lena Soje, Social Worker, Philip Aziz Centre Visiting Hospice / Emily's House Children's Hospice (Day 2)
		Dr. Madeleine Durand, CHUM, CIHR CTN
1:25pm ET	Break-Out Discussions	Question 1: Tell us a bit about how you or the people living
		with HIV that you work with have experienced pain over time
1:45pm ET	Break	
2:00pm ET	Full Group Discussion	Question 2: How are you asked about pain when you are seeking services? How do you ask about pain when someone is seeking care?
		Question 3: What else needs to be done in Canada related to chronic pain and HIV?
2:50pm ET	Next Steps & Closing	

Think Tank Post-Survey: HIV and Chronic Pain in Canada

Introduction

Thank you for taking the time to complete our post-event survey. We encourage you to complete this form with honesty and with confidence that the results are anonymous and confidential. We use evaluations to inform the ongoing development of initiatives and to report to our funders regarding the impact of our activities.

Think Tank Post-Survey: HIV and Chronic Pain in Canada

About You

1. What sector do you primarily identify with in terms of y	our affiliation/your work?
○ HIV	
Pain	
Other chronic/episodic illness (diabetes, arthritis etc.)	
Mental Health	
Rehabilitation	
Academic/University	
Health Care (general)	
Other (please specify)	

2. Which best describes your role/position? (Please chose all that apply)
Person living with HIV
Person living with another chronic/episodic illness
Frontline worker/clinician
Educator/Academic
Manager/Executive Director
Researcher
Policy Maker
Program Planner/Developer
Funder - Research/Program
Other (please specify)
3. What is the reach/scope of your work? If you are responding as a community member, wha
province or territory do you currently live in?
My work is local/regional in scope
Alberta
British Columbia
Manitoba
Newfoundland and Labrador
New Brunswick
Northwest Territories
Nova Scotia
Nunavut
Ontario
Prince Edward Island
Quebec
Saskatchewan
Yukon Territory
My work is national in scope
I don't live or work in Canada
Prefer not to answer
Other (please specify)

Knowledge							
4. How would you rate your knowledge of the unmet needs of people living with HIV and chronic pain in Canada?							
	Very Low	Low	Moderate	High	Very High		
Before the Think Tank							
After the Think Tank		\bigcirc					
5. How would you rate your knowledge of the comprehensive impact of chronic pain on people living with HIV in Canada?							
	Very Low	Low	Moderate	High	Very High		
Before the Think Tank							
After the Think Tank							
6. How would you rate your knowledge of programs and services that respond to the needs of people living with HIV and chronic pain?							
	Very Low	Low	Moderate	High	Very High		
Before the Think Tank		\bigcirc		\bigcirc			
After the Think Tank			\bigcirc		\bigcirc		
7. In terms of today's discussion, what was the most relevant take-away for you?							

Think Tank Post-Survey: HIV and Chronic Pain in Canada

Application

8. Please indicate your level of agreement with each of the following statements about how you might apply the content from the Think Tank in your work and/or life:

	Strongly Disagree	Disagree	Agree	Strongly Agree	N/A
I will talk to my doctor about pain at my next visit.	\bigcirc	\bigcirc			
I will discuss the material covered in the session with a colleague or friend.	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc
I will talk to someone about the content of this session and how it could influence my organization's policies, practices and/or services.					
I will to seek out more training and/or professional development on the topics covered in this session.	\bigcirc	\bigcirc		\bigcirc	
I will to reach out to a new partner (individual/organization/institution) to collaborate on a project on HIV and chronic pain.		0		\circ	
This session sparked a new research idea in me.	\bigcirc	\bigcirc	\bigcirc	\bigcirc	
I would like to use the material covered in this session, but I'm not sure how.		\bigcirc		\circ	
I have no plans to use the material covered in this session.	\bigcirc	\bigcirc	\bigcirc		

	Thin	k T	ank i	Post-	Sur	vey:	
HIV	and	Ch	ronic	c Pair	n in	Can	ada

Think Tank Feedback

9. Overall, how would you rate the following aspects of the Think Tank

	Not Satisfied	Somewhat satisfied	Neutral	Satisfied	Very Satistified
The relevance of the topic		\bigcirc		\bigcirc	
The objectives of the day were met		\bigcirc			\bigcirc
Participant diversity in terms of expertise, experience and ideas		0	\bigcirc	\circ	0
Quality of the facilitation		\bigcirc			\bigcirc
Opportunities to network and connect with others		\bigcirc			\bigcirc
10. Any recommend	dations to impro	ove the Think T	ank model of k	nowledge excl	nange?
11. Any additional o	comments?				
			<u> </u>		
Think Tank Post-Survey:					

HIV and Chronic Pain in Canada

Thank You

Thank you for completing this survey.

Please remember to let us know if you would like to claim the \$32 Wellness Credit available to all Think Tank attendees.

Your participation in the Think Tank is much appreciated!