

Living Your Best Life:

Defining *Living* versus
Living Well with HIV in Canada



Project Report

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Realize

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Réseau canadien
pour les essais VIH des IRSC

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Background

Since combined antiretroviral therapy (cART) was introduced in 1996, HIV treatment has transformed HIV from a progressive condition with a high fatality rate into a manageable chronic condition. Today, with early diagnosis and appropriate treatment, people living with HIV can expect to live almost as long as the general population. This shift from deadly infection to long-term condition requires a corresponding shift in focus from saving lives to improving health and wellbeing. In 2015, Canada adopted the UNAIDS 90-90-90 targets in their response to HIV.¹ While this was a positive step, there has recently been increasing conversation about what happens after viral load suppression. Where does quality of life, wellness and wellbeing fit within the cascade?

Each year **Realize** brings together the community, subject matter experts, and policy makers to discuss an issue related to living with HIV and/or other episodic disabilities. The goal of this *policy dialogue* is to assess where things stand and what next steps might be. In 2020 we planned to discuss what optimal health and wellbeing means for people living with HIV.

In January 2020, the CAN LhIVE WELL Grant team, led by Principal Investigator Dr. Jason Brophy (Children's Hospital of Eastern Ontario) and Principal Knowledge User Muluba Habanyama connected with **Realize** to discuss a shared interest in the comprehensive health and wellbeing of people living with HIV in Canada. The potential to co-host a meeting on wellness was apparent from the start. The initial plan was to work together to organize and host a two-day event in October 2020. In March 2020, after the initial COVID-19 lockdown in Ontario, the team paused to better understand the public health situation and the potential impact on in-person events.

During the summer of 2020, the team reconvened and decided to organize a virtual event over a series of four afternoons in January/February 2021. This would allow for a pan-Canadian audience to participate in the meeting series. Due to the new format of the meetings, attendance at all events was recommended but not mandatory.

Pre-Meeting Activities

With the shift from in-person to virtual meetings, we recognized that we may experience a loss of connection with our participants. Our solution was to organize community consultations in advance of the *Living Your Best Life* (LYBL) meeting series to engage with communities of people living with HIV that were not well represented in the original meeting agenda. These

¹ CATIE (n.d.). A history of HIV/AIDS. <https://www.catie.ca/en/world-aids-day/history>

consultations would be facilitated by *community consultants*, people living with HIV, and would explore participants' ideas and experiences about wellness and wellbeing for people living with HIV.

Community Consultants

Recruitment

In September 2020, we put out a call for community consultants which was circulated to community-based HIV organizations, the mailing lists of the hosting organizations (***Realize*** and CIHR CTN) and CHIWOS study partners. Of the 65 applicants, 13 were interviewed and four community consultants were hired and trained to facilitate the English consultations. A separate recruitment and on-boarding process for two Francophone community consultants followed as the initial search did not identify community members who were comfortable facilitating a consultation in French.

Training

The LYBL Community Consultants had varying levels of experience facilitating small group discussions with peers living with HIV in the community. Four project orientation and training sessions were held to ensure that the Community Consultants were well prepared to engage in all aspects of the consultation process from the development of the facilitators' guide to the analysis of the data. Training was delivered synchronously over Zoom, a video conference platform. Included in the training were:

- Opportunities for Community Consultants and members of the Core LYBL Team to get to know one another and build team cohesion
- An introduction to the LYBL project
- An overview of the role and responsibilities of a Community Consultant, including ethical considerations
- An in-depth tutorial and ongoing coaching on focus group methodology
- Several interactive planning sessions used to develop the consultation guide, recruitment strategy, and analysis plan
- Facilitation practice/role-plays
- Facilitated discussions on managing biases to minimize their impact on project outcomes, and the importance of self- and community-care for Community Consultants
- A dedicated workshop on principles of anti-oppressive practice

In addition to their orientation, the Community Consultants also took part in weekly capacity-building sessions over a four month period. These weekly meetings between the LYBL Core Team and the Community Consultants provided ongoing opportunities for planning, troubleshooting, skills practice and debriefing.

Meaningful Engagement

The meeting logo, community consultation participant recruitment materials, facilitator script and consultation questions were developed in collaboration with the consultants.

The development of the logo was a collaborative and iterative process. The consultants brainstormed about images and colours that signified wellness and wellbeing to them and gave feedback on several different logo options. Consensus was attained for the butterfly suggesting a rebirth after diagnosis with HIV, using fingerprints as the wings to indicate that the wellness journey for each person is unique.

The consultants were also involved in brainstorming a list of communities of people living with HIV whose voices were not represented among the invited speakers for the LYBL meeting. Ultimately, we worked together to identify four groups of people living with HIV to engage through our English consultations. Given *Realize's* national mandate, we also planned for one Francophone consultation.

Community Consultations

Communities Engaged

Five community consultations were planned for December 2020/January 2021. Each was to be co-facilitated by two community consultants. The consultations would engage the following communities of people living with HIV:

- 1) Middle-Eastern, East/South/Southeast Asian Men
- 2) Women
- 3) People who have experience with drug use and/or sex work
- 4) Youth aged 16-29 years old
- 5) The Francophone community

Participant Recruitment Process

A single ad promoting the four English consultations was created and shared widely by the LYBL Core Team and the Community Consultants. Potential participants were screened for eligibility using a recruitment script. The Francophone group ad was circulated separately after the English consultations were completed. Honouraria were offered to all participants in the form of a \$50 electronic gift card of their choice.

Participant numbers and demographics

A demographic survey was filled in by almost all of the consultation participants prior to or during the consultation.

Group	Number of Participants	Number who filled in the survey
Middle-Eastern, East/South/Southeast Asian Men	10	10
Women	12	11
People with experience with drug use and/or sex work	8	8
Youth	8	8
Francophone	10	11

Demographic Summary

- Most consultation participants were between the ages of 40 and 69 which is consistent with the average age of people living with HIV in Canada.
- Responses to the question *how long have you been living with HIV?*, were fairly evenly distributed over five-year increments between 5-9 years and 30+ years.
- Most participants identified as cis women or men, though four people identified as being Two-Spirit.
- Heterosexual and gay were the most common sexual orientations reported.
- The vast majority of participants were from Ontario, followed by British Columbia and Quebec, and most reported living in urban settings.
- There was an approximately even split between those born in Canada and those born outside Canada and most identified as Canadian citizens.
- More than half of respondents identified as non-White.
- The participants were highly educated and about half were employed while the others reported collecting either social assistance or a pension.

Emerging Themes

Community consultation participants were asked a series of five questions:

- 1) Do you prefer the term wellness or well-being?
- 2) What does well-being mean to you, as a person living with HIV?
- 3) What outside factors impact your well-being?
- 4) What actions do you take [or have you taken in the past] to improve your well-being?
- 5) What recommendations do you have for improving quality of life for people living with HIV?

There was no consensus among community consultation participants whether they preferred the term 'wellness' or 'well-being'. Definitions of each term were uniquely personal and there were different levels of agreement about these concepts both within and across the five groups. Even so, there appeared to be a shared understanding that to *live well with HIV* requires a comprehensive approach that attends to the many intertwined domains of life, including the physical, emotional, mental, social and spiritual realms.

Participants shared a multitude of personal wellness strategies, including:

Physical: Healthy eating, rest, exercise, medication use, walking, drinking tea, pampering

Emotional: Self acceptance, journaling, counselling, making changes to reduce stress

Mental: Practicing mindfulness, a positive attitude, volunteering/advocacy, setting goals

Social: Seeking support from others (peers, friends, family, pets), community involvement

Spiritual: Meditation, spending time outdoors, prayer

They also discussed external factors that impact their well-being. Relationships and community involvement supported wellness for some individuals and hindered it for others. HIV stigma and other forms of discrimination were frequently raised. Social determinants of health such as job security, food security, ability to navigate systems of care, language and culture, and housing were brought up by our consultation participants, often in ways that indicated that they had inequitable access to these resources for wellness. There were mixed feelings about COVID-19 and related public health measures. Some said the pandemic carved out space for them to reflect on their own goals and values, but for many others being physically separated from one's social network was a significant source of distress.

As participants offered recommendations for policy and practice change to improve their collective well-being, it was evident that many had honed their ability to advocate for themselves and their communities. Addressing inequitable access to services, care and resources, for example, by implementing universal pharmacare and establishing a living wage for people who rely on income supports, was seen as fundamental. The need to move research into action was strongly articulated in one group. A desire to find effective ways to reduce HIV stigma, including changing curriculum in schools, and spreading the message that U=U, came up in every consultation.

Living Your Best Life – Virtual Meetings

Planning and Invitations

In an effort to ensure our virtual meetings were as interactive as possible, we used Whova, a platform that contributes to a seamless conference experience by integrating meeting processes such as registration, communications, and participant engagement.

Realize and the CAN LhIVE WELL teams invited the speakers, and promoted the event among their project partners and members of their respective communities. Additionally, broad invitations were sent to the Executive Director of each HIV organization in Canada and the event was promoted on social media (Facebook, Twitter, Instagram, LinkedIn).

Attendance

142 individuals registered across all four sessions of LYBL. Of those registered, 98 downloaded the Whova ‘app’ which was required for attendance. The attendance at each session was as follows:

Session # / Date	#1 – Fri Jan 29th	#2 – Mon Feb 1st	#3 – Thurs Feb 4th	#4 – Fri Feb 5th
# of attendees	65	57	56	56

The Meetings

Meeting Format

Each session of the LYBL meetings had a different focus and theme:

- Session #1: Wholistic Healing Map as a Potential Framework
- Session #2: Indigenous Peoples in Canada
- Session #3: Key Populations
- Session #4: Impacting Policy and Practice

The first session was led by Donald Turner and Jack Haight who provided an in-depth description of how the Medicine Wheel can be used as a Framework for Wellness. The following three sessions were all structured similarly and included speakers (10 minutes each), panel discussions, breakout sessions and presentations by one or two community consultants. Agendas and detailed speaker information for each session can be found in **Appendix XYZ**.

Interactive Meeting Elements

Opportunities for meeting participants to interact with one another and reflect on the material shared by presenters were built into each LYBL session. Throughout each session the team from **Realize** and CAN LhIVE WELL engaged with the participants via the chat. Any links that were shared within the chat were saved and circulated to all participants after the meeting series ended.

During session #1, meeting participants were divided into three break-out groups and engaged in a facilitated discussion about where, when and how the Seven Grandfather Teachings could be used to foster well-being for people living with HIV in Canada.

During sessions #2-4 interactive discussion took place in a plenary format. The sailboat analogy was used to guide the conversation and each day engaged with a different aspect of the sailboat. This analogy uses the sails to represent the four areas of the Medicine Wheel Wholistic Healing Map – Spiritual/Spirit, Emotional/Heart, Physical/Body and Mental/Mind. The wind represents things that propel a person toward the goal of optimal wellness. The anchors represent things that hold a person back from achieving optimal wellness, or slow them down. The icebergs represent obstacles that could become barriers to optimal wellness in the future. The water represents systemic factors, positive or negative, that contribute to optimal wellness in the context of living with HIV.

What We Learned

The Sailboat Analogy: Conceptualizing Wellness with Meeting Participants

The wind, or what propels a person living with HIV toward the goal of optimal wellness, was the focus of discussion during Session #2. Meeting participants who were living with HIV were invited to share their ideas first followed by allies. People spoke about activities and supports that contributed to wellness in each of the four quadrants of the medicine wheel including: the spiritual (God, religion, seeking out the teachings of elders, connection to nature); the emotional (connection to peers and community, balancing giving of the self and receiving from others, self acceptance); the physical (honouring one's body, resting, exercise, meeting basic needs), and the mental (learning, meditation, visualization, taking a break from focusing on HIV, maintaining a positive attitude). For some, wellness was promoted by achieving balance across these four areas, while others expressed feeling that one area was of particular importance to them.

Anchors, things that hold a person back from achieving optimal wellness, and icebergs, obstacles that could become barriers to wellness in the future, were explored during Session #3. Participants described being held back by changes in their physical health (sensory changes,

managing multimorbidity), competing responsibilities in their lives (taking care of others means little time for the self), inadequate resources (financial insecurity, cost associated with wellness activities like exercise) and poor mental health (anxiety, depression). The impact of current events (systemic racism, covid-19, politics) and the external environment (cold winter weather) on the lives of people living with HIV was also discussed. Loss of connection to others and limited freedom of movement were cited as particular barriers to wellness in the context of the covid-19 pandemic. Potential future obstacles to optimal wellbeing for people living with HIV in Canada (icebergs) were identified as: the uncertainty and anticipated losses attributable to aging with HIV, the perceived instability of funding for HIV services, and stigma and discrimination. Several strategies for ‘lifting the anchors’ were shared by meeting participants, including exercise, meditation, prayer, spending time with others, being outdoors, and connecting to culture.

During Session #4, the final day of the LYBL meetings, we revisited the concept of the wind and asked participants to reflect on what positive healthy actions would put wind in their sails moving forward. Their ideas were captured using Google Jamboard. In summary, there was broad recognition that each person living with HIV needs to define and set individual priorities and goals around wellness – there is no ‘one size fits all’ prescription for well-being. The importance of integrating movement, nature, healthy food and social support into one’s life were acknowledged by multiple participants.

This session also addressed the water, the systemic factors that impact well-being, as participants shared their ideas about what we can do, collectively, to support the journey toward optimal wellness for people living with HIV in Canada. Common themes emerging from this discussion included:

- Addressing the social determinants of health and making sure that all people living with HIV have their basic needs met
- Amplifying the voices of people living with HIV, the need to share stories, and fostering a culture within the HIV community of lifting each other up
- Sustainable funding for organizations and programs that support various aspects of well-being for people living with HIV
- Tackling stigma and ensuring inclusion and access to education and resources for all people living with HIV
- Mentoring the next generation of community advocates
- Making wellness the new ‘hot topic’ within the HIV community and collaborating more with those outside the HIV community

Evaluation

At the end of each of the four sessions, participants were provided with a link to an online evaluation form. The form asked questions related to where participants live and work, their level of knowledge related to meeting topics before and after the session, intention to use information learned during the sessions and satisfaction with the agenda and overall experience. Each participant was also provided with the opportunity to provide policy, practice and research recommendations related to optimizing wellness for people living with HIV across Canada. As an incentive to complete the surveys, participants were offered the opportunity to be entered into a draw for a \$50 Shoppers Drug Mart gift card; one entry was provided for each survey completed.

Evaluation Results

The majority of participants were from Ontario (between 45-65% depending on the session) and identified as being affiliated with the HIV community. Approximately 60% of participants who attended each of the sessions identified as a person living with HIV.

Most reported an increase in their knowledge related to the meeting topics and intended to use what they learned in at least one way after the meetings. Respondents most often indicated the following new or renewed future intentions:

- To reflect on whether and/or how Indigenous concepts of wellness might influence their research activities with people living with HIV
- To reflect on the potential impact(s) of their past, present, and future research on the well-being of Indigenous people and communities living with HIV
- To integrate concepts of optimal wellbeing for people living with HIV into their research

Participants were satisfied overall with the agenda and experience of the meetings. Some participants liked the interactivity that Whova and Zoom made possible while others found it difficult to navigate a new application. The LYBL Core Team also reflected on the experience of hosting a virtual meeting series. We experienced some difficulty integrating Whova with Zoom, the video conference platform. Both applications had features that would have been useful to us, but they were not supported when the two were used together.

Common themes among participants' recommendations for changing policy, practice and research to optimize wellness for people living with HIV across Canada included:

- Increasing representation of underrepresented groups in policy, practice and research, including women and Black, Indigenous and other People of Colour (BIPOC communities)

- Increasing inclusion of people living with HIV in policy, research and practice, including strengthening the commitment to the GIPA/MEPA principles
- Taking action against both HIV stigma and racism
- Ensuring that the comprehensive needs of older adults and people aging with HIV are included in policy, practice and research (e.g. mental health)
- A focus on social determinants of health (e.g. housing, income supports and/or universal basic income, universal pharmacare, childcare, etc.)
- De-criminalization initiatives
- Harm reduction
- A more holistic focus on policy, practice and research
- A broader, more comprehensive focus on wellness and wellbeing

Project Conclusions

We were able to gather diverse perspectives on the factors that contribute to optimal wellness for people living with HIV through the LYBL project. We summarized our learnings into six key themes and five calls to action.

Key Themes

- 1) Culture is an important contributor to wellness
- 2) Well-being is defined differently by each individual and this definition may change across their life course; this necessitates individualized approaches to maintaining and enhancing well-being
- 3) Having one's basic needs met is a pre-cursor to achieving optimal wellness
- 4) Wellness should be conceptualized broadly and wholistically, and should encompass all domains of health (e.g. emotional, spiritual, physical, mental, sexual, etc.)
- 5) Community is an important contributor to wellness for people living with HIV
- 6) Multi-level positive healthy actions, including those at the individual, community, and structural levels, are required to foster optimal well-being among people living with HIV in Canada

Calls to Action

- 1) Move Research to Action through practice and policy change
- 2) When defining wellness and responding to wellness needs, involve community meaningfully, starting with understanding what community wants
- 3) Take an intersectional approach to wellness, acknowledging that each person embodies multiple social/personal identities and these intersect to impact their wellness. Take direct action to combat racism and the many other forms of stigma and discrimination to ensure inclusive and equitable spaces and services
- 4) Address the basic needs (housing, income, food etc.) of people living with HIV as a pre-requisite to optimal well-being
- 5) Move beyond a clinical focus on HIV to address wellness more holistically

Reflecting on Process

The LYBL meetings were successful as a result of the collaborative efforts of **Realize** and the CAN LhIVE WELL research team. The partnership allowed the project team and our meeting attendees to explore optimal well-being for people living with HIV through both policy and research lenses. In a sense, this project embodied the cross-disciplinary approach required to move research findings into action emphasized by participants in both our community consultations and our LYBL virtual meeting series.

Finally, the project team tested various tools and methods for engaging meeting stakeholders in a virtual environment. This experience has built **Realize's** capacity to deliver highly interactive, effective virtual meetings with stakeholders from across Canada which will enhance future projects.

About *Realize*

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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