

LIVING YOUR BEST LIFE WITH HIV

RECOMMENDATIONS FOR POLICY MAKERS

BACKGROUND

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 as long as the general population.¹ Additionally, the number of new HIV cases diagnosed annually in Canada increased 25.3% between 2014 and 2018.² Increasing longevity and HIV incidence rates have led to a growing number of people living with HIV (PLWHIV) across Canada.

This shift from deadly infection to long-term condition requires a corresponding shift in focus from saving lives to improving health and wellbeing. At a national level, in 2015 Canada adopted the UNAIDS 90-90-90 targets in their response to HIV.³ 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?

Realize has taken a leadership role in investigating what optimal health and wellbeing mean to people living with HIV in an effort to better understand the issues, barriers, and gaps that interfere with their ability to achieve it. This process has included: consensus-building activities with researchers, and health professionals; holding community consultations with people with lived experience of HIV; and co-hosting a series of meetings with subject matter experts and people living with HIV to conceptualize optimal health and wellbeing for this population. From this comprehensive process, the following issues and recommendations emerged:

1 People living with HIV are experts on the programs and services they need to optimize their health and wellbeing. Existing programs and policies have been developed in ways that create gaps for people living with HIV. Policy makers have a responsibility to actively engage with people living with HIV to create policies and programs to improve their quality of life.

2 People living with HIV have been researched extensively over the past 40 years; their medical status, their needs, results from pilot programs, program evaluations and more. These research projects have been funded by multiple government and arms length organizations throughout the years. However, people living with HIV and community-based HIV organizational staff indicate that although successful programs have been developed and researched, they have rarely been provided with long-term funding to implement these programs after the research is complete.

RECOMMENDATIONS

- ✓ Involve people living with HIV in decisions about policy and programming related to HIV, health and wellbeing

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- ✓ Move research into action by developing policies to encourage long-term funding of successfully researched HIV programming

3 People living with HIV recognize that wellbeing is attainable only if their basic needs are met. Since HIV often impacts marginalized populations who already experience barriers to service access on account of their gender, race, class, or ability, it is imperative that programs that provide housing, food, income, and comprehensive healthcare (including medications) for people living with HIV are low-barrier.

4 HIV policy has focused on medical management of the disease. In many instances, HIV is still categorized as a sexually transmitted or blood borne infection. This classification reduces HIV to measurement and management of its infection rate, prevalence, and incidence. Health related quality of life for people living with HIV needs to be considered in conjunction with infection control measures. Well-being should be considered at each step of a person's journey along the HIV care continuum (diagnosis, treatment, undetectable viral load) and beyond.



RECOMMENDATIONS

- ✓ Strengthen social and healthcare policy to prevent gaps and barriers in access
 - ex. Acknowledge and address the financial cliff that older adults experience when moving from provincial support programs to Old Age Security

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- ✓ Ensure people living with HIV have access to health-promoting services beyond clinical care by updating social and health related policies
- ✓ Develop holistic and comprehensive policies that focus on health-related quality of life and wellbeing

OVERALL GOAL: IMPROVING QUALITY OF LIFE THROUGH POLICY CHANGE

The recommendations put forward in this brief will be most effective if implemented concurrently. People living with HIV are experts in their own well-being, and they are recommending that existing research evidence be used to justify the delivery of much-needed programming. The basic survival needs of people living with HIV need to be met before they can move towards optimal wellbeing. Finally, the focus needs to broaden from medical management of HIV disease to promotion of health-related quality of life. Together these broad recommendations should shape the future direction of HIV policy and broader health and social policies that impact people living with HIV. Living well with HIV is something that can be achieved, with the right policies in place.

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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. Haddad, N., Robert, A., Weeks, A., Popovic, N., Siu, W., & Archibald, C. (2019). HIV in Canada—Surveillance Report, 2018. Centre for Communicable Diseases and Infection Control. Retrieved from <https://www.canada.ca/content/dam/phac-aspc/documents/services/reports-publications/canada-communicable-disease-report-ccdr/monthly-issue/2019-45/issue-12-december-5-2019/ccdrv45i12a01-eng.pdf>
3. CATIE (n.d.). A history of HIV/AIDS. <https://www.catie.ca/en/world-aids-day/history>