

Optimal Health and Wellbeing in HIV: Opinion Paper

Optimal Health and Wellbeing in HIV: From Prolonging Life to Quality of Life

An Opinion Paper from the Optimal Health & Wellbeing in HIV Steering Committee

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The Optimal Health & Wellbeing in HIV Steering Committee

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Executive Summary

Since Highly Active Antiretroviral Therapy (HAART) was introduced in 1996, HIV treatment has transformed HIV from a condition with a high fatality rate into a manageable chronic condition. Today, early diagnosis and appropriate treatment mean that people with HIV can expect to live almost as long as the general population. This shift from deadly infection to long-term illness requires a corresponding shift in focus from saving lives to improving health and wellbeing.

In April of 2018, the Optimal Health and Wellbeing in HIV Steering Committee was formed to address the current challenges associated with long-term management of HIV in a Canadian context. Through our deliberations, we arrived at six key “Calls to Action”, each with important next steps and recommendations. Our goal with this paper is to provide a jumping off point for discussion and debate on how to maximize the quality of life for people aging with HIV in Canada.

Calls to Action

1. **Increase systematic participation of people living with HIV in decisions about their care.**
2. **Secure a high quality of life for people living with HIV.**
3. **Develop programs and tools to counteract HIV-related stigma and discrimination in healthcare while improving understanding of these issues through research.**
4. **Maintain a focus on the health of older adults with HIV, emphasizing prevention, testing, and treatment.**
5. **Integrate services for mental health, substance use and neurocognitive impairment with routine HIV care.**
6. **Eliminate barriers that prevent equal access to services and treatment.**

Below we provide a summary of the content of each call to action; however, for a more fulsome review, please see the full paper.

Call to Action 1: Increase systematic participation of people living with HIV in decisions about their care.

Since it was first articulated in 1983, the idea that people with HIV should play an active role in their own care decisions has evolved into such concepts as “greater involvement of people with AIDS” and “meaningful engagement of people living with HIV.” The scope

Purpose, process and limits of this paper

In developing this opinion paper, the Committee’s goals were threefold:

1. To examine the experience of Canadians living with HIV;
2. To propose specific measures that can empower members of the HIV community and improve their health, wellbeing and quality of life; and,
3. To spark a conversation between members of the community, healthcare providers, government, and community organizations across Canada.

The Steering Committee, a group of healthcare providers, community organizations, and people living with HIV, developed a draft of this paper and revised it following consultation with healthcare providers, AIDS Service Organizations (ASOs) and other community groups, and community members.

This paper is not a scientific literature review and is not peer reviewed. The final paper reflects the opinions and experience of the authors and those interviewed during the consultation process. People with HIV were consulted and served as members of the committee and their views are reflected here as well as those of members of the larger HIV community.

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of this participation has broadened to include people with HIV becoming actively involved in HIV-related research, working as peer health navigators, and developing peer-initiated campaigns. Networks play a key role in fostering participation, facilitating support groups, and educating people with HIV on health-related issues, the law, and human rights. However, people with HIV are not always central to healthcare decisions, including those that affect their lives. We call on healthcare providers, ASOs, and governments to actively seek out people living with HIV (including aging people), so that they can actively contribute to HIV research, community organizations and education and more effectively address important issues that face people living with HIV.

Call to Action 2: Secure a high quality of life for people living with HIV.

Now that Canada is close to achieving the UNAIDS “90-90-90” targets, and people with HIV can expect a near-normal lifespan, the emphasis of treatment must expand from keeping people living with HIV alive to improving their health-related quality of life. An integrated, outcomes-focused, patient-centred approach to HIV care is needed in order to achieve a new target: that 90% of people with viral load suppression have good health-related quality of life. This “fourth 90” requires overcoming significant HIV-related health challenges, included those associated with aging. Among other proposals, we recommend reaching a consensus on adopting high quality of life as a goal for all Canadians living with HIV, investigating the possibility of adopting specific quality of life measurement tools for use in Canada, developing clinical guidelines for HIV comparable to those in other countries, prioritizing innovative HIV medicines that will improve quality of life and ensuring that people living with HIV have access to health services beyond HIV treatment required to achieve high quality of life.

Call to Action 3: Develop programs and tools to counteract HIV-related stigma and discrimination in healthcare while improving understanding of these issues through research.

People living with HIV are vulnerable to stigma and discrimination because the history of HIV/AIDS has linked the condition to sex, death and marginalized groups such as gay men. A complex array of healthcare needs makes them vulnerable to stigma or discrimination from healthcare providers. HIV-related stigma, and especially stigma from health providers, can significantly impact physical and mental health: people may avoid health services, resulting in late presentation at diagnosis or only receiving treatment when emergency care is required. In Canada, marginalized groups such as men who have sex with men (MSMs), people who use injection drugs, sex workers, transgender people, people of colour, indigenous people and immigrants are likely to experience both HIV-related stigma as well as one or more stigmas related to their particular identity: racism, homophobia, transphobia, bias against sex workers. Other marginalized groups who may experience multiple stigmas following an HIV diagnosis include women (who are impacted by misogyny and sexism) and people who are impacted by ableism. As members of marginalized communities are more likely to be diagnosed with HIV, it is crucial that governments and health organizations develop evidence-based policies informed by relevant data to create policies and programs to reduce all forms of stigma directed at people with HIV, that anti-stigma policies be publicized and enforced, and that healthcare providers receive relevant cultural education and diversity training while employers work to increase diversity in healthcare organizations.

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Call to Action 4: Maintain a focus on the health of older adults with HIV, emphasizing prevention, testing, and treatment.

While older people are a growing proportion of the Canadian population and Canadians over 50 account for approximately one in five new cases of HIV, they are often overlooked. Incorrect assumptions that older people are not sexually active and healthcare providers' discomfort in discussing sex-related matters with middle aged (or older) patients mean older people may miss opportunities to discuss sexual health, STIs and HIV. Research also tends to overlook this group. HIV research and HIV care as a whole, from prevention and medical management to home care, must shift its focus to accommodate two groups of older people with very different needs: older people recently diagnosed with HIV and those who have been living with HIV for many years. This will require addressing HIV-related health issues, health risks specific to people living with HIV long term, and providing the necessary care and support to meet the health, social and material needs of people as they age. An emphasis on patient-centred care is essential to increase quality of life in older adults with HIV.

Call to Action 5: Integrate services for mental health, substance use and neurocognitive impairment with routine HIV care.

HIV is associated with a high risk of mental health disorders (such as depression, anxiety, and suicidality), drug use,¹ and neurocognitive impairment.² As many as half of Canadians with HIV may qualify for one or more psychiatric diagnoses,³ while illicit drug use has been reported by substantial minorities of both younger (45.1%) and older (29.7%) people with HIV.⁴ Both mental health issues and substance use disorders negatively impact adherence to antiviral therapy (ARV).^{5,6} From 40% to 90% of mental health and substance use issues are undetected in primary care settings.⁷ Neurocognitive impairment (NCI) in the HIV population ranges from mild impairment to full-blown dementia. Diagnosis is complex and challenging, as numerous factors other than HIV may contribute to NCI, while relatively recent long-term survival of people with HIV means that both research and clinical experience are lacking. Patients living with mental illness, substance use or NCI in addition to HIV require increased funding for mental health, mental health supports that meet the need of older populations, and improved access to mental health treatment. Mental health treatment and support should be integrated with broader health strategies, and should emphasize the ability to recognize medical health needs and ensure patients quickly receive the support and treatment they need.

Call to Action 6: Eliminate barriers that prevent equal access to services and treatment.

While the Canada Health Act states all Canadians should have reasonable access to medically necessary services, not all Canadians have equal access to healthcare or receive the care they need. People with HIV must navigate a fragmented healthcare system with 18 public healthcare plans provided primarily by provincial and territorial governments, with the federal government responsible for healthcare directed to specific groups. Residents of rural and remote areas and people living on First Nation reservations, Inuit hamlets and Métis settlements have much less access to healthcare than their urban counterparts. Medication access is both complex and fragmented, as it is provided by a mixture of provincial and territorial programs, HIV-specific programs, and catastrophic drug coverage for those who do not qualify for other coverage. Each program has its own list of approved medications and specific criteria. Navigating this maze of programs can be a confusing and challenging experience. As ARV therapies are crucial to prevention of HIV and survival following diagnosis, a national HIV strategy and

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pharmacare system are necessary in order to provide access to today's lifesaving treatments and to ensure that people with HIV will have access to innovative treatments that will be developed in future.

Conclusion

Advances in the treatment and prevention of HIV mean that many people who would have died in the early days of the AIDS epidemic can now expect to survive for years and even decades after diagnosis. This in itself comes with considerable challenges, from a higher risk of age-related conditions and mental illness to the side effects of lifesaving treatment and stigma and discrimination that serve as barriers to that same treatment.

As a first step to meeting these challenges, we have identified calls to action and outlined specific recommendations for each. Our aim is to spark discussions in the national HIV community and beyond, so that healthcare providers, community organizations, policymakers and government can work together to develop effective strategies to improve the health and wellbeing of people living with HIV.

This content was developed by a national Steering Committee, furthered by community consultation, and reflects the opinion of its authors. The Committee's independent efforts were made possible through the support of Gilead Sciences Canada, Inc.

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Introduction

In many ways, HIV seems like a different disease than at the beginning of the epidemic nearly 40 years ago. Once mainly associated with younger gay men, it is now understood to affect people of all genders and ages – including, increasingly, people aged 50 and older.⁸ The efficacy of antiretroviral (ARV) therapy has transformed HIV from a disease with a high fatality rate into a manageable chronic condition. Early diagnosis and appropriate treatment mean that many people living with HIV can look forward to living almost as long as members of the general population. At the same time many countries, including Canada, are approaching the UNAIDS 90-90-90 target for diagnosis and treatment of HIV.⁹ Recently, an even more positive finding has been documented: people with HIV who receive effective treatment, and no longer have detectable amounts of HIV in their bloodstream, cannot pass the virus on to their sexual partners.¹⁰ This protects the health of the person living with HIV and prevents new infections.¹¹ The confirmation that “undetectable equals untransmittable” (or “U=U”) has been described as a “game changer” because it has the potential to not only preserve health and prevent new cases of infections but to remove the fear and stigma long associated with HIV.¹²

While acknowledging these considerable achievements, it is important to be aware that this shift from deadly infection to long-term illness requires a corresponding shift in focus from saving lives to improving them. There is no lack of challenges from which to choose: a higher risk of age-related conditions such as heart disease and osteoporosis; reduced quality of life resulting from years of treatment, side effects of treatment, and other health conditions that often accompany HIV; and persistent stigma and discrimination that can impact mental health and (when stigma or discrimination come from a healthcare professional) act as a barrier to accessing needed care.⁹

Purpose of this paper

The Optimal Health and Wellbeing in HIV Steering Committee was formed in April of 2018 to address these challenges in a Canadian context. This opinion paper seeks to examine the experience of people living with HIV in Canada and to propose specific measures that can empower members of the HIV community and improve their health, wellbeing and quality of life. A further goal is to spark a conversation between members of the community, healthcare providers, government, and community organizations across Canada.

Overview of the process

The Steering Committee – among them, people living with HIV, healthcare providers and representatives from community-based HIV organizations –collaborated to develop a draft version of the paper, followed by consultation with healthcare providers, community-based HIV organizations, community members across the country, as well as other community groups. Recommendations and suggestions from consultations were incorporated into a revised draft, which was reviewed, revised and approved by the Steering Committee.

Limits of this paper

This opinion paper is not a review of the scientific literature and is not peer reviewed. The final paper reflects the opinions and experience of the authors and of the healthcare providers, ASOs, other community organizations and people living with HIV interviewed during the consultation process. While

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people with HIV shared their ideas and opinions, the Steering Committee recognizes that their contributions reflect the views of only a small part of the larger HIV community.

Moving forward

The Steering Committee views this paper as the beginning of a larger, nationwide conversation involving all parties involved in supporting people living with HIV. We believe it will serve as a rallying point to focus discussions on how to move forward in Canada. It is our hope that by working together we will be able to better articulate the challenges of HIV and to develop effective strategies that will improve the health, wellbeing and quality of life of people living with HIV.

This content was developed by a national Steering Committee, furthered by community consultation, and reflects the opinion of its authors. The Committee's independent efforts were made possible through the support of Gilead Sciences Canada, Inc.

Call to Action 1: Increase systematic participation of people living with HIV in decisions about their care.

Background

The idea that people living with HIV should play an active role in their own care decisions was first articulated by two members of the Advisory Committee of People With AIDS (PWA), who coauthored a manifesto later known as the Denver Principles. This statement was presented by PWA at the closing session of a 1983 conference of lesbian and gay healthcare providers that was held in Denver, Colorado, in 1983.^{13,14} (Table 1-1)

Table 1-1. The Denver Principles.

<p>People with AIDS: recommendations and rights From the Denver Principles (<i>Statement from the Advisory Committee of People With AIDS (1983)</i>).</p> <p>We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People With AIDS.”</p> <p>RECOMMENDATIONS FOR PEOPLE WITH AIDS</p> <ol style="list-style-type: none">1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.2. Be involved at every level of decision-making and specifically serve on the board of directors of provider organizations.3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.

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4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel that people with AIDS have an ethical responsibility to inform their potential partners of their health status.

RIGHTS OF PEOPLE WITH AIDS

1. To live as full and satisfying sexual and emotional lives as anyone else.
2. To receive quality medical treatment and quality social service provision without discrimination of any form, including sexual orientation, gender, diagnosis, economic status or race.
3. To obtain full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.
4. To ensure privacy and confidentiality of medical records, to receive human respect and the right to choose who their significant others are.
5. To die — and to LIVE — with dignity.

Adapted from Wright J., 2013.¹³

The concept of “greater involvement of people with AIDS” (GIPA) was formalized at the 1994 Paris AIDS Summit. In the Paris Declaration, 42 countries agreed to “support a greater involvement of people living with HIV at all levels and to stimulate the creation of supportive political, legal and social environments.”¹⁴

While continuing to assert the right of people with HIV to participate in decision-making processes that affect their lives, the Paris Declaration supported involvement of people with HIV/AIDS at a societal level through an initiative to strengthen the capacity and coordination of networks of people with HIV/AIDS and community-based organizations.

Since the Paris Declaration, the concept of GIPA has broadened to include Meaningful Engagement of People Living with HIV (MEPA) and Meaningful Involvement of Women Living with HIV and HIV co-infections (MIWA).¹⁵ In Ontario, many community-based HIV support organizations have signed the Ontario Accord,¹⁶⁻²¹ a formal commitment to greater involvement and meaningful engagement of people with HIV.¹⁷ Recent years have also seen examples of increased participation of people living with HIV, including the use of peer research assistants,²² peer health navigators, and peer-initiated campaigns such as U=U (undetectable = untransmittable), which work to raise awareness of the recently established fact that when sustained antiretroviral therapy (ART) reduces viral levels to undetectable levels, a person has a zero risk of transmitting HIV to an uninfected partner.²³

An example of research that demonstrates a commitment to the greater and meaningful involvement of people with AIDS is “Positive Spaces, Healthy Places,” a community-based study that seeks to better understand housing issues faced by Ontarians living with HIV. Beginning in 2005, more than 600 people were interviewed about their housing experiences over a five-year period. People living with HIV were involved as researchers from the beginning of the project, while Peer Research Assistants conducted interviews with participants. This research provided valuable insight into the impact of unstable housing on quality of life and related issues. The results of the study have led to increased funding collaboration and policy changes both locally and nationally.^{24,25}

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Networks play a key role in fostering greater involvement of people with HIV in their communities. By encouraging people to be actively involved in decisions that affect them, helping them develop leadership skills, facilitating peer support groups, and educating people about health-related issues, the law, and human rights, networks make it possible for people to develop confidence in their ability to make their own decisions, and act independently, become involved in advocacy efforts or other community work. Priority population networks are organizations that support groups who are particularly at risk for developing HIV, who are marginalized, or both.²⁶ Priority support networks recognized by the Ontario government include the Gay Men’s Sexual Health Alliance, the Women & HIV/AIDS Initiative, and the African Caribbean Council on HIV/AIDS.²⁷ Networks organized by and for marginalized groups may be helpful in overcoming barriers to greater involvement such as difficulties with language, issues with literacy, and lack of knowledge about health issues.

The Positive Leadership Development Institute (PLDI) helps people living with HIV to develop their capacity for leadership and their ability to participate meaningfully in community life.²⁸ As a result, PLDI alumni are better prepared to become involved in systemic change. Last but not least, many older people with HIV who were part of the initial struggle for support and treatment have a unique perspective and valuable experience. They should be included in all community efforts to build systemic change.

Although involving people with HIV in research, program development and policy making is described as “one of the best examples of global progress in public health,” much work remains to be done before this involvement can reach its full potential.¹⁴ People living with HIV are not always central to national, provincial and more local health care decisions, including those directly affecting their own lives.

Recommendations & Next Steps

- Require healthcare providers specializing in HIV to actively implement GIPA rather than simply endorsing the principle of greater involvement.
- Encourage community-based HIV support organizations to recruit and include older people with HIV, offering opportunities to engage with others both online and in person as speakers to healthcare professionals and community organizations.
- Insist that people with HIV who provide services of value should be fairly compensated.
- Ensure engagement strategies for older people with HIV take into account their experience (which differs from that of younger people) and address systemic barriers that discourage involvement of marginalized communities.
- Acknowledge cultural differences in how aging is treated in different immigrant and cultural communities.
- Acknowledge the role of ageism in isolating older people living with HIV, especially in LGBTQ2+ communities.
- Advocate that governments address the “financial cliff” people with HIV face when age forces them to switch from provincial or territorial disability support programs to the Canada Pension Plan (CPP) programs, which provide significantly fewer healthcare supports.

Call to Action 2: Secure a high quality of life for people living with HIV.

Background

The UNAIDS “90-90-90” testing and treatment targets state that by 2020:

- 90% of all people living with HIV will know their HIV status;
- 90% of all people with diagnosed HIV infection will receive sustained antiretroviral (ARV) therapy; and,
- 90% of all people receiving ARV therapy will have viral suppression.

Canada endorsed the global UNAIDS targets in 2015.²⁹ That same year, the Public Health Agency of Canada (PHAC) began to provide estimates of HIV-related statistics such as incidence, prevalence and proportion of undiagnosed cases.²⁹ The most recent PHAC data indicate that Canada is close to achieving the “90-90-90” targets.³⁰ (Table 2-1)

Table 2-1. How Canada stands up against UNAIDS 2020 testing/treatment targets.

	UNAIDS 2020 targets	Estimated statistics for Canada in 2016
Proportion of people living with HIV who know their HIV status	90%	86%
Proportion of people with HIV diagnosis receiving sustained ARV therapy	90%	81%
Proportion of ARV-treated people achieving viral suppression	90%	91%

Adapted from United Nations Programme on HIV/AIDS (UNAIDS). 90-90-90: an ambitious treatment target to help end the AIDS epidemic³¹ and Public Health Agency of Canada. Summary: Estimates of HIV incidence, prevalence and Canada’s progress on meeting the 90-90-90 HIV targets, 2016.³⁰

Over the past thirty years, antiretroviral (ARV) therapies have helped transform HIV/AIDS from a life-threatening disease to a serious (but manageable) chronic condition^{31,32} and substantially increased life expectancy for people living with HIV.³³

Now that people with HIV can expect a near-normal lifespan, the emphasis of treatment must shift from keeping people with HIV alive to how well they are living — in other words, to their health-related quality of life (HRQoL).³³

A group of European researchers have suggested that quality of life be called “the fourth 90.” In relatively wealthy countries such as Canada, the group proposes that 90% of people with viral load suppression have good HRQoL.³⁴ Meeting this target is a substantial challenge due to HIV-associated health risks, a higher-than-average rate of comorbidities in aged (and aging) patients, and side effects associated with HIV treatment that can negatively impact HRQoL. Environmental factors related to provision of healthcare and social factors may also have an impact. (Table 2-2)

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In spite of this recommendation, there is no agreed-upon standard to measure HRQoL. The lack of quantitative assessment tools means that currently the “fourth 90” exists only in principle.

Table 2-2: Factors that can negatively impact quality of life for people living with HIV.

Aging-related health issues: as patients grow older, health issues related to aging may affect HRQoL. HIV carries an increased risk of developing cardiovascular disease (CVD), bone fractures, and renal (kidney) failure compared to the general population.³⁵ These issues may develop earlier than usual in patients with HIV, and the already substantial risks increase with age.³⁶ For example, the risk of renal failure is 16 times the average in patients with HIV between the ages of 41 and 50. This risk increases to *46 times the average* in patients who are at least 60 years of age. Meanwhile, drugs used to treat these issues may interact with medications prescribed for HIV or other health conditions.

Side effects related to ARV: ARV therapy can sometimes produce side effects that may be unpredictable, and may produce a “high degree of symptom-related stress.”³⁷

Environmental factors: fragmented healthcare delivery (particularly mental healthcare services and the challenges that come with navigating many different complex drug programs) can result in delayed treatment, limited access to specialists who can manage comorbidities (health issues), poorer outcomes, and decreased quality of life.³⁴

An integrated, outcomes-focused, patient-centred approach to HIV care is needed in order to achieve the “fourth 90.” People living with HIV will require access to services that go beyond HIV treatment to address all their needs. Services will need to address issues such as HIV prevention, treatment and management of comorbidities; mental health and neurocognitive impairment; and advice and support in relation to sexual and reproductive health.⁹

Recommendations & Next Steps

- Reach a consensus on adopting the goal of high quality of life for all Canadians living with HIV.
- Investigate the applicability and utility of specific HRQoL measurement tools in Canada for people living with HIV.
- Advocate for governmental health authorities (federal, provincial/territorial) to make high HRQoL a priority for this group, including support for research and treatment options with this objective in mind.
- Educate healthcare providers, frontline workers (such as social workers and sexual/reproductive health counsellors), nonprofit and advocacy organizations, and people living with HIV on the importance of achieving a HRQoL.
- Develop clinical guidelines for treatment of HIV that are comparable to those developed in other regions and countries.
- Adopt integrated, outcomes-focused, patient-centred approaches to long-term care in HIV. Treat the whole patient, not the disease.
- Ensure people living with HIV have access to health services beyond HIV treatment required to achieve high quality of life.

Call to Action 3: Develop programs and tools to counteract HIV-related stigma and discrimination in healthcare while improving understanding of these issues through research.

Background

The origins and history of the HIV/AIDS epidemic have linked it inexorably with sex, death and marginalized groups such as gay men and injection drug users.^{38,39} Today, although people living with HIV comprise a much more varied population, negative ideas, attitudes, and (mis)perceptions still colour the interactions between people with HIV and others in their lives.³⁸ Despite decades of public awareness and education campaigns, HIV-related stigma and discrimination continue to negatively impact the health and well-being of people living with HIV and limit access to healthcare, treatment and services.^{34,40}

People with HIV require access to a variety of healthcare services: prevention and treatment; management of comorbidities, mental health and neurocognitive impairment; and advice and support regarding sexual and reproductive health.³⁴ This complex array of healthcare needs makes people with HIV as a whole vulnerable to stigma and discrimination on the part of healthcare providers.

There has been relatively little research exploring the attitudes of Canadian healthcare professionals towards people with HIV, or the experience of stigma in Canadian hospitals and other healthcare settings.⁴¹ In the available literature, findings have been mixed: in some studies, people with HIV have described experiencing stigma in a healthcare context,⁴¹⁻⁴⁴ but other studies have documented improvement: medical students being more willing to treat people with HIV than 12 years previously^{41,45}, 80% of a group of Indigenous youth describing their interactions with healthcare providers as positive,^{41,42} and an overwhelming majority of surveyed healthcare providers expressing positive attitude to pregnancy and adoption for people with HIV.^{41,46}

In Canada, the people most likely to contract HIV are men who have sex with men (MSMs), individuals who use injection drugs, sex workers, and immigrants from countries where HIV is prevalent. Indigenous people, who make up less than 5% of the population, represented 10.8% of new diagnoses in 2014.^{38,47} Transgender people are another group who are at high risk of developing HIV.^{34,48} And older people are a growing proportion of the population^{49,50} who currently constitute about one in five people diagnosed with HIV.⁴⁹

All of these groups experience HIV-related stigma. Each also deals with group-specific stigmas, such as homophobia (MSMs), racism (Indigenous Canadians, people of colour, and immigrants), bias against sex workers or those who use “hard” drugs,³⁸ or ageism (older people).^{51,52} Each of these populations, therefore, has its own unique collection of stigmas, but all share the common experience of HIV-related stigma accompanied by multiple overlapping stigmas.

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HIV-related stigma impacts people in a variety of ways: poor physical health, reduced access to healthcare, lower quality of life, and an increase in mental health concerns.^{38,53,54} Anecdotal evidence from interviews with community-based HIV organizations suggests that even a single negative experience may result in a person avoiding the hospital or clinic where the experience occurred. This avoidance means they are less likely to receive treatment until an emergency occurs – a less than ideal way of managing one’s health.

Another consequence of stigma is late presentation at diagnosis, which is cause for concern, as later detection of HIV is associated with an elevated risk of some comorbidities and more severe immunosuppression, potentially causing death.⁵³ For women who plan to have children, stigma can be a barrier to prenatal care and complicate interactions with child welfare agencies.^{34,55}

For marginalized groups such as MSM, immigrants, or transgender people, additional stigmas may significantly impact detection and access to appropriate healthcare. For example, an online survey of 8,607 MSM across Canada found that only about half the men surveyed had disclosed their sexual orientation to their primary healthcare provider.⁵⁶ More than 10% of respondents had dropped their care provider because of the provider’s attitude. In many provinces and territories these numbers were significantly higher in rural areas compared to urban centres.⁵⁶

Some of the stigma directed at people with HIV is rooted in ignorance: healthcare providers receive minimal education or training on HIV. In four years of residency, physicians may spend as little as two hours learning about HIV. Despite their lack of expertise in this area, health practitioners may dismiss corrections from better-informed patients with HIV simply because they are laypeople rather than trained medical professionals.

A healthcare provider’s background plays a role in stigmatization. Each practitioner brings their own biases and cultural upbringing into the hospital or clinic. Combined with a lack of knowledge regarding HIV, this introduces the possibility that stereotypes, incorrect assumptions and biases (quite possibly unconscious) may influence how the provider treats some patients.

People living with HIV represent a cross-section of the Canadian public and are more likely to come from marginalized communities. For HIV specialists who do not come from these marginalized communities, a “perspective gap” may exist between providers and patients who have lived very different lives, unless that specialist has received significant cultural training. It can be difficult for patients to be treated by a practitioner who lacks an understanding of what is sometimes called “lived experience.” While diversity training may help to close this gap, efforts should be made to increase the representation of individuals from within affected populations to better reflect the diversity of patients. Doing so would bolster specialists’ insights and ability to connect with their patients.

Recommendations & Next Steps

- Collect and use relevant data to inform evidence-based policies and programs that will reduce stigma, discrimination, and barriers to services for people living with HIV.⁵⁷

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- Implement evidence-based initiatives to eliminate the stigma and discrimination associated with HIV and all stigmas that interact with it (including but not restricted to homophobia, transphobia, and racism).⁵⁷
- Review (and if necessary, revise) laws and policies that may contribute to stigma and discrimination against people living with HIV.⁵⁷
- Actively monitor healthcare experience of people with HIV, and enforce laws and policies created to protect this group.
- Expand programs that facilitate access to basic needs support services for people living with HIV.⁵⁷
- Implement educational programs to ensure all healthcare providers specializing in HIV care stay current with the latest advances in the field.⁵⁷
- Develop, publicize and enforce rules that clearly articulate healthcare providers' duty of care towards people living with HIV.
- Work to increase diversity in healthcare organizations and to create a culture of empathy and acceptance towards people living with HIV.
- Ensure healthcare providers working in HIV are taught to understand the healthcare experiences of people with HIV, including issues of stigma, comorbidities and cultural barriers.
- Institute increased diversity training for healthcare providers working in HIV.
- Increase the use of peer navigators – often facilitated by community-based HIV organizations – to help older people living with HIV to advocate for their care and navigate the complexities of the health system.
- Some people living with HIV may need to see themselves represented within healthcare systems to feel comfortable and to be sure their cultural and societal sensitivities are taken into account. At a minimum, HIV specialists should receive training in cultural and socio-cultural issues in order to better support their patients.

Call to Action 4: Maintain a focus on the health of older adults with HIV, emphasizing prevention, testing, and treatment.

Background

In Canada, the sexual health needs of older adults are often overlooked. HIV prevention programs have tended to ignore this group, which has generally not been considered at risk of sexually transmitted infections (STIs).⁵⁸ Healthcare providers may avoid discussing sexual health with older people because providers assume they are not sexually active,⁵⁸ or because a provider feels uncomfortable discussing sex with patients who are middle-aged or older.⁵⁹ As a result, older people may miss opportunities to discuss sexual health, STIs and HIV.⁵⁸ Furthermore, HIV research may also ignore older people. For example, the vast majority of patients in studies evaluating HIV-preventive drug treatment (also known as pre-exposure prophylaxis or PrEP) are under the age of 50.⁶⁰ This oversight may result in important insights and avenues of investigation being missed.

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Older adults are a group whose numbers are growing in Canada⁴⁹ and around the world.⁵⁰ In 2017, the 50-and-over age group accounted for one in five new cases of HIV in Canada.⁴⁹ This group is both sexually active and at risk of HIV infection. One U.S. study found that many adults are sexually active into their 60s and 70s and even into their 80s.⁶¹

In addition to managing treatment-related side effects, older people face HIV-specific challenges related to aging.⁶² (Table 4-1) They are at a higher risk for developing some age-related conditions compared to the general population. Some of these conditions appear five to 10 years earlier in people with HIV, including neurocognitive decline, osteoporosis and fractures, impaired physical function, frailty, and falls.^{63,64}

While functional problems (physical issues related to mobility, self-care and daily activities) increase with age, older adults who are recently diagnosed with HIV are *less* likely to experience depression or anxiety.⁵⁰ Instead, a longer time with diagnosed HIV infection appears to be related to a higher prevalence of both depression and anxiety.⁵⁰ A similar relationship has been documented between time since HIV diagnosis and HRQoL: while people diagnosed with HIV had reduced HRQoL compared with the general population, the effect was greatest for those who had the longest time elapsed since diagnosis, even after age and other factors were accounted for.⁶⁵ These and other findings⁶⁶ suggest that the aging-related needs of people who have been living with HIV long-term may be different than those of older adults with a more recent diagnosis of HIV.

Canadian research has identified factors that both impede and foster health and well-being in older people with HIV. Obstacles to well-being included isolation resulting from social ties with family or friends disrupted, often due to HIV-related stigma.⁶⁷ Stigma may also play a role in mental health issues.⁵¹ Among older gay and bisexual men, internal and external stigma increased the likelihood of high-risk sexual behaviours,⁶⁸ while a sense of resilience and mastery were both independently associated with quality of life; social engagement and community support were positively associated with both.⁶⁹

Healthcare for older adults should take into account the relatively recent concept of the “long-term survivor,” an idea that did not exist during the early years of the HIV epidemic. As a result, many older people with HIV who did not expect to live into old age are struggling with financial and social support networks and experiencing uncertainty about the future.

Table 4-1. Factors potentially affecting quality of life in older adults with HIV.

Side effects of antiretroviral (ARV) therapy ³⁷
Fragmented healthcare delivery ³⁵
Uncertainty related to source of health challenges ⁶²
Concerns about healthcare providers’ knowledge and skill related to HIV care ⁶²

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Financial insecurity and resulting impact on ability to “age well” with HIV by accessing resources (e.g., home-based supports for maintaining independence, uninsured medical services) ⁶²
Concerns about accessing appropriate long-term housing ⁶²
Anticipatory anxiety about disclosing HIV status and/or sexual orientation when accessing aging-related services ⁶²
Worries about who will provide future care ⁶²
Social isolation related to the unpredictable nature of HIV ⁶²

Adapted from Guaraldi G, et al., 2011,³⁵ Erdbeer G, et al.,³⁷ and Solomon P, et al.⁶²

Recommendations & Next Steps

- Encourage HIV specialists to work in partnership with other specialists and healthcare providers to effectively manage both HIV and HIV-related comorbidities.
- Lobby provincial and territorial Ministries of Health to mandate that all staff providing home care, community care and long-term care regularly receive comprehensive training that enables them to address health and social issues affecting older adults with HIV.⁷⁰
- Shift the focus in medical management of HIV from specific comorbidities to screening for and responding to geriatric issues (such as frailty) that are likely to impact independence.^{71,72}
- Improve quality of life and reduce suffering by making high-quality palliative care an integral part of HIV management, and ensuring access in all care settings.^{73–75}
- Emphasize patient-centred care (engaging the patient in shared decision-making, attending to pain and symptom management) in order to increase quality of life in older adults with HIV.⁷⁶
- Integrate advance care planning into routine care for older people living with HIV.
- Ensure all healthcare and service providers accommodate aging-related sensory and cognitive changes (such as initiating appointment reminders or providing notes and resources in large print format) and institute policy and practice changes to address ageism.⁷⁷
- Counteract the health effects of social isolation and loneliness by facilitating peer support at all times for older adults with HIV.⁷⁸
- Provide comprehensive support to facilitate “aging in place” with HIV (i.e., within their homes and communities), including personal care, medical management, and practical non-medical support required to maintain independence.⁷⁹

Call to Action 5: Integrate services for mental health, substance use and neurocognitive impairment with routine HIV care.

Background

Mental health

People living with HIV are at increased risk of comorbid conditions, with mental health disorders of notable concern. As many as 50% of people living with HIV may meet criteria for one or more psychiatric disorders.⁵ Compared to the general population, people living with HIV are more likely to experience mental health disorders such as depression (the most common psychiatric diagnosis in this group),⁸⁰ anxiety, and substance use compared to the general population.^{1,3,81} An emerging group, older people with HIV, are likely to experience mood disturbances accompanied by suicidal thoughts and behaviours.⁵¹ Furthermore, mental health disorders and HIV have been shown to contribute detrimentally to one another in an escalating manner. Addressing mental health comorbidities is increasingly important to the QOL of patients as HIV transitions towards chronic care management.^{3,81}

In addition to QOL concerns, the mental health of people living with HIV can impact ARV adherence and biological disease progression.⁵ The Ontario HIV Treatment Network Cohort Study found that poor adherence and stress were associated with transitions from suppressed to unsuppressed viral load.⁸²

Substance use

A 2016 study of drug use among people living with HIV \geq 50 years old found a significantly higher incidence of substance use than the general population. Furthermore, older adults living with HIV have higher rates of substance use that do not decline with age, compared to the general population.⁸³

Despite this high prevalence, 40% to 90% of mental health/substance use issues are undetected in primary care settings.⁷ Illicit drug use (particularly “crystal meth,”) has been shown to decrease adherence to treatment programs, presenting these patients with more difficulty in reaching and maintaining an undetectable viral load.^{6,84}

Both counselling and pharmacotherapies (e.g., methadone) have been shown to improve outcomes and improved screening in primary care may better identify patients needing treatment.

Harm reduction services have direct HIV prevention benefits and have been shown to effectively link people living with HIV with substance use disorders to ARV treatment. A study in British Columbia examined the independent effects of harm reduction services (opioid agonist treatment uptake and needle distribution volumes) and ARV on HIV transmission via needle. It showed that both intervention services and ARV had substantial independent effects on the HIV epidemic in the province. The authors estimated that between 1996 and 2013, 3,204 incident cases of HIV were averted as a result of the combined effect of the expansion of harm reduction services and ART coverage on HIV transmission via needle sharing.¹¹

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Models for treatment

A systematic review synthesized the literature on interventions and approaches integrating mental health and HIV services. The review identified three models, each of which presented both advantages and disadvantages.¹ (Table 5-1)

Table 5-1. Advantages and disadvantages: three models of integrated care.

Model	Advantages	Disadvantages
Integration within a single facility	<ul style="list-style-type: none"> • Multidisciplinary team Reduces access barriers for patients • Enhances communication between providers • Reduces scheduling and coordination time • Potential for increased confidentiality and reduced stigma (a possible result of visiting a mental health centre) 	<ul style="list-style-type: none"> • May not be practical or affordable
Multi-facility integration (collaborative framework between specialize care agencies)	<ul style="list-style-type: none"> • May allow for better treatment of multiple comorbidities 	<ul style="list-style-type: none"> • Fragmentation and poor co-ordination can be barriers.
Integrated care coordinated by a single case manager	<ul style="list-style-type: none"> • May assist with continuity of care • Case manager can help patients access resources, provide education, social support, guide interaction with physicians 	<ul style="list-style-type: none"> • Case managers require appropriate professional training • Case managers may not be available

Adapted from Chuah FLH et al., 2017.¹

Neurocognitive impairment

HIV often produces varying degrees of neurocognitive impairment (NCI), also known as “HIV-associated neurocognitive impairment” (HAND), ranging from mild impairment to severe dementia. In clinical practice, however, there are numerous other factors (clinical, social, and psychological) that may contribute to NCI/HAND. As a result, it can be challenging to determine what role the virus may play in the case of an individual patient. For example, NCI often co-occurs with cardiovascular disease and sleep disorders, both of which are becoming more common as people with HIV are living longer as a result of successful long-term ARV.² A similar complication relates to depressive symptoms. These are common in people with HIV, but it is difficult to determine whether or not they are related to NCI/HAND.

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One potential concern is that symptoms of depression and cognitive impairment may overlap (cognitive impairment is a diagnostic criterion for major depressive disorder [MDD]), potentially resulting in depressive symptoms or an MDD diagnosis being confounded with cognitive impairment.^{85,86}

Neurocognitive impairment in the HIV population is evolving and changing as people survive for decades – long enough to experience the effects of aging. A variety of comorbid physical, social and psychological factors create a complex interplay in pathogenesis, clinical presentation, and outcomes. Some of the many diagnostic challenges include a lack of comparative normative data for some patients (people who are members of ethnic minorities or of low socioeconomic status) to permit accurate assessment using rapid screening instruments; the impact of “social comorbidities” such as poverty or trauma that may impact cognition; physical comorbidities associated with aging, including cardiovascular disease; and the potential role of ARVs (especially protease inhibitors) which may be implicated in the development of metabolic syndrome, which may contribute to vascular dementia.²

Important priorities for research include development of validated rapid screening tools with population-specific normative data to allow clinicians to identify cognitive impairment in clinical practice, improving the scientific understanding of NCI pathogenesis, which may lead to identifying biomarkers or targets for therapeutic intervention, and behavioural interventions to allow prevention or treatment of neurocognitive disorders.²

Recommendations & Next Steps

- Establish peer navigator or “buddy” systems to aid people living with HIV in expressing their needs and articulating the challenges they face.
- Provide mental health supports in light of the challenges faced by older populations living with HIV, including guilt and loss experienced by long term survivors.
- Recognize the concept of the “disease burden” and its impact on mental health.
- Ensure clinical guidelines for HIV include screening for other comorbidities, including mental health issues.
- Improve access to mental health treatment and support, integrated with broader health strategies. In particular, aim to improve the ability to recognize mental health needs and quickly provide access to support and treatment where required.
- Increase funding for mental health to address this societal challenge.
- Continue to explore and research best practices and models of integration to provide the highest possible quality of life for people living with HIV.

Call to Action 6: Eliminate barriers that prevent equal access to services and treatment.

Background

Reasonable access to medically necessary services is a standard set out in the Canada Health Act.⁸⁷ All too often, however, Canada’s healthcare system falls short of this standard. Instead of benefiting from

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an integrated, outcomes-focused and patient-centred approach, people with HIV must navigate a complicated healthcare system while seeking the care they need.

Provincial and territorial governments are primarily responsible for delivery of healthcare.⁸⁷ Each province or territory is responsible for management, organization and delivery of healthcare services to its residents. Provinces and territories ensure all medically necessary services provided in hospitals or by physicians, as well as dental services when the service must be performed in a hospital.⁸⁷

The federal government sets standards (as outlined in the Canada Health Act) and provides some funding to provincial and territorial governments to help support delivery of healthcare services.⁸⁷ The federal government is also responsible for supporting healthcare delivery to several defined groups, including First Nations people living on reserves, Inuit, serving members of the Canadian Forces (and eligible veterans), inmates in federal prisons, and some groups of refugee claimants.⁸⁷

With 18 public health care plans operated by multiple different governments, it is not surprising to learn that people have very different experiences depending on where they receive healthcare services.³⁴

Figure 6-1. UNAIDS “90-90-90” testing and treatment targets for 2020

90%		90%		90%
of people with HIV know their HIV status		of people diagnosed with HIV will receive sustained ARV treatment		of people on ARV therapy will achieve viral suppression

Adapted from Joint United Nations Programme on HIV/AIDS (UNAIDS), 2014.

Disparities in healthcare resources in remote and rural communities and in First Nations reserves, Inuit hamlets and Métis settlements compared to urban settings directly impact the ability of these populations to achieve the UNAIDS “90-90-90” targets. Lack of trust, lack of access to testing and the absence of well-integrated, accessible services are part of the challenges that these communities face in achieving the first two targets. (Figure 6-1) While most of Canada has achieved all three targets, this is not true of all communities in Canada.

For example, data from all First Nations communities in Saskatchewan (representing more than 80 on-reserve communities) showed that of those known to be living with HIV, 77% were on treatment and 75% of those on treatment had achieved viral suppression.⁸⁸ In most cases, the most remote and rural communities in Canada have the least access and success in achieving these goals.³⁴

In response to similar challenges, a satellite clinic program launched in Washington state in 2007 brought HIV care to rural and urban-underserved regions via academic satellite clinics. This program has shown that geographic isolation and transportation barriers can be overcome to provide care.⁸⁹ In Canada, Saskatchewan’s “Know Your Status” program is reaching out to the community, while in Alberta the Drum and Sash research project is investigating the implementation of Shared Care models.

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In Canada, a new model of healthcare delivery to First Nations people is being tested. The First Nations Health Authority (FNHA) is a collaboration of the BC First Nations, the Government of Canada, and the BC provincial government. The FNHA will result in health programming being designed and implemented by First Nations for First Nations and is the first regional health authority of its kind in Canada.³⁴ The outcomes and learnings of these efforts should be reviewed and leveraged in order to better serve indigenous populations.

Refugees and undocumented workers represent a significant group of people living with HIV who have only limited healthcare access, and as a result are not receiving treatment for HIV.

People new to Canada face particular challenges when it comes to HIV testing and treatment. The immigration system requires that immigrants be tested for HIV, but provides little support or access to treatment for new Canadians with HIV. Those who do test positive must somehow learn how to navigate an unfamiliar healthcare system to obtain treatment for a serious chronic illness as well as adapting to a new country, culture, and often a new language.

Discrimination and oppression are major challenges to equitable access to healthcare services and treatment for people with HIV. Racism, homophobia, transphobia and similar social conditions make life much more challenging for marginalized groups. These socially imposed obstacles may make it more difficult to seek out healthcare services. If discrimination comes from healthcare providers, people may actively avoid the healthcare system. They are less likely to engage the healthcare system and therefore less likely to obtain HIV treatment and support. As a result, many marginalized people are not receiving the treatment they need.

Members of three marginalized groups (people who are homeless, living with mental illness, and substance users) all experience difficulties accessing health services in Canada.^{90–92}

Disparities across the country are not restricted to healthcare services; inequities in medication access also occur Canada-wide. Prescription drug coverage in Canada is fragmented. All provinces and territories have some degree of public drug coverage for some residents, but who is entitled to public drug coverage, and what medications are covered, varies widely between plans. Meanwhile, people with private insurance may have access to treatments not covered by public insurance.³⁴ This patchwork quilt of private and public services fails to provide universal coverage: approximately one in ten Canadians cannot afford to take their medications as prescribed.³⁴

People with HIV are more susceptible to developing non-infectious comorbidities such as cardiovascular disease, bone fractures, and renal failure than those without HIV, and more than half the deaths in HIV patients on sustained antiretroviral (ARV) treatment are attributable to such comorbidities.^{35,36} This suggests that the impact of fragmented drug coverage on people with HIV is twofold: they require disease-specific medications to treat their HIV, and also medications needed to manage any non-infectious comorbidities.

As is the case with public drug plans, disease-specific drug plans for HIV vary based on a person's province or territory of residency.³⁴ People with HIV who are not covered by private insurance or

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disease-specific plans rely on catastrophic drug plans that are more expensive than HIV-specific plans. Catastrophic drug coverage typically requires deductibles or co-payments that are geared to income. This produces dramatic inequities between provinces and sometimes within provinces, as small changes in income can affect the amount of deductibles or co-payments.³⁴

According to the Canadian AIDS Treatment Information Exchange (CATIE), pre-exposure prophylaxis (PrEP) and nonoccupational postexposure prophylaxis (nPEP) are important strategies for preventing HIV transmission and should be the standard of care and part of a strategy that includes behavioural interventions, such as condoms and counselling on risk reduction.^{92,93} However, only Quebec, Ontario, the federal Non-Insured Health Benefits (NIHB) formulary (which covers First Nations and recognized Inuit), and some private drug plans provide access.³⁴

A survey by the Public Health Agency of Canada (PHAC) of Canadian civil society organizations regarding the HIV epidemic between 2013 and 2015 showed that there is a need for a national HIV strategy and a national pharmacare system to ensure important medications are provided consistently and universally.²⁹

Whether used for prophylaxis or treatment, ARV therapies are absolutely essential for the survival and wellbeing of people living with HIV. A national HIV strategy and pharmacare system are necessary in order to provide access to today's lifesaving treatments and to ensure that people with HIV will have access to innovative treatments that will be developed in future.

Recommendations & Next Steps

- Champion a national pharmacare program to ensure equitable access to prescription medication nationwide.
- Ensure the cost of HIV prevention and treatment is covered in all provinces and territories, including ARV and PrEP.
- Use learnings from Saskatchewan's "Know Your Status" outreach program and results of the Drum and Sash research into Shared Care models to guide improvement of current programs and creation of new programs for people with HIV.
- Improve diagnosis in rural and resource-limited communities using a novel rapid HIV test²⁹ while implementing programs to provide necessary practical and emotional support to people with HIV in these communities.
- Advocate for a comprehensive approach to HIV prevention and treatment which addresses the full spectrum of life needs, from housing and food to substance use treatment and mental health supports in addition to clinical care.
- In order to engage effectively with people with HIV, healthcare providers, and the system as a whole, must become more aware of the communities they serve and the identities of those communities.
- Ensure healthcare organizations make efforts to be reflective of the diversity of the people they serve in order to create an environment that feels as supportive as possible for those using their services.

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- Explore the feasibility of implementing measures used in other countries to provide healthcare to remote locations (e.g., mobile clinics).
- Leverage tools such as telehealth and online and technological innovations to provide support in more remote communities
- Wherever possible, take an integrated approach to HIV treatment and support, offering all needed services at a single facility in order to make the healthcare system more accessible
- Assess the feasibility of empowering other health professionals (such as social workers, nurses and pharmacists) to provide HIV services in communities lacking sufficient healthcare support or specialized HIV care.

Conclusion

As a result of advances in the treatment and prevention of HIV, many people who would have died in the early days of the AIDS epidemic can now expect to survive for years and even decades after diagnosis. While challenges remain, there is considerable reason for optimism. The discovery that reducing HIV levels in the bloodstream to undetectable levels and maintaining this viral suppression makes the disease untransmittable (known as “U=U”) and maximizes a person’s health, opens up the possibility of significantly reducing development of new infections and offers a way to fight the stigma so long associated with HIV.

As a first step to meeting these challenges, this paper identifies six action strategies and outlines specific recommendations for each. It is hoped that the suggestions in the preceding pages will help to spark discussions in the national HIV community and beyond, so that people living with HIV, healthcare providers, community organizations, policymakers and government, can work together to develop effective strategies to improve the health and wellbeing of people living with HIV.

Appendix 1: Acronym Glossary

AIDS: Acquired immune deficiency syndrome.
ARV: Antiretroviral therapy.
CATIE: Canadian AIDS Treatment Information Exchange
CVD: Cardiovascular disease.
HAART: Highly Active Antiretroviral Therapy
HAND: HIV-associated neurocognitive impairment
HRQoL: Health-related quality of life.
MSM or MSMs: Men who have sex with men.
NCI: Neurocognitive impairment
NIHB: Non-Insured Health Benefits
nPEP: Nonoccupational postexposure prophylaxis
PHAC: Public Health Agency of Canada.
PLDI: Positive Leadership Development Institute
PrEP: Pre-exposure prophylaxis.
PWA: People With AIDS
STI: Sexually transmitted infection.
WHO: World Health Organization.
UNAIDS: Joint United States Programme on HIV/AIDS.
U=U: Undetectable = Untransmittable

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