

# Canadian Consensus Statement on the health and prevention benefits of HIV antiretroviral medications and HIV testing

Prepared by CATIE, CTAC and PositiveLite.com

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## 1 Why We Need a Consensus Statement

Despite significant scientific and medical advances over the past few years, the HIV epidemic continues in Canada. Specific populations continue to be disproportionately affected by the HIV epidemic, including gay, bisexual, Two-Spirited and other men who have sex with men, transgender people, people who use drugs, Aboriginal peoples, people from countries with high rates of HIV infection, people from African, Caribbean and Black communities, and newcomers to Canada who face challenges related to their immigration status. Women also face added challenges because of gender inequities that are woven throughout Canadian society. People from these groups are more likely to be socially, politically and economically marginalized than other people in Canada. Because of this marginalization, some people from these groups may have increased chances of getting HIV. As a result, the rates of HIV among some of these groups of people are often much greater than their share of the population in Canada.

We are at a crucial moment in the HIV epidemic in Canada. A comprehensive, community-driven, holistic response that combines HIV treatment and prevention, and health and human rights is needed. *This Consensus Statement will provide us with fundamental shared principles to help guide us as we build that response.*

### HIV science and medicine today

Medical science has provided the knowledge and tools to drastically improve the health and extend the lives of people living with HIV, increase HIV testing, and decrease HIV transmission.

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For More Information

- **We can screen for HIV in less than a minute with tests that can be used outside of labs and medical offices.**
- **The antiretroviral medications used to treat HIV are highly effective and are well-tolerated by most people living with HIV.**
- **People living with HIV who start taking HIV antiretroviral medications soon after diagnosis have better long-term health outcomes than people who start HIV medications later.**

- **HIV antiretroviral medications are also highly effective at preventing HIV transmission.**
  - **People living with HIV on antiretroviral treatment with an undetectable viral load have a negligible risk of sexual transmission of HIV.**
  - **For an HIV-negative person, taking HIV antiretroviral medications is a highly effective strategy to avoid getting HIV.**



When people know about these medical and scientific breakthroughs they are in a better position to make informed decisions about their health and wellbeing. Broader social awareness of these breakthroughs might help reduce the fear and stigma that too often surround HIV.

## **Working together**

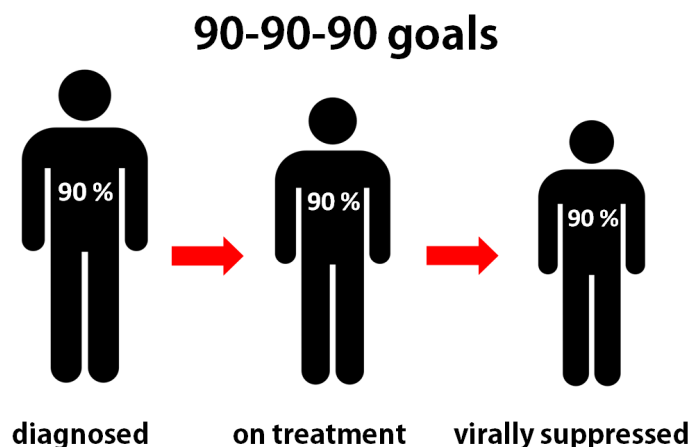
Many people in Canada have not fully benefited from the tremendous potential of these medical and scientific advances. In 2014 in Canada, over 2000 people found out that they were living with HIV. Public health authorities estimate that about one in five people who has HIV doesn't know it. Too many people diagnosed with HIV face significant barriers when they try to access healthcare and psychosocial and other support services. As a result, only a minority of people living with HIV is taking HIV antiretroviral medications *and* has achieved an undetectable HIV viral load. Marginalized people and communities continue to experience unequal treatment that negatively impacts their access to many health and social services.

Over the past decade community leaders and communities affected by HIV have remarked upon the lack of political and public health leadership at the federal level, and the need for a renewed and adequately funded national strategy to respond to HIV. HIV-related stigma and discrimination persist and prevent people from getting tested for HIV, and from getting the healthcare and psychosocial and other support services they need. The overbroad criminalization of HIV non-disclosure fuels HIV-related fear, stigma and discrimination. Other laws, policies and practices that take a criminal approach to addressing public health and human rights issues negatively impact the health and wellbeing of sex workers, people who use drugs, Aboriginal and other racialized peoples, and prisoners.

By working together, it is possible to build a comprehensive, community-driven, holistic response. Promoting the health and human rights of people living with HIV, and people from specific populations affected by HIV, must be at the centre of that response. Partnerships and coordination of efforts will be crucial. The shared responsibility for health in Canada means that all levels of government (federal, provincial, territorial, self-governing peoples and health authorities) must work together.

## Setting goals and working towards them

Leading global HIV and health organizations have adopted ambitious goals to end the HIV epidemic: by 2020, 90% of people living with HIV will know their HIV status, 90% of those people will be taking HIV medications, and 90% of those people will have a suppressed HIV viral load. These organizations acknowledge that the only way to achieve these goals is through an approach based on evidence and lived experience, human rights, mutual respect and inclusion. The commitments that underpin the 90-90-90 approach should also focus our attention on addressing the barriers faced by the 10% of people who are excluded at each step, often because of extreme social and economic marginalization.



On World AIDS Day 2015, the Canadian government adopted the **"90-90-90"** goals. Policies, programs and services must be based on the latest medical and scientific evidence, community experience, and human rights principles. Marginalized people and communities continue to experience inequality that negatively impacts their access to health and social services. Therefore, it is crucial to promote people's health and wellbeing by reducing the underlying social inequality and health inequities that put people at risk of HIV, and that result in poor health outcomes for people living with HIV. We need to build a comprehensive, community-driven, holistic response that combines treatment and prevention, rather than treating these separately. Monitoring and evaluation is an integral part of our collective efforts, and needs to be adequately resourced so that we can track progress towards these goals.

CATIE, CTAC and PositiveLite.com hope that the Consensus Statement will be supported and adopted by communities and people living with or affected by HIV. This includes people who work or volunteer in community-based and AIDS service organizations, healthcare professionals and public health staff. We also hope that the Statement will assist funding agencies, policy- and decision-makers, and policy advocates in their work. We built consensus over a 20 month period by consulting widely with people throughout Canada. For more information about these consultations, please see Appendix B.

## 2 Objectives

The Consensus Statement has three related objectives.

1

### **Promote awareness and understanding**

The Consensus Statement, and materials developed based on the Statement, is intended to address gaps in knowledge, awareness and understanding among people in Canada regarding the health and prevention benefits of HIV medications and other technologies, including HIV testing.

2

### **Create a shared understanding of how we can effectively respond to the HIV epidemic**

Guiding principles, in the form of Consensus Statements, can guide principled responses that proactively address challenges as we move from what is known (evidence and experience) to what needs to be done. The Consensus Statement can help inform policy, standards and guidelines, the development, delivery and evaluation of programs and interventions, and public health research.

3

### **Gather people and organizations committed to working together**

It is time to break down the artificial dividing lines between treatment and prevention, traditional healthcare and supports delivered by community, research and implementation, human rights and public health, community members and professionals, and HIV negative and HIV positive people. The ultimate goal is to promote greater integration and innovation in policy and programs to better support people throughout the continuum of HIV prevention and treatment services. The Greater Involvement of People Living with and Affected by HIV/AIDS (GIPA) and Meaningful Engagement of People Living with and Affected by HIV/AIDS (MEPA) should guide our collective work.

## 3 Commitments and Principles

This section is based on an understanding of the HIV epidemic in Canada, informed by community knowledge and experience and research evidence about the factors that continue to drive the epidemic and the types of responses that are needed. These overarching Commitments and Principles inform the Consensus Statements that follow: HIV counselling and testing; HIV antiretroviral medications for people living with HIV; and HIV antiretroviral medications for people who are HIV-negative. We have also included a section suggesting Potential Directions for Research, which does not include Consensus Statements but nonetheless reflects applicable Commitments and Principles.

### Our commitments

#### Taking action

As individuals and organisations we commit to taking action to end the HIV epidemic in Canada. We will work to expand access to and uptake of HIV testing and of HIV antiretroviral medications to treat and prevent HIV in ways that respect human rights, remove barriers, and promote social equality and health equity.

#### Choice and shared responsibility

We commit to safeguarding and promoting the health, wellbeing and human rights of people living with HIV. It is up to each person living with HIV to make the decision whether to take HIV antiretroviral medications, based on their own assessment of what is best for their health and wellbeing. Our commitment stands whether or

not people diagnosed with HIV choose to go on HIV antiretroviral medications, whether or not they are able to adhere to antiretroviral medications, and whether or not they have an undetectable HIV viral load.

We commit to the principle of shared responsibility for HIV prevention, among HIV-negative people, those who do not know their HIV status, and people diagnosed with HIV.

We commit to safeguarding and promoting the health, wellbeing and rights of people who belong to populations most affected by HIV. It is up to each person to decide whether and when to get tested for HIV. Our commitment stands whether or not people choose to get tested for HIV.

### Inclusion and respect

We commit to respecting the cultures, traditions and human rights of all people living with HIV and people from specific populations. Because they continue to be disproportionately affected by the HIV epidemic in Canada, we owe a special responsibility to specific populations, including gay, bisexual, Two-Spirited and other men who have sex with men, transgender people, people who use drugs, Aboriginal peoples, people from countries with high rates of HIV infection, people from African, Caribbean and Black communities, and newcomers to Canada who face challenges related to their immigration status. We also owe a special responsibility to respect the self-determination and other rights of Aboriginal peoples, recognizing the devastating effect of historical and ongoing state-sanctioned violence against them, including colonization, forced resettlement, residential schools, their treatment by the child welfare and criminal justice systems, and the failure of governments to respect peoples' inherent rights of self-determination. Women face added challenges because of gender inequities that are woven throughout Canadian society.

### Evidence and experience

We commit to continuing, developing and supporting HIV policies, programs and interventions that are informed by evidence and experience. HIV prevention programs that have proven effective should not be replaced by programs that focus solely on increasing the number of people getting tested for HIV or taking antiretroviral medications. We continue to need programs and interventions that promote sexual health, reduce harms associated with drug use, and safeguard values and practices that community members have relied on since the beginning of the HIV epidemic to prevent HIV and protect physical and mental health and wellbeing. Similarly, the diversity of people living with HIV need more, not fewer, programs that meet their needs and promote their health and wellbeing.

### Social equality, health equity, and universal and affordable access

We commit to continuing, developing and supporting policies, programs and interventions that promote social equality and health equity. In Canada, many people most in need of HIV antiretroviral medications, HIV testing and counselling, and healthcare do not have equitable access to these services. Marginalized and racialized people are least likely to benefit from scientific and medical advances in diagnosing, treating and preventing HIV. Holistic health and wellness promotion programs are most likely to increase access for these people, which can significantly reduce HIV-related illness and death, and HIV transmission.

We commit to advocating alongside people living with HIV and people from specific populations. This includes advocating for universal, affordable or no-cost access throughout Canada to medications, testing and other supplies to treat and prevent HIV. It also includes advocating for barrier-free access to culturally proficient healthcare and psychosocial and other support services that affirm the full range of people's gender identities and expressions. Canada is a vast country and many people living with HIV and from specific populations live in rural, remote and northern areas. The healthcare and psychosocial and other support services people need often do not exist in their community or region. To promote universal access and health equity, advocacy, policies and programs should also address access barriers related to geography.

## GIPA and MEPA

We are committed to respecting and implementing the Greater Involvement of People Living with and Affected by HIV/AIDS (GIPA) and the Meaningful Engagement of People Living with and Affected by HIV/AIDS (MEPA) principles in our work.

## Opposing HIV criminalization

We commit to opposing the use of the Canadian criminal law against people living with HIV accused of HIV non-disclosure and exposure. Criminalization has had a disproportionate impact on African, Caribbean and Black people living with HIV and communities in Canada. We support the [consensus statement](#) of leading Canadian HIV physicians and medical researchers regarding HIV transmission and the criminal law. In too many cases, the criminal law has been applied without taking into account up-to-date and accurate scientific and medical information about HIV. As a result, the criminalization of people living with HIV has promoted uncertainty, fear and stigma, which can stop or delay people from getting tested for HIV, or seeking health and other services. This undermines effective public health measures used to prevent HIV transmission, and negatively affects the health of people living with HIV and people from specific populations.

## A human rights-based approach

We support a human rights-based approach to expanding access to and uptake of HIV testing and the medications used to treat and prevent HIV. Specifically, the following human rights should be respected, protected and promoted in the context of HIV testing, and the use of medications to treat and prevent HIV: life, liberty and security of the person; non-discrimination and equality; privacy; enjoyment of the benefits of scientific progress and its application; freedom of expression and information; the highest attainable standard of physical and mental health; an adequate standard of living and social security services; and freedom from violence, and cruel, inhuman and degrading treatment or punishment.

In international human rights law, health is a fundamental human right necessary for peoples' enjoyment of other human rights. The Canadian government has recognized and committed to realizing for everyone the highest attainable standard of physical and mental health. The right to health includes a right to a functioning adequate healthcare system, equitable distribution of health services, access to medicines, and recognizes that special attention should be paid to the needs of vulnerable populations. Governments have an obligation to ensure that health systems, services and medications are available, accessible, acceptable and of good quality. The right to health also includes the right to underlying social determinants of health, such as nutritious food, safe water, sanitation, safe and secure housing, access to education and gender equality.

The right to equality and to be free from discrimination is closely linked to fulfilling the right to health for people living with HIV and specific populations. In general, Canadian laws protect people from discrimination based on factors such as race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability. We oppose policies, programs, interventions and actions that violate people's human rights and that interfere with efforts to bring about an end to the HIV epidemic.

- People should never be forced or coerced into taking an HIV test, or undergoing HIV treatment or other medical interventions.
- People should not be denied access to HIV testing and counselling based on preconceived or prejudiced ideas about which groups of people are at risk of HIV.

- People should not be denied access to medications used to treat and prevent HIV based on their immigration status, or preconceived or prejudiced ideas about which groups of people are able to take HIV antiretroviral medications correctly and consistently.
- Where a person chooses not to test for HIV, or not to start or continue HIV antiretroviral medications, penalties should never be imposed on that person or care withheld from that person.

Public health staff, healthcare providers and social service providers should be mindful of the inherent power imbalances in their relationships with clients. Public health staff, healthcare providers and social service providers should also watch for other sources of coercion in the lives of clients living with HIV or from specific populations. For more information, please see Appendix D: *A Rights-Based Approach: How to safeguard and promote health and wellbeing in the context of the HIV epidemic.*

## Consent to medical care in Canada

Consent must be a foundation for expanding access to and uptake of HIV testing and the medications used to treat and prevent HIV. HIV testing and counselling, and the prescription of medications to treat or prevent HIV, are important aspects of medical care. People's health is best protected and promoted where they are able to make fully informed and voluntary decisions about their own medical care.

Ensuring a person's informed consent to medical interventions is both a legal and an ethical requirement. A healthcare provider must get consent from a person before starting a medical intervention on that person, except in extraordinary circumstances. Consent to medical treatment is valid where it is:

- about a specific medical treatment or a plan of treatment,
- given voluntarily,
- not obtained by misrepresentation or fraud, and
- informed.

To obtain "informed consent" from a person, a healthcare provider must give the person the information that any reasonable person in the same circumstances would want. A reasonable person would want information about the:

- nature of the treatment,
- expected benefits of the treatment,
- material risks of the treatment,
- material side effects of the treatment,
- alternatives to the treatment, and
- likely consequences of not having treatment.

The healthcare provider must answer the person's questions about the treatment.

Finally, a person can refuse treatment, or withdraw their consent to treatment at any time.

## 4 HIV Counselling and Testing

### Consensus Statement

We support **expanded access to voluntary HIV counselling and testing** that respects human rights, including the principle of informed consent.

People should have access to a range of HIV testing options and service delivery approaches, including the **routine offer of testing**. People who request an HIV test should not be unreasonably refused HIV counselling and testing.

We support expanded access to **rapid (also known as point-of-care)** tests for HIV.

We support expanded access to **anonymous and non-nominal testing** for HIV and for other sexually transmitted infections.

Before being tested, people must be offered **HIV pre-test counselling**. Pre-test counselling, in its process and in the information provided, should reflect the **principle of informed consent**.

People who test HIV-positive must be offered **post-test counselling**, including information about how to prevent the onwards transmission of HIV, and provided with **opportunities and support** to be linked to HIV health services and psychosocial and other supports, including those delivered by community-based organizations.

HIV pre- and post-test counselling should provide information about the **collection, use and disclosure** of HIV-positive test results and HIV-status, and any opportunities available to the person being tested to limit the collection, use and disclosure of their personal health information. Pre- and post-test counselling should also provide people with information on the legal implications of an HIV diagnosis, including legal rights and obligations under criminal law and public health law.

Comprehensive guidelines are needed to support HIV counselling and testing. The federal and provincial/territorial governments and Aboriginal health authorities should consult with health care providers, public health experts and community advocates to develop and adopt minimum standards for HIV testing applicable throughout Canada. These standards should address, at a minimum, **the five essential “Cs” of HIV testing** consistent with international standards: consent, confidentiality, counselling, correct result, and connection to HIV prevention, treatment and care. Standards should also provide guidance regarding new service delivery approaches and new HIV testing technologies.

### Rationale

The Consensus Statements set out principles and general approaches to increase the offer and uptake of voluntary HIV testing and counselling in Canada. HIV testing is not just a medical procedure. HIV testing and counselling involve complex interpersonal relationships and interactions, with legal, ethical and social dimensions.

HIV testing and counselling is a crucial starting point for engaging people in HIV treatment and prevention. People living with HIV can only benefit from the health benefits and prevention advances of HIV medications if they know their HIV status. However, many people who might benefit from HIV testing and counselling are not getting tested. In 2015, the Public Health Agency of Canada estimates that one in five people living with HIV in Canada is undiagnosed. When people do not know that they have HIV they do not access healthcare for HIV, and



are more likely to pass on HIV. In fact, the majority of new HIV infections are passed on from people who do not know that they are living with HIV.

More people will get tested, and get tested sooner and more often, if HIV testing and counselling meet their needs and preferences, and address their fears and concerns. New service delivery approaches and new testing technologies can provide people with more, and more acceptable, HIV testing options. Comprehensive practice guidelines can set out national standards for HIV testing and counselling, and provide concrete guidance on implementing the five essential “Cs” (consent, confidentiality, counselling, correct result and connection to care and services) into HIV testing and counselling programs and services.

## Consent – Confidentiality – Counselling – Correct result – Connection

Voluntary HIV testing and counselling is the first step in the HIV treatment cascade for people living with HIV. The HIV treatment cascade refers to the path a person follows from a positive HIV test result, to being linked to ongoing medical care, to starting HIV medications, to taking HIV medications consistently and correctly, to achieving and maintaining an undetectable HIV viral load. HIV medications can greatly improve the health and increase the life expectancy of people living with HIV. When a person reaches and maintains an undetectable viral load, their risk of passing on HIV is greatly reduced. Reaching and maintaining an undetectable HIV viral load can benefit a person living with HIV by improving their sense of wellbeing and easing their fear of passing on HIV. It also benefits society, as new HIV cases are reduced.

As it stands, many people in Canada are not learning about their HIV status for years. Too many people find out they are living with HIV only after HIV has damaged their immune system, when they start to have symptoms of HIV and other infections. This is a missed opportunity. People who start taking HIV antiretroviral medications soon after their HIV diagnosis have better long-term health outcomes than people who start medications later.



Voluntary HIV testing and counselling can also promote the health and wellbeing of people who test HIV negative. People who test HIV negative may benefit from increased knowledge and health promotion strategies provided during HIV pre- and post-test counselling. HIV-negative people can find out where to get HIV prevention counselling and tools like condoms, lubricant and sterile injecting supplies. HIV testing and counselling staff can identify HIV-negative people who are at an ongoing risk of getting HIV, and link these people to other services. People at ongoing risk of HIV might benefit from longer-term healthcare and psychosocial and other support services, like mental health and substance use counselling and treatment, housing support services and primary healthcare. HIV testing and counselling staff can also link people to doctors who prescribe HIV antiretroviral medications to HIV-negative people to prevent HIV infection. This HIV prevention strategy is known as PrEP, which is short for “pre-exposure prophylaxis”. This Consensus Statement includes a section on PrEP, below.

# 5 HIV Antiretroviral Medications for People Living with HIV

## Consensus Statement

**Barriers to access to HIV antiretroviral medications** faced by people living with HIV should be recognized and addressed in ways that promote health equity for specific populations disproportionately affected by HIV.

HIV antiretroviral medications should be **offered to every person diagnosed with HIV**, as soon as possible after diagnosis.

People diagnosed with HIV have the **right to decide** whether to take HIV antiretroviral medications, based on their own assessment of what is best for their health and wellbeing

Every person living with HIV should be **provided with the information they need** to give informed consent to treatment with HIV antiretroviral medications. This includes the opportunity to ask questions and receive responses from a healthcare professional who knows about HIV and HIV antiretroviral medications.

Provincial, territorial and federal authorities should put in place mechanisms to **ensure that cost does not act as a barrier** to people living with HIV who want to take HIV antiretroviral medications.

People living with HIV should be provided with **access to healthcare and psychosocial and other support services** required to achieve optimal adherence to HIV antiretroviral medications and to promote their health and wellbeing. This care and support should include routine medical care, addiction, mental health and sexual health services, harm reduction services and supplies, safe and secure housing, and nutrition support services.

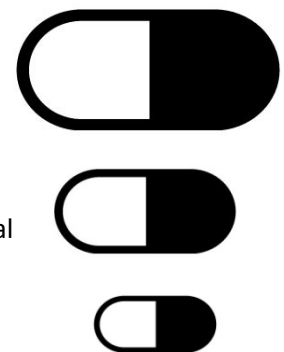
**We oppose the coerced use of HIV antiretroviral medications.** People living with HIV must not be subject to penalties or withholding of healthcare or psychosocial or other supports if they choose not to take HIV antiretroviral medications.

**Treatment literacy and community preparedness campaigns** explaining the individual and public health benefits of HIV antiretroviral medications should be implemented for people living with HIV and people from specific populations.

**Professional development and training** should be implemented for the full range of health care and psychosocial and other support service providers who support people living with HIV.

## Rationale

HIV antiretroviral medications can help people living with HIV take control of their health and wellbeing, and HIV prevention. This can help reduce the fear and stigma people living with HIV often experience. HIV antiretroviral medications greatly reduce illness and death caused by HIV. People who are diagnosed with HIV and start HIV antiretroviral medications soon after getting HIV can live a near normal lifespan. The sooner a person begins HIV antiretroviral medications, the better their chances of being healthy over the long term. People on antiretroviral treatment with an undetectable viral load have a negligible risk of sexual transmission of HIV.



## Empowerment

Healthcare providers should use the *offer* of HIV antiretroviral medications, and the *process of obtaining informed consent*, as an opportunity to empower each person living with HIV. Until there is a cure for HIV, most people living with HIV will have to take HIV antiretroviral medications for the rest of their lives. Starting HIV antiretroviral medications is a decision that most people will need time to consider. People living with HIV should not be pressured into making the decision quickly. Healthcare providers should empower people living with HIV with information so that they can make an informed decision about when to start HIV antiretroviral medications. Healthcare providers should make every effort to deliver information in ways that overcome any cultural, linguistic, cognitive and educational barriers that might prevent the person living with HIV from understanding the information.

## Adherence

The benefits of HIV antiretroviral medications depend upon a person taking the medications correctly and consistently, as prescribed by their doctor. Unfortunately, some people living with HIV face significant barriers to entering and staying connected to the HIV care cascade. A person's abilities and motivations to start and continue taking HIV antiretroviral medications are influenced by many interconnected factors. Factors include people's interpersonal relationships (for example, with spouses and other family, healthcare and other service providers, police and corrections workers) and broader structural factors (for example, lack of income and employment opportunities, lack of safe and secure housing, criminalization and imprisonment, barriers to accessing mental health services and supports). Healthcare providers should link people living with HIV to the services that can help them to take their HIV antiretroviral medications correctly and consistently over the long-term. Programs designed to meet the needs of socially and economically marginalized people living with HIV have been effective at linking the most vulnerable people to appropriate longer-term HIV care, treatment and supports. Intensive case management, health navigation and peer support have improved people's connection to medical care and social and income supports, their adherence to HIV antiretroviral medications, nurtured their independence, and provided people with hope in their lives.

# 6 HIV Antiretroviral Medications for HIV-Negative People

## A. Pre-exposure Prophylaxis (PrEP)

### Consensus Statement

Access to pre-exposure prophylaxis (PrEP) for people at substantial risk of getting HIV is **an essential component of HIV prevention**. There is a pressing need to make HIV antiretroviral medications as PrEP available and accessible to HIV-negative people at substantial risk of HIV infection.

People taking PrEP should be provided with **access to healthcare and psychosocial and other support services** they need to achieve optimal adherence to PrEP, and to promote their health and wellbeing. People should have **access to routine medical care, addiction, mental health and sexual health services, harm reduction services and supplies, safe and secure housing, and nutrition support services**.

There is a pressing need **to develop and disseminate clinical practice guidelines, and to develop and deliver healthcare provider education, on PrEP**.

Provincial, territorial and federal authorities should put in place **mechanisms to ensure that cost is not a barrier to PrEP** for people who could benefit from it.

**We oppose coerced PrEP in all its forms.** People must not be subject to penalties or withholding of medical care or psychosocial or other supports in circumstances where they choose not to take PrEP.

PrEP **treatment literacy** and community preparedness campaigns should be implemented for people from specific populations.

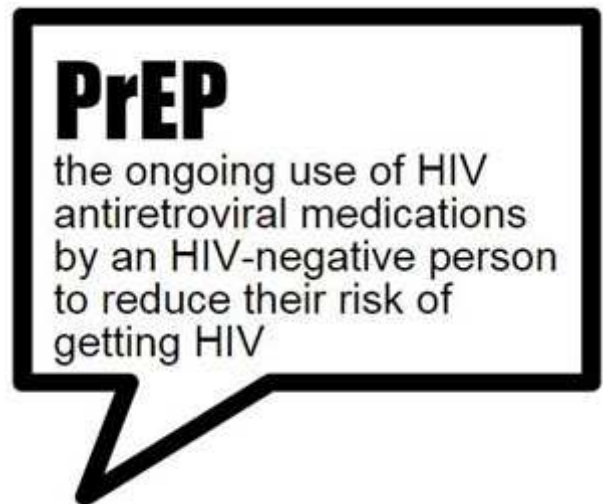
**Professional development and training** about PrEP should be implemented for the full range of health care and psychosocial and other support service providers who need to be engaged in PrEP prescription and adherence support.

## Rationale

The above Consensus Statements set out the principles and general approach to promote broad access to affordable PrEP for all people who could benefit from it.

### About PrEP

PrEP stands for pre-exposure prophylaxis. PrEP refers to the use of HIV antiretroviral medications by an HIV-negative person to reduce their risk of getting HIV. PrEP does not prevent other sexually transmitted infections. PrEP is not intended to replace condoms for HIV prevention. The HIV antiretroviral medication Truvada has proven safe and highly effective at preventing HIV-negative people from getting HIV. **In February 2016, Health Canada approved Truvada for HIV PrEP, to reduce the risk of sexual transmission of HIV when used in combination with safer sex practices.** Truvada is a brand name medication produced by Gilead Sciences; TDF/FTC is the abbreviation for the two drug compounds that are combined in one Truvada capsule. Large research studies involving heterosexual men and women, and men who have sex with men, have studied PrEP in controlled conditions and in real world settings. Truvada can reduce by 90% or more the risk of getting HIV when taken every day as prescribed by a doctor, and accompanied by HIV prevention counselling and services. Truvada is less effective at preventing HIV when people do not take it as prescribed. PrEP programs include regular testing for HIV and sexually transmitted infections, and referral to HIV care for those who test positive. Community-based PrEP programs have successfully engaged people at substantial risk for HIV in ongoing health care services.



### Clinical practice guidelines

Quebec has published interim advice on Truvada for HIV PrEP and BC has published guidelines on PrEP. Draft Canadian consensus guidelines for PrEP and non-occupational post-exposure prophylaxis (nPEP) were released for consultation in Spring 2016. (See the next section for PEP Consensus Statements and rationale.)



In 2012, Truvada was approved for use as PrEP in the United States. According to guidelines published in 2014 by public health officials in the US, doctors should consider prescribing PrEP as a prevention option for sexually active adults at “substantial risk” of getting HIV through sex or injecting drugs. The guidelines are accompanied by a written tool doctors can use to determine whether a person is at “substantial risk”. These guidelines recommend that people who are on PrEP should see their doctor every three months. Doctors should test people for HIV before starting PrEP, then test people every three months for HIV and potential side effects of Truvada. Doctors should provide people with medication adherence support and HIV risk-reduction counselling, or refer people for this support and counselling.

## Affordability and access

Currently, a relatively small number of doctors in Canada are prescribing Truvada as PrEP for people at substantial risk of getting HIV. Public health authorities in Quebec have published interim advice for doctors who prescribe PrEP, and the Quebec government’s universal drug plan includes Truvada for PrEP. Truvada for PrEP is also covered for eligible First Nations and Inuit people under the federal Non-Insured Health Benefits plan. In other places in Canada, a person who does not have insurance or other cost coverage will pay between \$800 and \$1000 per month to get Truvada. Anecdotal evidence indicates that most of the people who have been prescribed Truvada to date are gay men and other men who have sex with men, or HIV-negative partners of people diagnosed with HIV.

## Barriers to access

Many HIV-negative people in the United States have faced significant barriers to accessing Truvada and taking it correctly and consistently. People in Canada may be able to learn from the US experience. Simplistic comparison between the US and Canadian health care systems is unwise. However, the HIV epidemics in Canada and the US are characterized by the over-representation of certain socially marginalized groups of people who face structural and institutional barriers to health services. Research studies have found: people who could benefit from PrEP did not know about it; people who have had previous negative experiences avoided or did not trust the healthcare system; people did not have money or insurance to pay for PrEP; people had difficulties taking Truvada as prescribed; doctors lacked the knowledge and willingness to prescribe PrEP; and the healthcare system was unprepared to provide PrEP. Because of these barriers, many socially and economically marginalized people at greatest risk of HIV in the US have not been able to benefit from Truvada as PrEP. The US experience reminds us to address health inequities when developing PrEP policies and programs.

## B. Post-Exposure Prophylaxis (PEP)

### Consensus Statement

Access to post-exposure prophylaxis (PEP) for people who have had a potential high-risk exposure to HIV is **an essential component of HIV prevention**.

Where they do not already exist, **PEP clinical practice guidelines** for potential high-risk exposures to HIV should be developed and disseminated. These guidelines should include exposures resulting from **workplace injury or accidents, sex, sexual assault, and injecting**.

Provincial, territorial and federal health authorities should put in place **mechanisms to ensure that cost is not a barrier to PEP** for people who could benefit from it.

**PEP treatment literacy** and community preparedness campaigns should be implemented for specific populations.

**Professional development and training** about PEP should be implemented for the full range of health care and psychosocial and other service providers who need to be engaged in PEP access, prescription and adherence support.

## Rationale

### About PEP

Post-exposure prophylaxis, which is often referred to as PEP, can play a small but important role in preventing HIV in Canada. PEP is a way for an HIV- negative person to reduce their risk of getting HIV after a potential high-risk exposure to HIV. In order to be effective, a person must start taking a combination of HIV antiretroviral medications within 72 hours of being exposed to HIV. The person must take these medications every day for 28 days. The sooner the person starts PEP after an exposure, the more likely it is to reduce the risk that the person will get HIV.

Doctors prescribe PEP to people who have been exposed to HIV in the course of their work. This is known as “occupational” PEP. Doctors can also prescribe PEP to people who were exposed to HIV during a sexual assault, during consensual sex, or while sharing injecting equipment. This is known as “non-occupational” PEP. Non-occupational PEP has not been widely publicized or promoted in Canada, and it is not widely available. It may be possible to obtain non-occupational PEP in some emergency rooms, urgent care clinics, and specialized HIV and sexual health clinics in Canada.

### Clinical practice guidelines

PEP guidelines for healthcare practitioners are needed. These guidelines should include minimum standards for counselling, assessment and treatment and care, and apply throughout Canada. This is an area where federal, provincial, territorial and First Nations governments can work together to ensure that people can access safe and effective PEP where and when they need it. Healthcare staff needs guidelines and professional development to know when to use PEP, the most suitable HIV antiretroviral medications to use, and how to provide appropriate clinical care to clients.

Without appropriate practice guidelines and professional development, some healthcare providers may not be willing to prescribe PEP for non-occupational exposures. Practice guidelines for PEP for occupational exposures have existed throughout Canada for many years, yet there are many reports that these guidelines have not been properly implemented, and some guidelines encourage forced HIV testing as part of the PEP protocol. However, not every province or territory (or health region or institution) has clinical guidelines for non-occupational PEP. Where such clinical guidelines exist, healthcare providers may not be aware of them or may not have received professional development about non-occupational PEP.



## Affordability and access

Some public government programs pay the cost for PEP after a sexual assault. Public government drug programs should ensure that the cost of occupational or non-occupational PEP is covered for everyone who cannot otherwise afford it. The HIV antiretroviral medications used for PEP are expensive: four weeks of HIV antiretroviral medications can cost between \$1,000 and \$2,000, depending on the medications used. While private insurance plans and some public government programs will pay the cost of PEP for occupational exposures, these plans may not pay for non-occupational PEP.

## PEP to PrEP

Raising awareness, and making non-occupational PEP easier to access and more affordable, will encourage people to seek it out. When a person asks for PEP in emergency rooms, urgent care clinics, and specialized HIV and sexual health clinics, the healthcare staff can engage that person in HIV risk reduction counselling. People who are at significant and ongoing risk of getting HIV can be offered PrEP for preventing HIV, and linked to doctors and clinics that prescribe PrEP.

# 7 Potential Directions for Research to Address Community Needs and Priorities

When informed by community needs and priorities, research can continue to increase knowledge and understanding to promote the individual and public health benefits of HIV medications and HIV counselling and testing. Yet, it is time to consistently focus our efforts and resources on ensuring that the knowledge generated through research is used to improve the health and wellbeing of people living with HIV and people from specific populations, and to promote health equity and social justice. Research knowledge about *access to and uptake of HIV antiretrovirals and testing* can play a vital role in our holistic, community-based response to HIV grounded in evidence and human rights. But this will require renewed and deeper commitments from the research community.

## Committing to GIPA/MEPA and knowledge mobilization and implementation

The HIV research community should give priority to meaningfully involving and engaging communities of people living with HIV and specific populations, and to engaging, informing and influencing policy and decision makers. Research should be undertaken according to the principles and processes of community-based research, and ever mindful of the GIPA/MEPA principles. People living with HIV and people from specific populations, community-based organizations, front-line healthcare professionals and psychosocial and other support providers should be active participants in the development of research agendas and funding priorities, in the review of research applications, on research ethics and advisory boards, and in all phases of research itself. Community members and organizations should be supported to play a leading role in the mobilization and implementation of research knowledge to make positive changes to policies and programs. This would include identifying needed supports and identifying valuable knowledge mobilization and implementation roles for academic and institutional researchers. Consistent with GIPA/MEPA, people living with HIV and members of specific populations should be provided with sufficient resources to enable them to participate meaningfully in these processes alongside academic and institutional researchers.



We support Aboriginal HIV and other health organizations in Canada in their call for research that respects the [OCAP](#) (Ownership, Control, Access and Possession) principles. Chapter 9 of the Canadian [Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans](#) also provides specific guidance on research involving First Nations, Inuit and Métis peoples.

The research identified below focuses on identifying barriers and implementing effective policies, guidelines and programs to promote the health and wellbeing of people living with HIV and people from specific populations.

***This list of potential directions for research might serve as a starting point for meaningful consultation with communities regarding their research needs and priorities.***

- **HIV testing and counselling**
  - o Access to voluntary HIV counselling and testing, and barriers to access, for specific populations
  - o Factors that contribute to the success of HIV testing programs, how to start more pilot programs, and how to move from pilot programs to permanent programs (implementation science)
  - o Pilot programs to increase access to voluntary HIV counselling and testing, including rapid HIV testing, for specific populations and people who do not live in large metropolitan areas
  - o Programs that effectively link people who test HIV-positive to healthcare and psychosocial and other support services
  - o Quality of HIV testing practices and people's experiences of HIV testing, evaluating the five essential “Cs” of HIV testing: consent, confidentiality, counselling, correct result, and connection to HIV prevention, treatment and care
  - o Programs that effectively link people engaged in high risk behaviours who test HIV-negative to appropriate healthcare, and psychosocial and other support services
  - o Public health, legal and ethical issues related to expanding HIV counselling and testing in non-healthcare settings, including community-based and home testing, and participation of non-regulated health professionals in delivering HIV counselling and testing
  
- **HIV antiretroviral medications for people living with HIV**
  - o Access to HIV antiretroviral medications, barriers to access, and ways to address those barriers, with a focus on people living with HIV from specific populations who are socially and economically marginalized
  - o Long-term health effects of HIV antiretroviral medications, with specific focus on populations underrepresented in such research, including women
  - o HIV antiretroviral medication initiation, adherence and adherence support, with a focus on reducing side effects and the limitations they pose for people, and on psychosocial and other support programs that effectively link and engage people living with HIV in healthcare
  - o Factors that contribute to the success of HIV antiretroviral medication adherence support programs, and how to start more of those programs (implementation science)
  
- **Pre-exposure prophylaxis (PrEP)**
  - o Access to PrEP, and barriers to access
    - Attitudes, opinions, beliefs, intentions and needs of specific populations, HIV-negative partners of people living with HIV, and healthcare providers
    - Systemic and institutional barriers, including affordability
  - o Event-based or time-based intermittent dosing for PrEP
  - o Risk compensation behaviours associated with the use of PrEP
  - o PrEP adherence and adherence support programs with a focus on specific populations
  - o Research on the long-term effects PrEP use
  - o Factors that contribute to the success of PrEP awareness and initiation programs, and how to start more of those programs (implementation science)



- **Post-exposure prophylaxis (PEP)**
  - o Access to PEP, and barriers to access
    - Attitudes, opinions, beliefs, intentions and needs of key populations, HIV-negative partners of people living with HIV, and healthcare providers regarding PEP
    - Systemic and institutional barriers to PEP, including affordability
  - o Programs that link people accessing PEP who are at significant and ongoing risk of HIV to PrEP, and how to start more of those programs (implementation science)

## 8 Appendices

### Appendix A: Glossary of Key Terms and Concepts

#### **Aboriginal peoples**

Refers to First Nations, Inuit and Métis peoples. Many organizations in Canada now use the umbrella term Indigenous to refer to First Nations, Inuit and Métis peoples.

#### **AIDS service organization (ASO)**

Local or regional organizations that provide direct services to people living with and affected by HIV. ASOs often provide a range of psychosocial and other support services.

#### **HIV antiretroviral medications**

Medications prescribed by a doctor (and some nurse practitioners) used to treat HIV infection or prevent someone from getting HIV.

#### **Healthcare services**

Services provided by registered health professionals such as doctors, nurses, pharmacists and psychologists and that involve the prevention, diagnosis and treatment of physical or mental health conditions.

#### **HIV treatment cascade**

The path a person follows from a positive HIV test result, to being linked to ongoing medical care, to starting HIV medications, to taking HIV medications consistently and correctly (sometimes referred to as “adherence”), to achieving and maintaining an undetectable HIV viral load.

#### **Post-exposure prophylaxis (PEP)**

An HIV-negative person can reduce their risk of getting HIV after a potential high-risk exposure by taking a combination of HIV antiretroviral medications. In order to be effective, a person must start taking the HIV antiretroviral medications within 72 hours of being exposed to HIV, and take these medications every day for 28 days.

#### **Pre-exposure prophylaxis (PrEP)**

The use of HIV antiretroviral medications by an HIV-negative person to reduce their risk of getting HIV.

#### **Psychosocial and other support services**

People living with HIV and specific populations often access a wide range of services in addition to healthcare services to promote their health and wellbeing. These services include counselling, housing and income supports, food programs, distribution of harm reduction supplies, group programs, employment supports, drop-ins, medication adherence support, service navigation, transportation and accompaniment. These services may

be provided by registered professionals such as social workers, social service workers, occupational therapists and nurses or by peers, outreach workers, or other trained staff or volunteers. Many of these services are provided by community-based AIDS service organizations (ASOs), alone or in partnership with other organizations and service providers.

### **Specific populations**

Data collection and research has demonstrated that specific groups of people in Canada continue to be disproportionately affected by the HIV epidemic, including gay, bisexual, Two-Spirited and other men who have sex with men, transgender people, people who use drugs, Aboriginal peoples, people from countries with high rates of HIV infection, people from African, Caribbean and Black communities, and newcomers to Canada who face challenges related to their immigration status. Women face added challenges because of gender inequities that are woven throughout Canadian society. People from these groups are more likely to be socially, politically and economically marginalized than other people in Canada. Because of this marginalization, some people from these groups may have increased chances of getting HIV. As a result, the rates of HIV among some of these groups of people are often much greater than their share of the population in Canada.

### **Undetectable viral load**

Undetectable viral load means that there are fewer copies of HIV in the blood of a person living with HIV than the viral load diagnostic test can measure. It does not mean that a person has been cured of HIV. The virus is still in their body. However, people living with HIV on antiretroviral treatment with an undetectable viral load have a negligible risk of sexual transmission of HIV.

## **Appendix B: Consensus-Building Process**

**October 2014:** CATIE, CTAC and PositiveLite.com identified the need to come together and agree on how to fulfil the potential of HIV-related medical and scientific breakthroughs to bring an end to the Canadian HIV epidemic. CATIE, CTAC and PositiveLite.com struck a working group, which reviewed existing statements and guidelines, identified key issues to include in a consensus statement, and developed a process for community consultation.

**April 2015:** We held a national consultation attended by community members, staff of frontline organizations, health care professionals and other interested people. Participants identified key issues related to policy and regulation, health systems, and frontline programming. Participants also brought forth the lived experiences of people living with HIV, HIV-negative people, and people who didn't know their HIV status. Participants suggested that community members needed a DRAFT statement to reflect upon and respond to. The working group drafted the Consensus Statement based on notes from the consultation, statements and guidelines prepared by organizations in Canada and internationally, and additional research into the key issues.

**October 2015:** At a workshop at the CATIE Forum, we presented a draft Consensus Statement for feedback.

**December 2016 and January 2016:** The draft Consensus Statement was sent to more than 40 key opinion leaders in the community-based HIV sector in Canada for their feedback. The working group met, considered the key opinion leaders' feedback, and the document was revised to reflect that feedback.

**May 2016:** We publicized and made available copies of the draft Consensus Statement at the annual CAHR conference in Winnipeg, and launched [www.hivconsensusvih.ca](http://www.hivconsensusvih.ca).

**June 2016:** A public, on-line consultation survey was opened for responses for four weeks. The working group reviewed and analyzed the survey responses, and incorporated this feedback into a final version of the Consensus Statement.

**July 2016:** The final Consensus Statement is launched at the Canada Pavilion (and at a conference poster session) at AIDS 2016 in Durban, South Africa, and posted to [www.hivconsensusvih.ca](http://www.hivconsensusvih.ca). People are invited to sign on to the Consensus Statement.

## Appendix C: Summary of the Evidence Regarding the Health and Prevention Benefits of HIV Antiretroviral Medications and HIV Testing

The Consensus Statement is based on a large body of research and clinical practice guidelines on the health and prevention benefits of HIV antiretroviral medications and HIV testing and counselling. Below is a list of sources that summarize this evidence up to the fall of 2015.

### HIV Counselling and Testing

- Public Health Agency of Canada. *Human Immunodeficiency Virus: HIV Screening and Testing Guide*, 2012. [http://www.catie.ca/sites/default/files/EN\\_HIV-Screening-Guide-2013.pdf](http://www.catie.ca/sites/default/files/EN_HIV-Screening-Guide-2013.pdf)
- Wilton J. *HIV Testing Technologies*. CATIE Factsheet, 2015. <http://www.catie.ca/en/fact-sheets/testing/hiv-testing-technologies>
- Wilton J. *The State of HIV Testing in Canada: A systematic review*. *Prevention in Focus*, Spring 2015. <http://www.catie.ca/en/pif/spring-2015/state-hiv-testing-canada-systematic-review>
- Broeckhaert L and Challacombe L. *Rapid Point of Care Testing*. *Prevention in Focus*, Spring 2015. <http://www.catie.ca/en/pif/spring-2015/rapid-point-care-hiv-testing-review-evidence>

### HIV Antiretroviral Medications for People Living with HIV

- Becker M, Cox J, Evans GE, et al. *AMMI Canada Position Statement: The use of early antiretroviral therapy in HIV-infected persons*, 2016. <https://www.ammi.ca/download/Guidelines/ALL-Final-Web-posted-AMMI-Position-Statement-Early-ART-April-18-2016.pdf>
- Panel on Antiretroviral Guidelines for Adults and Adolescents. *Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents*. Department of Health and Human Services. 8 April 2015 <https://aidsinfo.nih.gov/guidelines/html/1/adult-and-adolescent-treatment-guidelines/0>
- Hosein S. *Anti-HIV therapy: TreatmentUpdate 210*, August/September 2015. <http://www.catie.ca/en/treatmentupdate/treatmentupdate-210>
- *CATIE Statement on the Use of Antiretroviral Treatment (ART) and Undetectable Viral Load to Prevent the Sexual Transmission of HIV*, 2015. (See section called *Evidence*.) <http://www.catie.ca/en/prevention/statements/tasp>
- Loutfy M, Tyndall M, Baril J-G, et al. *Canadian consensus statement on HIV and its transmission in the context of the criminal law*, *Canadian Journal of Infectious Disease and Medical Microbiology*, 2014. [http://www.cfenet.ubc.ca/sites/default/files/uploads/news/releases/Statement%20\(May%202-14\).pdf](http://www.cfenet.ubc.ca/sites/default/files/uploads/news/releases/Statement%20(May%202-14).pdf)

### HIV Antiretroviral Medications for HIV-negative People

#### A. Pre-Exposure Prophylaxis (PrEP)

- US Public Health Service. *Pre-exposure Prophylaxis for the Prevention of HIV Infection in the United States-2014: A clinical practice guideline*, 2014. <http://www.cdc.gov/hiv/pdf/prepguidelines2014.pdf>
- *CATIE Statement on the Use of Pre-Exposure Prophylaxis to Prevent the Sexual Transmission of HIV*, 2015. (See section called *Evidence*.) <http://www.catie.ca/en/prevention/statements/prep>

## B. Non-Occupational Post-Exposure Prophylaxis (PEP)

- Smith D, Grohskopf L, Black R, et al. *Antiretroviral Postexposure Prophylaxis after Sexual, Injection-Drug Use, or other Nonoccupational Exposure to HIV in the United States: Recommendations from the US Department of Health and Human Services*, MMWR, 2005.  
<http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5402a1.htm>
- Davey H, Challacombe L, Wilton J. *Can We Prevention Infection with HIV after Exposure? The world of post-exposure prophylaxis*. *Prevention in Focus*, Fall 2010.  
<http://www.catie.ca/en/pif/summer-2010/can-we-prevent-infection-hiv-after-exposure-world-post-exposure-prophylaxis-pep>

## Appendix D: A Rights-based Approach: How to Safeguard and Promote Health and Wellbeing in the HIV Epidemic

Human rights are universal rights. In other words, all people have human rights because they are human. Human rights flow from the dignity and worth of every human being. They cannot be given away or taken away. Laws have been created throughout Canada to protect human rights. For example, anti-discrimination laws make it illegal to treat a person unequally and unfairly based on their personal characteristics. These laws promote equality and dignity among people, regardless of their race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status, disability or because the person is on public assistance.

Human rights play a crucial role in our work to address the HIV epidemic. Overwhelming evidence proves that people who are socially, politically or economically marginalized and disadvantaged have higher rates of illness and disease than other people. These disadvantages and harms are unfair, but can be changed. When we respect, protect and fulfill the human rights of people living with HIV and people from specific populations we promote their health and wellbeing.

In Canada, many people most in need of HIV antiretroviral medications and HIV testing and counselling are the least likely to benefit from the scientific and medical advances we have made in these areas. Over thirty years after the discovery of HIV, peoples' general knowledge and awareness of HIV and of the recent advances in science and medicine is too low. People living with HIV continue to face stigma, discrimination and other human rights violations. Specific populations continue to be disproportionately affected by the HIV epidemic, including gay, bisexual, Two-Spirited and other men who have sex with men, transgender people, people who use drugs, Aboriginal people, people from countries with high rates of HIV infection, people from African, Caribbean and Black communities, and newcomers to Canada who face challenges related to their immigration status. Women also face added challenges because of gender inequities that are woven throughout Canadian society.

Leading global HIV and health organizations including UNAIDS have adopted ambitious goals to end the HIV epidemic: by 2020, 90% of people living with HIV will know their HIV status, 90% of those people will be taking HIV medications, and 90% of those people will have a suppressed viral load. On World AIDS Day 2015, the Canadian government adopted the 90-90-90 goal. But we will not be able to achieve the "90-90-90" goal in Canada unless we respect human dignity and work to end injustice. Laws, policies, programs and services must be based on scientific and medical evidence and human rights. When people are treated with respect and dignity they are more likely to use and benefit from health care and psychosocial services. [Insite](#), Vancouver's supervised injection site, is a good example. Insite was based on evidence of how to improve health outcomes for people who inject drugs. It was also designed to respect, protect and fulfill the human rights and dignity of people who inject drugs. As the Supreme Court of Canada has recognized, Insite has promoted health and saved lives.

Human rights can guide people creating policy, and designing and delivering programs. The following human rights should be **respected, protected and promoted** in the context of the HIV epidemic in Canada: rights to life; liberty

and security of the person; non-discrimination and equality; privacy; enjoyment of the benefits of scientific progress and its application; freedom of expression and information; the highest attainable standard of physical and mental health; an adequate standard of living and social security services; and freedom from violence, and cruel, inhuman and degrading treatment or punishment.

## For More Information

For more information visit [hivconsensusvih.ca](http://hivconsensusvih.ca) or email [hivconsensusvih@catie.ca](mailto:hivconsensusvih@catie.ca).