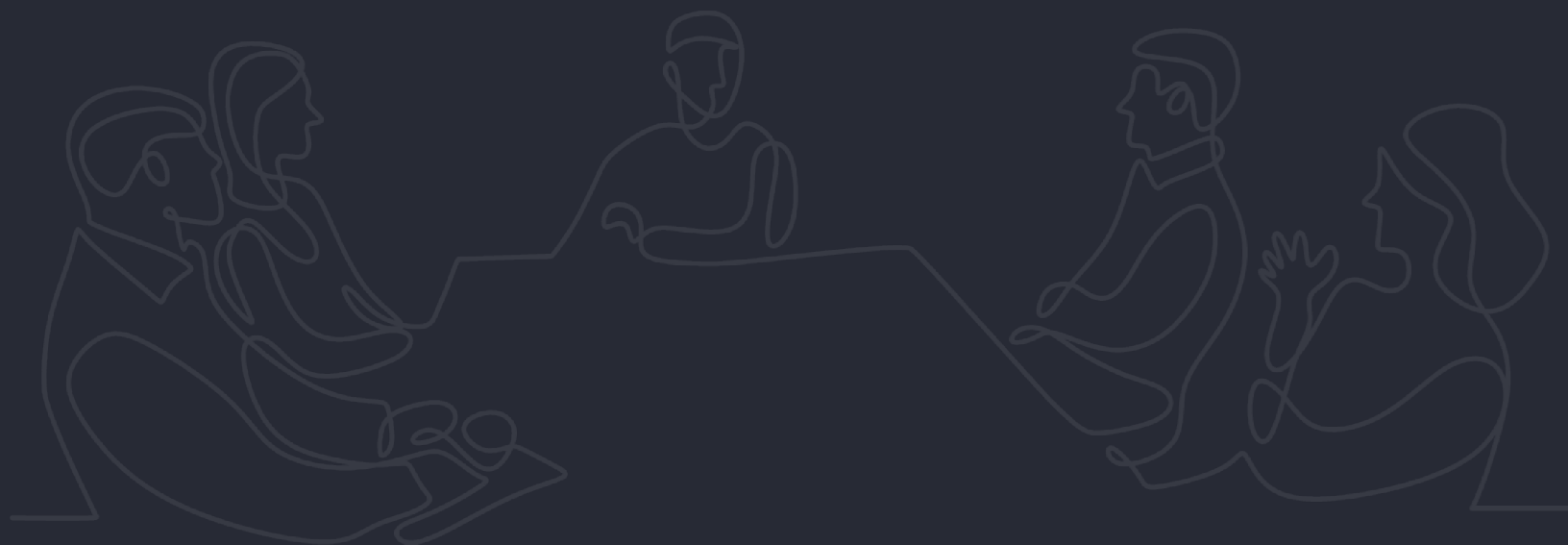


DECEMBER 2023



HIV/AIDS Roundtable

# WHAT WE HEARD



## Table of Contents

About Gilead Sciences Canada, Inc. ....	1
Executive Summary.....	3
Background .....	5
Working Group Approach .....	7
Key Themes and Recommendations .....	8
Improved Model of Funding.....	11
Supporting the Three Key Pillars: Access, Coverage and Prevention.....	15
Conclusion .....	21
References .....	22
Appendix: Roundtable Event.....	25

Gilead Sciences engaged Santis Health to co-develop this report and the roundtable discussions.

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## About Gilead Sciences Canada, Inc.

Gilead Sciences Canada, Inc. (Gilead) is a biopharmaceutical company that has pursued and achieved breakthroughs in medicine for more than three decades, with the goal of creating a healthier world for all people. Gilead is committed to advancing innovative medicines to prevent and treat life-threatening diseases, including HIV, viral hepatitis, COVID-19, and cancer. Gilead operates in more than 35 countries worldwide, with Canadian headquarters in Mississauga, Ontario.

At Gilead, we're committed to creating a healthier world for everyone – no matter the challenges ahead of us. For more than 35 years, we've pursued the impossible, chased it down, tackled it for answers and surrounded it for a way in. We have worked tirelessly to bring forward medicines for life-threatening diseases.

Through bold and transformative science, we're driving innovation that has the potential to become the next generation of life-changing medicines. Our ambition is evident in our mission. Because the impossible is not impossible. It's what's next.

Gilead is investing in solutions to support those afflicted and at risk of HIV/AIDS. Gilead is supportive of broad measures that governments and stakeholders can take to meet the Government of Canada's 2030 HIV/AIDS targets. While our role was one of a convener to build consensus among a wide range of stakeholders, we will continue to bring forward innovative products and spearhead the promotion, while also participating in initiatives to achieve health equity and end the HIV/AIDS epidemic for everyone everywhere. Gilead is proud to be part of this necessary conversation and gives thanks to the many organizations and government officials that have contributed to this report as a launch pad for greater collaboration.



## On June 12, 2023 and October 4, 2023, Gilead Sciences organized working group discussions on HIV/AIDS in Canada.

The purpose of the initial working group discussion was to bring together federal health agencies, health care providers, researchers and patient groups to share ideas and collaborate on how Canada can achieve the UNAIDS goal of ending the HIV/AIDS epidemic by 2030.

The information that follows is a summation of the discussion at this roundtable and additional stakeholder interviews and reflects the ideas, passion, and commitment to this cause by Canadians incredibly dedicated to reaching these targets and improving life for those living with HIV/AIDS .

A second roundtable discussion was held to verify a draft of this report as well as clarify and enhance themes to ensure it is representative of the decades of work the HIV/AIDS community has already undertaken to improve the lives of people in this land we call Canada. The following information is not the official policy position of Gilead Sciences and is merely a reflection of the discussions that have been held between June and October this year.

As we work collectively to achieve the 2030 HIV/AIDS targets, we hope that this what we heard report can be leveraged as a point in time reflection on **what needs to happen to meet those targets.**

## Executive Summary

Canada is experiencing an HIV/AIDS crisis, as infection rates continue to rise, immediate and decisive action is needed. To better understand what needs to be done to reach Canada's 2030 HIV/AIDS targets, Gilead prepared this 'What We Heard' Report. The report reflects the discussion from a roundtable and is intended to help guide actions of governments and stakeholders in addressing the challenges of HIV/AIDS in Canada.

**Six key themes emerged from the discussion, along with several key recommendations:**

### #1 COLLABORATION

Participants were in strong agreement around the importance of collaboration between stakeholders. The diverse participation in the roundtable was a prime example of the enthusiasm that participants had to come together and the willingness they had to continue the discussion.

Recommendations were to:

- Implement an all government approach;
- Ensure First Nations, Inuit and Métis leaders have a seat at the table and are involved in decision making;
- Reevaluate, integrate, and clarify the objectives and scope of existing working groups, especially internal-to-government working groups;
- Involve frontline workers in decision making processes;
- Broaden scope of practice for health care workers; and
- Create opportunities to bring the HIV/AIDS communities together from across the country.

### #2 IMPROVED MODEL OF FUNDING

Participants recognized the continued funding efforts from the Government of Canada, including the \$17.9 million for the distribution of HIV self-testing kits and the \$9.9 million to expand community-based testing initiatives in northern, remote, or isolated communities<sup>1</sup>. As well as the \$18.1 million for projects to support the work of community-based organizations<sup>2</sup>.

There was consensus among participants that there is a need for a more coordinated funding approach from the Government of Canada's departments and their agencies as well as an increase in funding from all levels of government to ensure that more resources are available to reach the intended targets.

Recommendations were to:

- Review past funds that were successful;
- Implement multiple Parliamentary report recommendations to increase federal funding to \$100 million annually; and
- Improve funding by:
  - Streamlining funding accessibility, saving small organizations time and resources focused on multiple and complex small funding applications;
  - Increasing the flexibility of funding (not just project based);
  - Sustained multi-year funding to meet 2030 targets; and
  - Focus on research and development to help inform evidence-based decisions.

### **#3 EQUITABLE ACCESS, COVERAGE AND PREVENTION**

Participants agreed that equitable access, coverage, and prevention each play a significant role in reaching the UNAIDS targets.

Recommendations were to:

- Collect indicators and biomarkers to determine best delivery of care;
- Encourage federal agencies to work together in the provision of essential medications for both prevention and treatment;
- Implement a specific medication access program to ensure that all Canadians can access HIV/AIDS medication;
- Prioritize and strengthen preventative health measures, including greater public health messaging and PrEP; and
- Provide additional training and education for health care workers.

### **#4 GOOD QUALITY, CONSISTENT, AND WELL-COORDINATED RACEBASED AND INDIGENOUS IDENTITY DATA**

There was overwhelming support from participants that the Government of Canada – as part of their ongoing health data initiatives – develop a collaborative approach with Indigenous communities and HIV organizations to collect and develop a shared governance model for data, with a specific focus directed towards race-based and Indigenous identity data.

### **#5 SOCIAL DETERMINANTS OF HEALTH**

Participants desired to see all governments in Canada prioritize supporting efforts that focus on addressing the upstream factors that impact HIV/AIDS in Canada, particularly

the opioid crisis, homelessness, basic income, affordability of broader health care support, and punitive laws and policies.

Recommendations were to:

- Revisit punitive laws and policies, including:
  - HIV non-disclosure;
  - Substance use; and
  - Sex work.
- Establish tailored programs that cater to the individualized needs of patients, thereby honoring their dignity;
- Provide shelter-based HIV prevention programs;
- Address housing policies and programs; and
- Develop specialized programs and services for people who inject drugs.

## #6 LESSONS FROM THE COVID-19 PANDEMIC

Participants discussed how the COVID-19 pandemic disrupted HIV/AIDS progress in Canada but also considered how the successful rollout of the COVID-19 vaccine immunization campaign serves as a great example of how aspects of this pan-Canadian campaign can be leveraged for HIV testing and screening programs.

## Background

In the summer of 1981, the New York Times published the now famous headline: “Rare Cancer Seen in 41 Homosexuals,”<sup>3</sup> unaware what was being foreshadowed. In March of the next year, Canada reported its first case.<sup>4</sup> Initially dubbed “Gay-Related Immune Deficiency (GRID),” the disease was soon renamed to Acquired Immune Deficiency Syndrome (AIDS). A few years later, the virus responsible for AIDS was identified as the human immunodeficiency virus. The disease quickly began impacting more and more people; an entire generation of queer people came of age fearing that their intimacy could lead to their infection.

Governments and scientists began, slowly at first, to take notice of HIV/AIDS and started providing resources to fight the spread and find a treatment. Impacting more than just queer people, an intense outbreak occurred among Vancouver’s injection drug users in 1998, giving the city the distinction of having the highest percentage of people with HIV in the developed world.<sup>5</sup> In Indigenous communities, the historical trauma and systemic issues stemming from colonialism created poor socio-economic conditions leading to high rates of HIV/AIDS. By 2013, nearly 25,000 Canadians had lost their life to HIV/AIDS.<sup>6</sup>

Fortunately, treatments have advanced since HIV/AIDS was first identified and today, the disease is not the death sentence it once was. Still, HIV/AIDS is a serious chronic disease and despite scientific advances, Canada is going in the wrong direction.

Rates of HIV infections in Canada are on a steady rise. By the end of 2020, there were 62,790 Canadians living with HIV.<sup>7</sup> The following year, there were 1,472 additional diagnoses in Canada – a 11.3% increase from the previous year<sup>8</sup>. Racialized and at-risk communities, such as Indigenous peoples, immigrants, and members of African, Caribbean and Black communities, are disproportionately impacted by HIV.<sup>9</sup> Women are also disproportionately affected, especially among Indigenous populations where onethird of new HIV infections were among Indigenous females in 2020.<sup>7</sup> Participants articulated that these statistics are being driven predominantly by poor access to health care, the rising opioid crisis, a lack of awareness and education about new treatments and therapeutics, a lack of access to housing and people in Canada living longer with HIV/AIDS.

The Government of Canada has shown they believe in taking this issue seriously. In the summer of 2022, following the 24<sup>th</sup> International AIDS Conference hosted in Montreal, Canada's then Minister of Health Jean-Yves Duclos reaffirmed Canada's commitment to meeting the newly adopted interim global HIV/AIDS targets. These targets – agreed to by 193 nations – commit Canada to ensure that 95% of all people living with HIV will know their HIV status, 95% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy, and 95% of all people receiving antiretroviral therapy will have viral suppression by 2025.

During the 2022 Montreal conference, the Government of Canada also committed to 2030 global targets of zero new HIV infections, zero AIDS deaths, and zero stigma and discrimination, and highlighted their recent endorsement of the Undetectable=Untransmissible global declaration, announcing 18 million dollars in funding for decentralized forms of HIV testing and 15 million in funding for UNAIDS for 2023-2025<sup>10</sup>.

In addition to the top line targets outlined above, Canada has agreed to undertake further work, including<sup>11</sup>:

- Expanding HIV services, including increasing access to testing and preventative drugs/services;
- Adoption of people-centred and context specific integrated approaches; and



- Removing social and legal impediments towards enabling environments that lead to limiting access or utilization of HIV services.

Despite plans to achieve these targets, the Government of Canada has been criticized for a lack of progress on meeting these commitments compared to the progress of other G7 countries.<sup>12</sup>

Concrete and practical commitments followed by tangible investments and actions is required – collectively – by all governments and stakeholders alike to address the growing challenges many people in Canada face with HIV transmissions on the rise. This report highlights the strengths of our Canadian community to support those afflicted with or who are at risk of HIV transmission. Further, it provides a set of practical recommendations that all stakeholders can support, including governments, to get Canada on the right track, supported and validated by key HIV/AIDS experts and stakeholders that represent a broad cross-section of communities in Canada, and research.

## Working Group Approach

On June 12, 2023, Gilead organized a working group discussion on HIV/AIDS in Canada and how collectively we can reach the government's international targets. The purpose of this working group discussion was to bring together federal health agencies, health care providers, and patient groups who share the same commitment to addressing HIV/AIDS in Canada. For Gilead, our global commitment is to help end the epidemic for everyone, everywhere. On October 4, 2023, a second working group discussion was held to review a draft what we heard report and improve how this report reflects the voices of stakeholders that have the experience and knowledge to guide Government to meet the 2030 targets.

Furthermore, with ambition to hear from all stakeholders involved in addressing HIV/AIDS in Canada, Gilead conducted additional interviews with stakeholders who were identified at the broader roundtable to be included.

This paper – and efforts surrounding this paper – are merely a starting point and launch pad for further collaboration that drives meaningful results for people afflicted with HIV/AIDS in Canada. Gilead aimed to have a wide representation of various groups to provide recommendations, and as further organizations and experts are identified, we would be pleased to curate further engagement opportunities.

In advance of the discussion, which included a cross-section of government and nongovernment stakeholders, the following goals were identified as objectives:

**Understand current government and non-government actions** that are underway and how those actions will drive meaningful progress to achieve the UN General Assembly’s global targets.

**Identify and share views of the role of the federal government** with respect to investments, coordination of efforts with provincial, territorial, and municipal governments, and the role of each of these entities and specific tactics each should consider.

**Discuss the top priorities that the federal government should focus on** over the next 3-4 years and ways stakeholders can support the government to meet the UN’s HIV global targets.

## Key Themes and Recommendations

### Further Collaboration Between HIV/AIDS Organisations, Federal, Provincial and Territorial Levels of Government, and First Nations, Inuit, and Métis

In the early days of the HIV/AIDS epidemic, many activists felt their concerns were not being heard by those in positions of power. From government to health care workers to scientific researchers, those advocating for better treatment for those living with HIV/AIDS couldn’t seem to break through to decision makers.

In the four decades since the disease has been in Canada, things have improved – but Canada cannot repeat this same history as the numbers continue to climb. To meet the ambitious 2030 targets, there needs to be an “all-of-government approach”, signifying enhanced collaboration and coordination between the federal government, provincial/territorial governments, Indigenous communities, and advocates.

### Ensuring Indigenous Leaders Have a Seat at the Table

Despite the Government of Canada’s initiatives to gain insights from First Nations, Inuit and Métis peoples, such as the *National Aboriginal Council on HIV/AIDS*, it was expressed that, still today, Indigenous issues are not highlighted and understood at some decision-

making tables, even though Indigenous communities are among those disproportionately impacted by HIV/AIDS. According to national estimates, there were 6,472 Indigenous Peoples living with HIV in 2020, representing about 10.3% of all people with HIV in Canada, with 276 new HIV infections among Indigenous Peoples that same year.<sup>7</sup>

Indigenous Peoples understand their communities; they have built trusted relationships by consulting their communities when any action plans or decisions are made. This type of engagement and involvement should be emulated at all the decision-making tables, where Indigenous Peoples are leaders in providing solutions that will make a difference in their communities. This kind of collaboration is essential to enable support that aligns with communities' ongoing endeavours and pledges the provision of culturally sensitive care.

### **Realigning HIV/AIDS Governance**

Currently, there are several federal, provincial and territorial working groups that influence the HIV/AIDS environment. These groups typically function independently of each other, which creates unnecessary hurdles for community HIV/AIDS organizations as they navigate multiple different government processes, particularly when applying for funding.

The importance of evaluating and streamlining the existing working groups at the federal, provincial, and territorial levels was emphasized during the roundtable discussion. This evaluation would aim to identify specific opportunities for the working groups to collaborate more effectively with each other as well as improve communication with HIV/AIDS stakeholders. It was expressed that all levels of government should come together to ensure that efforts are not duplicated, and resources are not wasted reinventing the wheel. Integrating working groups would also allow for resources to be streamlined. The resulting collaboration would enhance the government's understanding of the issues at hand at a grass-roots level and to gather valuable insights from those directly affected by HIV/AIDS. This would also allow for more strategic and complementary investments in resources desperately needed by the HIV/AIDS community groups to improve the treatment and care of those living with HIV/AIDS and to reach the 2030 targets.

### **Frontline Workers**

We heard from participants that frontline workers should become more involved in decision-making processes. Discussions with frontline workers are needed to assess what does and does not work and addressing current gaps when providing HIV/AIDS prevention and treatment options for patients. Therefore, frontline workers should be invited to the table when making decisions that will affect their work and the communities

they serve. It is critical to apply the knowledge and expertise of these professionals as they play an active role in working directly with patients on a day-to-day basis and putting in practice the decisions that were made.

### **Scope of Practice of Health Care Professionals**

Expanding the scope of practice of health care professionals refers to broadening the range of tasks, responsibilities, and interventions that they are authorized and trained to perform. It was suggested in the roundtable discussion that by expanding the scope of practice, health care professionals can offer a more holistic process of care and better support patients from testing to treatment.

By having a broader scope of practice, health care professionals can engage in earlier interventions and facilitate timely access to necessary treatments. This can lead to improved patient outcomes, as health care professionals can promptly diagnose conditions, initiate appropriate therapies, and closely monitor the patient's progress throughout the treatment process.

Moreover, an expanded scope of practice promotes collaboration and interdisciplinary care. When health care professionals have a wider range of skills and capabilities, they can work more seamlessly as part of a multidisciplinary team, sharing their expertise and contributing to comprehensive treatment plans. This collaborative approach ensures that patients receive integrated and coordinated care across various health care disciplines, optimizing their overall health outcomes. This is particularly important in remote and rural areas where access to health care is a challenge.

When HIV/AIDS care is extended to family health care teams, it optimizes the use of health human resources and prevents capacity challenges among community health care organizations. Expanding the scope of work can also help prevent burnout from already overburdened health care providers. By implementing routine testing for at risk patients in the family health care setting, it also removes barriers preventing people from obtaining an early diagnosis. Advocates recommend training and education for family practitioners to enable a cascade of care.

### **Bringing Stakeholders Together**

To effectively engage and collaborate, it is important for stakeholders to have the opportunity to gather, share perspectives and ideas, raise awareness and better understand the complex issues of HIV/AIDS in Canada. Currently, the community-based organizations that deliver HIV/AIDS care do not have the resources necessary to come

together and share their experiences with other organizations across the country. Without this type of valuable engagement, organizations are at a disadvantage.

We heard from participants that having a forum to share knowledge about what programs and services work best for their communities and certain challenges that their communities face would allow stakeholders to problem solve together advancing the delivery of care in their communities much more efficiently than when working separately. To achieve this, participants expressed their desire to see industry take on the role in facilitating an annual meeting for stakeholders. In the past, the *Canadian Aids Society* hosted an annual forum to bring together people living with AIDS and their strategic partners to discuss priority areas that needed to be addressed. Since the federal funding to the *Canadian Aids Society* was cut in 2016, there is no longer an occasion to have these kinds of conversations. Industry has the ability to bring stakeholders back together and enable and enhance the opportunity for stakeholders to work together and address the current and future state of HIV/AIDS in Canada.

## Improved Model of Funding

There are several federal governmental departments that are working to address HIV/AIDS across Canada including<sup>13</sup>:

- Public Health Agency of Canada
- Canadian Institutes of Health Research
- Correctional Service Canada
- The Department of Justice
- Department of National Defence
- Department of Women and Gender Equality
- Health Canada
- Immigration, Refugees and Citizenship Canada
- Indigenous Services Canada
- Privy Council Office – LGBTQ2 Secretariat

Although the scope of work and commitments vary across these departments, participants expressed that there were challenges with funding being too specific, hindering the ability of recipients to respond to community needs. Organizations would prefer to have flexibility over how the funding is used and would welcome the creation of a more sustainable funding model.

Participants encouraged the federal government to consider past funds that were successful, such as the *Intersectoral Action Fund*, to create a cohesive and effective framework for the delivery of funding. Especially since reaching the 2030 UNAIDS goals will take a collective effort from diverse sectors.

Without sufficient federal funding, programs and services offered by community-based organizations are forced to cut back. Leaving a gap in access to testing, preventative care, treating HIV and supporting individuals living with HIV.

In 2003 the House of Commons' Standing Committee on Health (HESA) recommended the government invest \$100 million annually for HIV/AIDS.<sup>16</sup> Again, in 2019, HESA reiterated that exact recommendation, that the federal government increase total funding for the *Federal Initiative to Address HIV/AIDS in Canada* to \$100 million annually.<sup>17</sup> **And today, advocates are once again calling on the federal government to increase the annual funding to \$100 million.**

In 2016, we saw the impact of the realignment of federal funding priorities to focus on prevention and education towards those who are currently living with HIV/AIDS.<sup>18</sup> This included defunding large and prominent organizations, including the *Canadian AIDS Society*, that are essential to supporting those currently living with HIV, putting more people at risk to contract the virus.<sup>18</sup> What we heard is that to move forward, organizations supporting prevention and education need to have that support maintained while governments make further investments to support areas of emerging concern.

Participants expressed that some of the funding conditions make it difficult for communities, like the Indigenous and rural and remote communities, to respond to the unique situations they face. In relation to the Public Health Agency of Canada's *Sexually Transmitted and Blood-Borne (STBBI) Action Plan*<sup>13</sup>, the Government of Canada invested over \$30 million to organizations that applied and were successful in the *HIV and Hepatitis C Community Action Fund (CAF)* or the *Harm Reduction Fund (HRF)*, with a maximum of 5 years of project funding.

One of the contractual agreements was that the projects supported by the CAF and HRF funding needed to include these four components<sup>13</sup>:

- a. **Community-based efforts reach key populations**, including people unaware of their HIV or hepatitis C status, and link them to testing, prevention, treatment and care;
- b. **Communities design** and implement evidence-based front-line projects to prevent new and reoccurring infections;
- c. **High impact interventions** are brought to scale so that more people benefit from them; and
- d. **Community-based efforts reduce stigma** toward populations disproportionately affected by STBBI, including people living with HIV or Hepatitis C.

During the roundtable, it was expressed that for funding to be useful to organizations and priority populations, including Indigenous Peoples, it needs to be a) flexible, to allow for these communities to respond to their unique emergencies, and b) sustainable; current federal funding is precarious, short-lived with possibilities of defunding in the future. Organizations also expressed challenges with seeking multiple, small and shortlived funding grants and contributions that require significant resources to undertake applications.

There was also widespread support among the roundtable participants for the Government of Canada, including its agencies like the Canadian Institutes of Health Research, to allocate resources towards ongoing research and development. This investment in research would aim to facilitate the development of new pathways for health innovations and solutions specifically tailored to support the HIV/AIDS communities. By actively promoting and funding research efforts, the government would contribute to advancing scientific knowledge, improving prevention and treatment strategies, and enhancing the overall well-being and quality of life for individuals and communities affected by HIV/AIDS.

Participants emphasized the importance of sustained funding and research in tackling the challenges posed by HIV/AIDS. By calling for a coordinated funding approach and increased investments in research and development, they sought to foster a supportive and innovative environment that would enable HIV/AIDS communities to thrive and progress towards better health outcomes.

## Supporting the Three Key Pillars: Access, Coverage and Prevention

There was consensus among participants of the equal importance of each of the three key pillars to deliver care, support and testing.

### Access and Coverage

Access to health care and more specifically, antiretroviral medicines is not consistent across Canada. Each province and territory has their own unique drug insurance programs. The realities of a federated country have unintentionally caused inequities for populations that have poorer access depending on their geographic location, including Indigenous Peoples and those in rural and remote communities.

Access to care may look different depending on the community and population that the system is serving. Organizations must find innovative ways to deliver care and essential medicines (like pre-exposure prophylaxis (PrEP)) to 'hard to reach populations' (e.g., people who inject drugs and sex workers). Working together with public health units, organizations can support the collection of health indicators which public health units would use to determine how to best deliver care to their unique populations.

To ensure equitable access to critical drugs and therapeutics, participants encouraged collaboration among the Public Health Agency of Canada, Indigenous Services Canada, Health Canada, and the provinces and territories. They urged these entities to work together to enhance access to essential medications while also identifying any gaps in coverage. The objective is to address equity issues in accessing HIV/AIDS drugs and therapeutics, particularly by recognizing the need for culturally appropriate care and acknowledging the distinction between medicine and medications for Indigenous Peoples. This approach aims to eliminate barriers and provide equal opportunities for individuals from Indigenous communities to receive the necessary health care support they require.

Cost is a significant barrier when it comes to accessing lifesaving and preventative medicines. Implementing a National Pharmacare Program that expands access to HIV/AIDS therapies, no matter where patients reside in Canada, would help improve access.



## Education

Education of health care professionals is a key determining factor of access. Even though access to improved technology is a major advantage, humans working with humans is of utmost importance to reach the UNAIDS goals. Effectively working together calls for a foundation of standardized training. Despite the availability of information and improved training, some continue to have negative attitudes towards those living with HIV or seeking preventative measures. To ensure patients receive the best care, health care professionals, especially those working directly with people living with HIV, should have an in-depth, holistic, and inclusive training model. It is proposed that education institutions (colleges and universities) build this training into the curriculum of their program, and that there are courses available for health care professionals to continue their education when they are in the workforce. Health care worker training programs would also warrant greater awareness of preventative care and treatment options available for those with susceptibility to HIV or those living with AIDS. As well, it would create a more inclusive and welcoming health care provision space that would lead to better health outcomes.

## Prevention

Additionally, participants emphasized the need for the Public Health Agency of Canada to continue to prioritize and strengthen support for preventative health measures. This would involve maintaining existing initiatives and programs that have proven effective in preventing the spread of HIV/AIDS. However, they also emphasized the need to address emerging areas of concern in the field of prevention. A proactive approach is needed to ensure that prevention efforts remain effective and adaptable to changing circumstances.

By emphasizing the significance of access, coverage, and prevention, participants aimed to emphasize a comprehensive and holistic approach to addressing HIV/AIDS in Canada. Their recommendations highlighted the need for collaboration, equity, culturally appropriate care, and ongoing support for both treatment and prevention measures to effectively combat the HIV/AIDS epidemic.

Not only does prevention reduce HIV infections but it also reduces health care costs. Providing adequate prevention, including testing, PrEP, public health messaging and other services and programs, would save the Canadian health care system billions of dollars.<sup>19</sup> Every dollar invested into prevention programs saves about \$5 on the health care system<sup>20</sup>.

## **Good Quality, Consistent, and Well-Coordinated Race-based and Indigenous Identity Data is Lacking Across Canada**

Good quality, real-time, and consistent race-based and Indigenous identity data (or race ethnicity data) is required to understand where Canada stands in relation to the 95-9595 targets. According to the Canadian Institute for Health Information (CIHI), this data is vital for the “identification and monitoring of health inequities that stem from racism, bias and discrimination, and to inform interventions to improve equity in health care access, quality, experience and outcomes”<sup>21</sup>.

As it stands, the currently available race ethnicity and Indigenous identity data is extremely limited, with several gaps and inconsistencies with data collection across Canada, making it hard to draw meaningful conclusions for decision-makers. There are, however, some provinces that have seen some meaningful success. The Government of British Columbia, for instance, is producing quarterly surveillance reports on new diagnosis of HIV/AIDS.<sup>22</sup> In Saskatchewan, building trust and relationship with Indigenous Peoples over many decades has allowed the province to collect HIV/AIDS data in collaboration with Indigenous communities to produce estimates during pre-COVID-19 times. The work required by governments and Indigenous communities to collaborate and produce data that can support policy making takes time and trust, especially how data is collected and governed (i.e., data sovereignty), as well as thoroughly addressing privacy considerations.

Recently, CIHI developed pan-Canadian minimum standards for collecting race-based and Indigenous identity data in health care as a first step to address the gaps and inconsistencies with race ethnicity data.<sup>21</sup> More investments are needed for organizations like CIHI to improve the collection of this essential data for assessing where the country stands with respect to meeting the 2030 targets.

## **Addressing The Upstream, Social Determinants of Health That Drive The HIV/AIDS Epidemic in Canada**

Social determinants of health are non-medical factors that influence health. They include a ‘broad range of personal, social, economic and environmental factors that determine an individual and population health.’<sup>23</sup> Income and social status, employment and working conditions, education, and literacy as well as access to health services, race/racism and social supports are a few relevant determinants that often drive new HIV infections, and lead to increased morbidity and mortality for at risk populations if not supported appropriately.

While the following sections do not encompass all social determinants of health, they highlight the most pressing factors demanding immediate attention to address the issue.

Participants outlined several ways to address the key drivers to new infections, and more importantly, how these drivers could slow down progress in meeting Canada's 2030 targets:

### **Reduce Stigma and Discrimination, and Revisit Punitive Laws**

Stigma and discrimination remain significant barriers to ending the HIV epidemic<sup>24</sup>. Stigma towards people living with HIV negatively impacts health outcomes, social life, and physical and mental well-being<sup>25</sup>. Participants discussed that, if stigma is reduced, people are more likely to get tested, disclose their status, are more likely to start treatment early and remain adherent to their antiretroviral treatment, and are more likely to remain in HIV care.<sup>26</sup>

Stigma can also lead to unjust criminal prosecutions. Participants expressed that there is a need to revisit punitive laws and policies (criminality), especially criminalization of HIV non-disclosure, substance use, and sex work, to meet our HIV targets.

### **Address Homelessness and Housing Instability**

During the discussion, participants discussed the downstream health effects of homelessness and housing instability including, increased risk of HIV acquisition and transmission and decreased overall health. In fact, associations between housing status and HIV risk, the use of HIV care, adherence to treatment, and physical health are well documented.<sup>27</sup> According to the Centers for Disease Control and Prevention (CDC), people who experience homelessness or housing instability have higher rates of HIV than those with stable housing and are more likely to engage in activities that increase the likelihood of HIV acquisition and transmission, and have inadequate care/treatment.<sup>28</sup>

However, housing is not a one-size-fits-all solution and therefore, adaptive support is required to fit the needs of the individual. This includes warming and cooling centres and providing services that grant dignity, such as access to bathrooms and showers and other basic needs of life. It was also recommended that shelter-based HIV prevention programs are implemented into ongoing social supports provided by shelters. There is also a great need for long-term solutions to housing. The federal National Housing Strategy is a step in the right direction, however, with the current economic environment, it is almost impossible to build affordable housing that rely on federal programs. Now, more than ever,

governments need to rethink housing policies and programs to achieve affordable and accessible housing.

### **Address the Opioid Crisis**

People who inject drugs (PWID) represent an important group at risk of developing HIV. Oftentimes, PWID face barriers when accessing the health care system and therefore experience high rates of suboptimal treatment outcomes for HIV.<sup>29</sup> Many programs that were developed in the past were specific to gay men as they were the group that had the highest rate of infection. Those same programs do not work for PWID as they experience challenges accessing testing and following this maintaining their treatment regimen if positive.

Participants emphasized the importance of developing specialized programs to support this group through testing, preventative care and adherence to treatment. To encourage testing in this group, it was recommended that incentives be given, as testing is oftentimes a lower priority for PWID and expand the scope of those who can provide the testing, so it is not limited to just clinics or as “a medical act” and therefore prohibiting a variety of frontline workers who could improve access to testing PWIDs. Participants articulated those incentives in combination with the offering of other social services, such as filling out housing applications and providing birth certificates are both programs that have been shown to incite participation among PWID. As adherence to treatment is one of the main challenges for this group, it is recommended that PWID users are given long-acting HIV treatments that are taken less frequently. Ideally, services and programs should be offered with minimal barriers to allow for PWID to benefit.

### **Impacts from the COVID-19 Pandemic on HIV/AIDS Progress**

The COVID-19 pandemic emerged in early 2020 and for many it represented a once-in-a-generation health crisis – yet for older queer men, the situation was all too familiar. A study of queer men over the age of 50 found, “Maintaining some elements of previous pandemic experience was recognized by men as both beneficial and detrimental – that is, the confidence of having dealt with an experience previously but also the distress that comes from knowledge of some of the key challenges.”<sup>30</sup>

Navigating a second pandemic was not easy for the queer men with memories of the height of the HIV/AIDS pandemic, yet for the Canadian government, COVID-19 represented a setback for achieving HIV/AIDS targets. In particular, the pandemic strain on our health care system and services deepened barriers to access essential treatments and HIV services.

The impact of the pandemic on HIV/AIDS efforts was widespread throughout affected communities. Prior to the pandemic, Indigenous communities in Saskatchewan were making big strides to meet the 95-95-95 targets where testing improved, testing sites increased, and at the same time opened 42 harm reduction sites. However, priorities changed once the COVID-19 pandemic hit, leaving HIV behind, and causing more strain on an already overwhelmed system with a drug, STI and syphilis epidemic. This impacted the government's ability to produce accurate estimates and collect real-time data.

On the other hand, there is also opportunity to continue the momentum that the public health system gained during the COVID-19 pandemic and harness tools that were used for broad vaccinations and prevention. Participants recognized the successful implementation of the COVID-19 immunization campaign and proposed using it as a model or reference point for HIV testing and screening programs in Canada.

One key aspect that can be learned from the COVID-19 vaccine rollout is the development of a robust infrastructure and logistical framework. The COVID-19 vaccination campaign required coordination between various stakeholders, including government agencies, health care providers, and community organizations. This infrastructure facilitated efficient distribution, scheduling, and administration of vaccines on a large scale. By applying similar strategies and infrastructure to HIV testing and screening programs, it is possible to improve their accessibility and reach.

Another valuable lesson from the COVID-19 vaccine rollout is the importance of public awareness and education. The campaign involved extensive public messaging and education initiatives to inform individuals about the benefits, safety, and availability of the vaccine. By adopting a similar approach, HIV testing and screening programs can raise awareness, reduce stigma, and promote the importance of regular testing within communities. This can contribute to increased testing rates and early detection of HIV, leading to timely interventions and improved health outcomes.

Additionally, the COVID-19 vaccine rollout demonstrated the significance of collaboration and partnerships between government bodies, health care providers, and community organizations. These collaborations helped to mobilize resources, share expertise, and address specific population needs. By fostering similar collaborations in the context of HIV testing and screening, it is possible to enhance coordination, share best practices, and improve the overall effectiveness of these programs.

## Conclusion

HIV/AIDS is still an epidemic globally and unbeknownst to many Canadians is a rising issue in Canada. The Government of Canada committed to the UNAIDS goal of reaching zero new infections, zero deaths and zero stigma by 2030. To reach these ambitious goals and stay true to our commitments, all levels of government, community stakeholders and industry must come together to take decisive action and create meaningful change.

Currently, Canada is not on track to meet the HIV/AIDS 2030 targets it committed to last year and instead, rates are increasing and the communities that are the most disproportionately affected need immediate solutions and support to meet their unique needs. Community organizations have been leading efforts to combat the HIV/AIDS crisis for decades and continue to be the glue that supports communities in need from coast to coast to coast – but they need more support.

Thankfully, Canada has a strong and mobilized community of experts, health practitioners, community leaders, support groups, and policy makers that are invested in achieving these 2030 targets. This roundtable discussion alone brought forward significant strides that have been made and successful approaches to build upon that will help meet Canada's 2030 targets.

The working group discussion and research highlighted a set of key considerations that were informed by HIV/AIDS experts and key stakeholders in Canada. Many of these recommendations target government and organizational policies and structures, which are most impactful to enhance collaboration and coordination between all levels of government: federal, provincial/territorial, and Indigenous Peoples, and to access lifesaving drugs.

Our collective next steps should include acting upon the recommendations outlined in this What We Heard Report and continuing these collaborative discussions to ensure that meaningful action is progressing in order to achieve the 2030 UNAIDS goals.

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## Appendix: Roundtable Event

### Questions Used to Guide the Roundtable Discussion

#### The Role of the Federal Government

1. How does the Federal Government's plan support progress on Canada's Commitment?
2. How can non-government stakeholders support government efforts and what specific tactics could be beneficial/complementary?

#### Current Progress Towards UN HIV Global Targets

1. What progress has been made to achieve 2030 targets? How has the COVID19 pandemic impacted progress?
2. What are the key gaps that need to be addressed to meet 2030 targets?

#### Looking Forward

1. What are the top 2 to 3 priorities over the next 3 to 4 years that will make the most headway towards the 2030 targets?
2. How can stakeholders provide leadership, support, and engage to help implement / create actions to meet Canada's 2030 targets?

### Participants

Below is a list of participants at the roundtable who have given permission to publish their names.

- Andrew Matejcic (Canadian Association for HIV Research)
- Dr. Celia Lourenco (Health Canada)
- Dr. Tanya Ramsamy (Health Canada)
- Erin Love (Canadian Association for HIV Research)
- Gerard Yetman (AIDS Committee of NfL and Lab.)
- Holly Gauvin (Elevate NWO)
- Janet Butler McPhee (HIV legal Network)
- Jordan Ames-Sinclair (AFN)
- Ken Miller (Canadian AIDS Society)
- Margaret Kisikaw Piyesis (CAAN)
- Patrick O'Byrne (University of Ottawa)
- Sean B. Rourke, PhD. FCAHS (St. Michael's Hospital/ University of Toronto)
- Senator Mohamed-Iqbal Ravalia (Senate of Canada)
- Senator René Cormier (Senate of Canada)
- Steven Sternthal (PHAC)