COCQ-SIDA
MEMBRE DE COALITION PLUS

Funding the Community Response and Supporting Continuity of Care

Toward a Coherent Federal Response to HIV and STBBIs

Brief submitted by the Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-SIDA)

Presented to
the House of Commons Standing Committee on Health / HESA
Study: HIV Infections in Canada

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1. Introduction and Purpose of the Brief

The Coalition des organismes communautaires québécois de lutte contre le sida (COCQ-SIDA) brings together 37 community organizations involved in the response to HIV in Quebec. Its work combines prevention, capacity building, rights advocacy and improved access to care. It also houses Cercle Orange, a free referral and coordination service for people living with HIV who do not have access to health care, as well as the VIH INFO DROITS legal service.

COCQ-SIDA has contributed to federal parliamentary work on HIV for more than thirty years. As early as its appearance on May 9, 1995, before the Subcommittee on HIV/AIDS, it advocated for recurring funding for community organizations, equitable access to care in the regions and recognition of community expertise in public policy. In its May 2, 2019, brief to the Standing Committee on Health on the health of LGBTQ2E+ communities, it reaffirmed a rights-based approach, denouncing the effects of HIV criminalization, discrimination in health care and geographical and financial barriers to access. This brief continues that work: providing sustained support for community action and removing the structural barriers that undermine the response to HIV.

We call on the federal government to fully assume its responsibilities, provide sustainable funding for the community response and negotiate with Quebec, the other provinces and the territories the agreements needed to improve access to care. Measures affecting the organization, delivery or coverage of care in Quebec must be agreed upon with its government, respecting its jurisdiction, priorities and existing mechanisms. This collaboration must not, however, become a reason to delay corrections that fall directly within federal programs and policies.

Summary of Recommandations:

Recommendation 1 - Sustainably strengthen funding for community organizations

Recommendation 2 - Fund access to prevention methods and support for testing

Recommendation 3 - Ensure free access to antiretrovirals and continuity of care

Recommendation 4 - Establish federal interdepartmental responsibility grounded in public health and rights

2. Context: Making Progress Accessible in Practice

This study responds to significant concerns about the evolution of HIV in Canada. Our contribution focuses on the situation in Quebec: we wish to present it more clearly and also identify the needs that federal levers can address.

In 2024, Quebec recorded 462 new HIV diagnoses, an increase of more than 50% compared with 2019, the year before the COVID-19 pandemic. Among newly diagnosed people for whom the necessary data were available, 44% had a late diagnosis: their CD4 cell count indicated that the infection had already weakened their immune system at the time of testing.

These findings underscore the importance of achieving the UNAIDS 95-95-95 targets: that 95% of people living with HIV know their HIV status, that 95% of people who know their status receive antiretroviral treatment and that 95% of people receiving treatment have a suppressed viral load.

We have reached the point where 91% of people living with HIV know their status, while our target is 95%. The availability of HIV self-tests can help reach populations furthest removed from the health care system, but these tools are expensive, beyond the means of marginalized people and even the community organizations that succeed in reaching them.

Medical advances have considerably expanded the possibilities for prevention and treatment, but access to these tools still needs to be improved. Pre-exposure prophylaxis (PrEP), antiretroviral treatments and the diversification of testing options now play an important role in the response to HIV. The Federal Action Plan 2024–2030 recognizes this progress, as well as the need to improve access to prevention tools and testing.

The availability of a tool is not, however, sufficient to ensure access to it. Our request is intended to ensure that neither cost, administrative procedures nor a lack of support deprives people of the benefits of these advances.

Federal investments in testing are useful levers. In 2022, the federal government notably announced temporary funding that included $8 million for the purchase of HIV self-tests and support for their distribution by community organizations. In September 2026, it announced an additional investment of $5 million to expand access to self-tests and support peer interventions, while needs are even greater today.

We appreciate these investments. However, we ask that they be part of a sustainable offering: short-term projects must not replace ongoing funding for the necessary tools, teams and support. Accordingly, we also ask that these investments better meet the scale of the needs!

Free access to treatment and continuity of treatment. We advocate for free access to antiretrovirals used for prevention and treatment so that access does not depend on the ability to pay. We also ask that coverage plans be coordinated to prevent treatment interruptions when a person's status or program changes.

However, since May 1, 2026, the Interim Federal Health Program (IFHP) has required a $4 contribution for each eligible prescription medication dispensed or refilled. This contribution applies even when coverage under the program remains active.

Two distinct issues must therefore be addressed: fees charged despite active coverage and interruptions in access during transitions between plans. Community organizations can support people, but they should not have to compensate indefinitely for gaps in public mechanisms,

Stigma and structural barriers. Medical advances do not eliminate social and legal barriers. The Federal Action Plan recognizes that stigma, discrimination and structural inequalities affect access to prevention and care. It highlights, in particular, the barriers faced by people who work in the sex industry and people who use substances, as well as the possible effects of criminalizing HIV non-disclosure on the use of testing and treatment.

These findings call for a response that goes beyond funding services alone. Federal health, justice and immigration policies must pursue coherent objectives and must not create new barriers to access to health care.

3. Sustainably Strengthen Funding for Community Organizations

Community organizations turn prevention tools and opportunities for care into interventions that people can access. Our funding request covers all the work necessary to make this access possible: mobilization, tailored information, peer support, accompaniment, navigation of coverage plans and maintaining connections with services.

The evaluation of PHAC's STBBI activities for the period from 2018–2019 to 2022–2023, published in 2024, recognizes the contribution of community projects. According to information self-reported by funding recipients, projects funded between 2017 and 2022 generally achieved the expected outcomes, including greater knowledge of prevention methods, improved access to services and an increased ability among the populations reached to prevent infections and improve their health. The evaluation also highlights the importance of the meaningful participation of people with lived experience.

These results must be interpreted in light of the limitations identified in the evaluation, particularly regarding the measurement and synthesis of project effects. They do not, however, justify confusing persistent needs with the ineffectiveness of community action. Rather, they call for strengthening interventions, better documenting their effects and addressing the structural barriers that limit their reach.

Continuity in these functions requires stable teams. A succession of projects must not become the sole means of supporting ongoing needs. Funding must also maintain its real value: we call for indexation and increases that enable organizations to maintain their capacity to intervene.

Recommendation 1 - Sustainably Strengthen Funding for Community Organizations
That the federal government, through PHAC: -
-maintain, renew and increase the HIV and Hepatitis C Community Action Fund and the Harm Reduction Fund, without reducing their combined funding envelope;
-ensure multi-year, predictable and indexed funding that covers the actual costs of interventions, including salaries, coordination, peer support, training and necessary operating expenses;
-provide continuity mechanisms between funding cycles to avoid service interruptions and the loss of expertise;
-fund the meaningful and paid participation of the people concerned in the design, implementation and evaluation of interventions ;
-fund evaluation that is proportionate to organizations' resources, developed with them and allows results and lessons learned to be shared.

4. Fund Access to Prevention Methods and Support for Testing

The federal government already recognizes the importance of diversifying testing options, strengthening access to prevention tools and supporting peer-based approaches. Its recent investments in HIV self-tests and community support must now be placed within a framework of continuity.

We call for a sustainable offering rather than a succession of short-term initiatives. Promotional campaigns, the availability of self-tests and support capacity must be planned together. Organizations must not be placed in a situation where they promote a tool without having the resources needed to maintain access to it.

The support requested is not limited to purchasing kits. It must also cover tailored information, answers to questions, peer support and referral for confirmatory testing and care. Distribution must be integrated into a broader approach to prevention and harm reduction that takes into account the linguistic, cultural, geographical and social realities of the people reached.

Community organizations must be recognized as full partners in this offering, not merely as distribution points. We ask that their expertise and ability to reach people be supported through recurring resources.

Arrangements requiring the involvement of Quebec's health care network must be agreed upon with the Government of Quebec and the partners concerned. Federal funding must support access and accompaniment without replacing Quebec's organization of services.

Recommendation 2 - Fund Access to Prevention Methods and Support for Testing
That PHAC:
-sustainably fund the free distribution of HIV self-tests by community organizations
-fund the support necessary for their use, including tailored information, peer support and referral for confirmatory testing and care;
-support community prevention and harm reduction interventions, as well as support for accessing testing for other STBBIs;
-ensure continuity of funding for tools and their distribution so that their promotion is not followed by an interruption in availability;
-agree with Quebec, the other provinces and the territories on arrangements requiring the involvement of their health care networks, in collaboration with the community organizations concerned and respecting each jurisdiction's responsibilities.

5. Ensure Free Access to Antiretrovirals and Continuity of Care

Our objective is to ensure that all people who need antiretrovirals can access them, for both treatment and prevention, without financial barriers or avoidable interruptions. This objective requires distinguishing between measures that fall directly under federal government responsibility and those that require agreements with Quebec, the other provinces and the territories.

The federal government must first correct the barriers arising from its own programs. Fees imposed on IFHP beneficiaries for eligible medications are, in this respect, a measure on which it can act directly. We call for their abolition.

We also ask that federal programs include the measures necessary to prevent the end of eligibility from causing a treatment interruption before another plan has effectively taken over coverage. When a transition involves a Quebec, provincial or territorial plan, financial and administrative responsibilities must be clarified between the governments concerned.

Federal pharmacare initiatives must also serve as a lever to expand free access to antiretrovirals. Our request does not seek to impose a uniform coverage model on Quebec, but rather to negotiate a financial contribution and arrangements agreed upon with its government.

The Federal Action Plan 2024–2030 already recognizes the federal government's responsibility towards populations receiving its health services or coverage. We ask that this commitment translate into concrete measures coordinated among the departments that administer these programs.

Recommendation 3 - Ensure Free Access to Antiretrovirals and Continuity of Care

That the federal government:

- abolish copayments charged to IFHP beneficiaries for eligible medications;
- ensure free access to antiretrovirals used for treatment and prevention under coverage programs for which it is responsible;
- provide, within these programs, transitional coverage to prevent the end of eligibility from causing a treatment interruption before another plan has effectively taken over coverage;
- put emergency measures in place in the meantime, within the scope of its responsibilities, to prevent treatment interruptions caused by financial or administrative barriers;
- enter into negotiations with Quebec, the other provinces and the territories to conclude funded agreements to expand free access to antiretrovirals and prevent interruptions between plans;
- provide for asymmetrical arrangements with Quebec that respect its jurisdiction, priorities and existing mechanisms;
- fund community organizations that support people during coverage transitions.

Respect for jurisdiction must translate into effective coordination between governments. We ask that it serve neither to impose a unilateral mechanism nor to allow gaps to persist at the expense of the people affected.

6. Establish Interdepartmental Responsibility Grounded in Public Health and Rights

The Federal Action Plan recognizes that barriers to prevention and care do not stem solely from individual behaviours. Political and legal factors, stigma and structural inequalities also influence vulnerability to STBBIs. It notes, in particular, that criminalizing HIV non-disclosure can contribute to stigma and discourage the use of testing or treatment.

These findings call for coherent action across the federal government. PHAC's efforts must not be undermined by laws, administrative rules or policies that fall under other departments.

Some reforms extend beyond the immediate mandate of the Standing Committee on Health and require the involvement of other departments. Nevertheless, we ask the Committee to recommend that the federal Minister of Health take a leading role with her colleagues to ensure that federal decisions support public health objectives.

With respect to HIV, we call for legislative reform grounded in scientific knowledge and rights: remove HIV non-disclosure, exposure and transmission from the scope of sexual assault law and reserve criminal intervention for the rare situations involving actual and intentional transmission. Prosecution guidelines must not replace this reform.

We also ask that federal provisions relating to sex work, psychoactive substances and immigration be examined in terms of their effects on health, stigma and access to services. The people and communities concerned must participate meaningfully in this review and be paid for their participation.

The proposed mechanism seeks to ensure coherence among federal laws, policies and programs. It must not become a structure for directing Quebec's health services. When proposed solutions affect the responsibilities of Quebec, the other provinces or the territories, their implementation must be based on agreements with the governments concerned.

Recommendation 4 - Establish Federal Interdepartmental Responsibility Grounded in Public Health and Rights.

That the federal government give the Minister of Health a mandate to lead, with PHAC and the federal departments concerned, an interdepartmental mechanism responsible for:

- accelerating, with Justice Canada, legislative reform concerning HIV criminalization, ensuring that it is grounded in a public health approach;
- examining federal provisions relating to sex work and psychoactive substances and proposing the reforms needed to prioritize public health, rights and access to services;
- correcting barriers to health coverage and continuity of care arising from federal immigration policies and programs;
- ensuring the meaningful and paid participation of people living with HIV and the communities concerned;
- agreeing with Quebec, the other provinces and the territories on the collaboration arrangements and agreements needed when measures affect their responsibilities.

Conclusion

Scientific progress does not relieve governments of the responsibility to ensure the conditions for its implementation. We call on the federal government to provide sustainable support for community organizations, fund accessible prevention and testing with accompanying support, ensure free access to and continuity of treatment within its own programs and correct federal policies that hinder access to health care.

When measures require the involvement of Quebec, the other provinces and the territories, the federal government must negotiate the agreements and financial commitments needed to implement them, respecting each jurisdiction's responsibilities.

Community organizations are not an optional addition to this response. They must have the resources needed to be sustained partners in it, without having to compensate indefinitely for gaps in public plans.

Ensuring the rights of and access to health care for the most marginalized people is both an obligation towards them and an investment in the health of the entire population.

Respectfully submitted,



Ken Monteith, Executive Director



Benoit Racette, Coordinator, Rights and Advocacy

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Recommendations:

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