

Community-Based Research Priorities in Québec, Canada

Results of Community Consultations Using Focus Groups and World Cafés

Tanguy Hedrich ^{1, 2}, Janick Beaulieu ^{3, 1}, Ken Monteith ¹

¹ COCQ-SIDA, Montréal, Canada, ² UQAM, École de travail social, Montreal, Canada, ³ University of Ottawa, Ottawa, Canada

Introduction

Although biomedical advances have substantially improved life expectancy for people living with HIV in Quebec, **major social, structural, and service-related challenges remain inadequately documented from a community perspective.** In this context, COCQ-SIDA convened a **community consultation to identify research priorities** for the next five years and strengthen partnerships between community, public health, and research stakeholders. Building on two previous consultations (2013 and 2016), this initiative aimed to update priorities in light of emerging challenges and evolving community demographics.

Methods

11 Focus groups:

- **81 participants:** people with lived experience, frontline workers, coordinators
- In community HIV organizations in **four cities** in Québec
- **Content analysis:** Nvivo

Knowledge dissemination and World Café workshop

- **41 participants:** 3 focus groups participants, community representatives, researchers, medical practitioners, public health professionals
- **World Café:** 6 thematic tables, 3 rounds

Priority issues

Stigma and lack of awareness

One of the mothers called her children and disclosed her diagnosis. "Oh my God, you put on your gloves" Now she's isolated in her room; her children don't even say hello to her anymore.
— Outreach worker

Stigma is the most widely discussed issue and is present in romantic relationships, family relationships, professional relationships, and access to healthcare.

Examples of Proposed Research Projects

- ❑ Demystifying disclosure obligations versus personal choice.
- ❑ Romantic relationships among people living with HIV and the sense of obligation regarding sero-selection.

Access to care and prevention

If you're over 26 and aren't part of a priority group, it gets complicated, either it's going to cost money, or it's going to take a long time, or your family doctor is going to say, "You must be a slut if you want to do that"
— Outreach worker

Access to care, testing, PrEP, PEP, and treatment remains unequal, especially for migrants without health insurance, those living in rural areas, the homeless, and people who use substances.

Examples of Proposed Research Projects

- ❑ Pharmacists' support for access to PrEP.
- ❑ Acceptance and relevance of self-tests among different sub-populations.

Mental health

It becomes such a burden to carry, and you just don't feel like it anymore, so you give up—that's what I did this summer
— Person living with HIV

Mental health is a key issue, closely linked to isolation, stigma, and the risk of nonadherence to treatment.

Examples of Proposed Research Projects

- ❑ To document why sexual health interventions do not address mental health—and vice versa.
- ❑ Study on the mental health of people living with HIV in Quebec.

Structural vulnerability

During the hiring process: "Do you have any restrictions?" "Once every two months, I have to get treatment, so I'll have to miss work." "Okay, you're not hired—we don't care."
— Person living with HIV

There is an undeniable link between HIV and poverty, food insecurity, housing instability, employment challenges, and the accumulation of historical inequalities.

Examples of Proposed Research Projects

- ❑ Effects of the housing crisis on continuity of care and medication adherence.
- ❑ Food and financial insecurity among people living with HIV.

Ageing and comorbidities

With HIV, you age faster even though your life expectancy is the same (...) so all the checkups would be brought forward, so you need a sort of schedule of the various checkups to have at age 50.
— Person living with HIV

There is a significant lack of information on the long-term effects of HIV and antiretroviral treatment. There are also concerns about disclosing one's HIV status in long-term care facilities.

Examples of Proposed Research Projects

- ❑ Need for Confidentiality and Support in Services for Older Adults.
- ❑ Realities Faced by People Living with HIV in Long-Term Care Facilities and Retirement Homes.

Substance use and chemsex

During interviews with newcomers, (...) many say, "The other day, a guy asked me a question about PnP; I said yes and smoked a pipe." So it's easy for them, but there's a lack of information
— Outreach worker

We see an interplay between HIV, substance use, mental health, and social exclusion, and there is a need for more knowledge about chemsex in Québec.

Examples of Proposed Research Projects

- ❑ Access to safe consumption supplies, particularly disparities between Montreal and other regions.
- ❑ Research on the profile of chemsex in regional areas.

Transverse issues

Geographic Disparities

In the region, there used to be a doctor who not only provided HIV care but also served as the family doctor for the vast majority of patients in the area. He retired suddenly, and his entire patient base was left without a family doctor.

Geographical distance, a shortage of specialists, travel costs, and privacy concerns in small communities severely limit access to services in rural areas.

Examples of Proposed Research Projects

- ❑ A mapping project aimed at providing an overview of the resources available to people living with HIV by region.
- ❑ Relevance and acceptability of digital technologies (e.g. telemedicine).

Knowledge mobilization

We're seeing new cases—people who are much younger and less informed
— Outreach worker

There is a lack of accessible, easy-to-understand, translated, and culturally appropriate information, particularly for newcomers and young adults.

Examples of Proposed Research Projects

- ❑ Evaluation of multilingual, interactive, and culturally appropriate tools for newcomers.
- ❑ Study on population-level knowledge regarding HIV, testing, and U=U.



Populations of interest

Migrant populations

We hear people say, "But it was only after I came here that I was told I have HIV. I didn't know I had that." It's already a shock for them to learn they have a communicable infection, and then we don't use simple words.
— Outreach worker

This population is particularly affected by language barriers, a lack of information, and difficulties accessing care due to their immigration status.

Examples of Proposed Research Projects

- ❑ Action research involving immigrant peer supporters as models of support and referral.
- ❑ Specific needs of serodiscordant couples with immigrant backgrounds.

Women living with HIV

It's as if you're not a good mother because you don't breastfeed. Culturally, as a Haitian or African woman, you're expected to breastfeed. So if you don't, people start asking questions.
— Person living with HIV

Women living with HIV face specific challenges, such as menopause, pregnancy, or breastfeeding

Examples of Proposed Research Projects

- ❑ Effects of disclosure on the romantic and family relationships of women living with HIV.
- ❑ Study on support strategies during pregnancy, parenting, and when not breastfeeding.

People experiencing homelessness

The problem is that I'm homeless, and that makes it hard to stay on track (...) I have a hard time staying on track with my pills because they get stolen, because...
— Person living with HIV

This population is particularly affected by inequalities in access to care, treatment interruptions, and the conflict between basic survival needs, mental health, and adherence to treatment

Examples of Proposed Research Projects

- ❑ Research on the actual accessibility of care and treatment for people living with HIV who are experiencing homelessness.
- ❑ Feasibility of injectable antiretrovirals and flexible monitoring approaches for this population.

Similar research proposal were developed with other populations:

- Trans and non-binary people
- Indigenous people
- People in the prison system
- Sex workers
- MSM population
- Minors and adolescents
- "Non-key" population

Conclusion

Community consultation is a crucial step in community-based research. By taking into account the **opinions of workers and users of HIV grassroots organizations** working with various populations, we were able to achieve a unique outcome representing a diversity of perspectives. **The next steps include developing partnerships to implement new research projects and knowledge mobilization initiatives based on the identified priority issues.**