

MOVING FORWARD FROM THE CANADIAN POLICY DIALOGUE ON TB AND HIV: **KEY POLICY AND PROGRAMMING CONSIDERATIONS FOR THE CANADIAN RESPONSE TO TB AND HIV**

Background

In November 2018, the Interagency Coalition on AIDS and Development (ICAD), in partnership with Results Canada, hosted a multi-sectoral policy dialogue on tuberculosis (TB) and HIV. The dialogue complemented global and national activities surrounding the 2018 United Nations High-Level Meeting on Tuberculosis (UN HLM on TB) and ensured that civil society is engaged in shaping Canada's national and international response to commitments made at the HLM on TB. Participants and speakers represented several sectors (public health, community organizations, development non-governmental organizations (NGOs), research, TB/HIV responses, people with lived experience, organizations working with Indigenous communities and recent immigrants, government). Given the context of TB in Canada, there was a strong focus on Indigenous health and the health of newcomers, immigrants and refugees.

The following policy and programming considerations emerged from the discussion during the policy dialogue. They are initial thoughts shared by the group, worthy

of further attention. A next step could be developing a formal list of recommendations. This would require the group engaging in an extended consultation process with key stakeholders. Nonetheless, the policy dialogue convened participants from several sectors, working in many parts of Canada and internationally, including people with lived experience. Their collective perspectives, experience and wisdom provide an important foundation from which to enhance TB-HIV responses. For a full list of considerations, please consult the meeting report at: www.icad-cisd.com/tb-hiv.

The following key policy and programming considerations emerging from the policy dialogue will serve as a basis for next steps. Starting with a small Advisory Committee composed of policy dialogue participants and expanding to a broader range of stakeholders, these considerations will inform discussions on ways to move forward in the Canadian response to TB and HIV within Canada and globally.

Tuberculosis and HIV: Key Facts

TB is the world's leading infectious killer; it claimed the lives of 1.5 million people in 2018. Furthermore, people living with HIV are significantly more at risk of developing active TB than persons without HIV, and TB remains not only the most common presenting illness among people living with HIV—even when taking antiretroviral therapy—but is also the leading cause of death among people living with HIV globally.

In Canada, TB disproportionately affects Indigenous communities and newcomer immigrant and refugee communities. In 2017, nearly 1,800 people fell ill with TB, of which 17% were among Indigenous peoples. Half of these cases (49%) were among First Nations, 45% among Inuit people and 5% among Métis people. All Indigenous communities have higher rates of TB than Canadian born non-Indigenous persons. However, the rate among Inuit populations is particularly acute—almost 300 times higher than Canadian born non-Indigenous persons. In addition, 72% of TB cases are diagnosed among people born outside Canada.

Sources:

[World Health Organization. \(2019\). Global Tuberculosis Report.](#)
[Government of Canada. \(2018\). Tuberculosis Monitoring.](#)

1. Integrating TB and HIV Responses

While there are many intersections on social determinants of health, and we are sometimes working with the same communities, HIV and TB work is still largely operating in silos. As such, a person living with TB and HIV might have to access services from separate programs and providers. Likewise, medications might be covered through a combination of public and private programs. How can we maximize efficiencies? There is a need for integrated care and strengthened local systems. Separate services joined through a referral system have the disadvantage of requiring time, effort and expense for clients, increasing the likelihood that they won't access services. The global TB and HIV epidemics fuel each other. TB is the most common opportunistic infection and the leading cause of death for people living with HIV. It creates a double stigma. However, the extent to which TB and HIV are overlapping and connected epidemics in Canada within specific communities remains largely unstudied, though likely significant in some Indigenous, newcomer, immigrant and refugee communities.

Potential actions:

- Explore program models whereby HIV and TB services could be connected (e.g., collaboration between service providers; joint TB and HIV medication dispensaries).
- Conduct a mapping of HIV and TB services to identify potential linkages.
- Include proactive screening questions regarding TB as part of intake and assessment within existing services that reach our most affected communities. For example, out reach workers doing needle exchange could be doing TB screening with little training and a few additional assessment/intake questions. They have the relationships.
- Conduct enhanced surveillance and research to determine the extent to which TB and HIV are overlapping and connected epidemics in Canada within specific Indigenous, newcomer, immigrant and refugee communities.

2. Centering Lived Experience and Shifting Notions of Expertise

The Greater Involvement of People Living with HIV/AIDS (GIPA) Principles* have been a central tenet of the HIV movement since the beginning. We need something similar for the TB world, moving away from a paternalistic model of care by moving towards a model of care that is more inclusive, holistic, and based on lived experience.

Potential actions:

- Provide training for people with lived experience of TB and HIV and encourage them to participate in decision-making and service delivery, alongside community health workers, public health, policy-makers and healthcare professionals.
- The McGill International TB Centre's Summer Institute can provide training to TB champions, including people with lived experience pushing for a rights-based approach.
- Compensate people with lived experience when they are asked to engage.

* The Greater Involvement of People Living with HIV/AIDS (GIPA) Principles were created to make sure that people living with HIV are involved in the decisions that affect their lives. Most countries around the world support the GIPA Principles (and related MEPA: meaningful engagement of people living with HIV/AIDS).

3. Thinking Critically about Priority Populations

Naming priority populations is a double-edged sword. Unless we identify the most affected communities, the problem will not get addressed. It will perpetuate a lack of data, lack of attention, lack of funding, lack of effort. We need to align our interventions appropriately. However, those same communities are often the most marginalized, so we risk playing into stigmatizing narratives that see some communities (e.g., Indigenous and immigrant communities) as vectors of disease and as burdens. Furthermore, identifying priority populations allows those who are not part of those populations to think that it is not something with which they should be concerned, potentially increasing their risk.

Potential actions:

- Critically examine the use of potentially stigmatizing language relating to the communities most affected by TB (e.g., foreign-born), taking the lead from these communities)
- Advocate for more research, funding and interventions focussed on the most affected communities, while being mindful of the perverse effects of highlighting that these communities have high rates of TB on prevailing stigmatizing attitudes.

4. Addressing Gender Disparities

We need to recognize how HIV and TB affect women, men and non-binary folks, how disease burden typically falls on women in terms of caregiving, and how stigma affects them differently. Men are not expected to carry out regular roles when they have TB; women are. Men are well supported; women are told not to talk about it. It is harder for women to access social work supports. We recognize the need to deepen gender-based analysis (GBA) as it relates to TB and HIV within our responses.

Potential actions:

- Integrate gender-specific questions within the analysis of TB-HIV responses
- Include GBA training as part of capacity-building efforts with stakeholders involved in the TB and HIV responses
- Invite gender experts to join in our next steps

5. Adopting a Rights-Based, Person-Centred Approach

The TB response needs to be equitable, rights-based and person-centred. This requires changes in terms of language, cultural appropriateness and programming sensitivity. We need to work closely in partnership with most affected communities to develop appropriate approaches, and competent staff. A rights-based approach requires protecting immigrants from the threat or perceived threat of deportation or visa refusal. Health providers can on occasion use this as a means to retain patients in care. On the other hand, health providers can also be loath to take on the task of migrant stewardship and wish to have no role in those decisions.

Potential actions:

- Hire and train workers who speak Indigenous languages and the languages of newcomer, immigrant and refugee communities affected by TB.
- Hire and train workers who can provide trauma-informed care.
- Provide health navigation services.
- Develop culturally-grounded patient education resources available in the languages of communities most affected.
- Support patient empowerment and survivor groups (including arts-based approaches).
- Engage in efforts to protect the rights of immigrants in terms of both legal status and access to healthcare.

6. Moving from Control and Containment to Health Promotion and Protection

Approaches to public health surveillance and disclosure need to be examined critically. Participants questioned the ongoing role of Direct Observed Therapy (DOT), which was developed as a strategy to make sure people adhere to their TB treatment. Participants expressed the desire to see TB management approaches move beyond nurses watching people swallow pills. Among First Nations, DOT is seen as a colonial tool. How do we transform this into health promotion, whereby treatment is seen a partnership leading to health and well-being rather than a power imbalance? Would other approaches such as Video DOT (VDOT) be any more acceptable?

Potential actions:

- Critically examine approaches to TB that are founded in control and containment, such as Direct Observed Therapy (DOT).
- Use the treatment encounter as a means to connect to patients (rather than just monitor them) on a medical and personal level, and provide other supports, which can promote empowerment, inclusion and retention.
- Develop culturally relevant approaches to TB grounded in health promotion and protection, including through community workers who know the language and culture of the communities they serve, building on examples of wise practices such as efforts within Inuit communities.

7. Addressing Social Determinants of Health and Reconciliation within the Context of the TB Response

We need to address the inequalities that Indigenous people face when speaking about the Canadian HIV and TB epidemics. It took 500 years to get here. TB has its roots in colonization, residential schools and other social determinants of health (SDOH). We need to consider whether TB is a problem or a symptom. We have been dealing with TB forever and we need to consider the underlying conditions that perpetuate it (e.g., housing, colonization) without contributing to a deficit narrative. We have an obligation to do better, which among other things requires addressing poverty—which should be at the root of efforts to reduce housing overcrowding and to increase access to nutrition and healthcare.

Potential actions:

- Address overcrowded housing, access to healthcare and nutrition, as well as other social determinants of health among Indigenous communities as a matter of urgency and as part of the fundamental response to disproportionate rates of TB.
- Engage in Reconciliation by contributing to the dismantling of the ongoing colonization, racism, multi-generational trauma, stigma and discrimination that fuel TB.

8. Leveraging the Response to Health Issues among Newcomers, Immigrants and Refugees

What are successes and gaps that we should keep in mind when addressing TB? When people are diagnosed with TB, they are connected to a public health nurse and treatment team. What are the opportunities to connect TB and HIV services? There are lots of services for people living with HIV but not TB. There is a big fear around deportation. The process is not clear to many newcomers. Certain services are not available to all newcomers, only to refugees. When people arrive in Canada, they have concerns around housing, employment, health care, schools, transportation, taxes, new relationships, new culture. TB may not be high on the list. Addressing TB among newcomers, immigrants and refugees means addressing the SDOH. We need to understand the worldview that people bring, how TB is viewed in their country of origin.

Potential actions:

- Bridge the gap in services between HIV and TB for newcomer, immigrant and refugee communities through enhanced linkages and referral systems within existing services.
- Address gaps in health services based on legal status and concerns regarding deportation among newcomers, immigrants and refugees with TB.
 - Explore models such as The Netherlands, where the policy for those on treatment is to postpone eviction, to provide health insurance and to reimburse living and housing expenses.
- Embed TB services within broader settlement programs in order to relativize TB within the range of concerns for newcomers, immigrants and refugees.

9. Valuing Community-Led Responses

In the TB world we often see community involvement as a threat, and that must change. How do we make this type of work on behalf of civil society organizations palatable to donors? Strong community engagement and ownership of the process is key. This has been a hallmark of the Inuit response, which has actively engaged regional Inuit representatives and individuals (TB survivors, young advocates, health systems peer navigators). There is an opportunity for further community engagement at local levels in the development of regional plans. We need to resource the effort. Community driven responses are often dependent on volunteers and this is becoming a human rights issue. Putting communities at the centre of the response is not “capacity building”, it’s “capacity releasing”.

Potential actions:

- Provide funding to community-level efforts to address systems-level gaps.
- Promote active community engagement in the development of TB responses by creating spaces and opportunities for grassroots community leadership to determine how they want to engage.
- Value and resource community health workers as a cost effective and probably more effective way of reaching affected communities (i.e., Indigenous and immigrant communities) in culturally grounded ways.

10. Reaching Global Targets

We must reach the undiagnosed and untreated, requiring a focussed response and addressing the cost of diagnostics and treatment. Globally, the TB incidence rate is falling 2 percent per year—we must accelerate this progress to meet 2020 and 2030 milestones. 36 percent of people with TB are undiagnosed and untreated—often from key populations that include prisoners, people working in mines, healthcare workers, migrants and mobile populations, Indigenous populations, urban populations and people who use drugs. The cost of diagnostics and medicine is a barrier to TB care. There is a need to double current investment in TB responses and to address intellectual property mechanisms that pose barriers to accessing essential medicines.

Potential actions:

- Push for a scaled-up response to TB in order to reach global targets.
- Explore and leverage opportunities such as TRIPS and product development partnerships (PDPs) – a model grounded in open access, public accessibility of products, not profit-based, and designed to work in areas where there is little market interest in R&D.
- Promote enhanced TB detection and closer monitoring of latent TB infection (LTBI), using a person-centred approach.

11. Leveraging Lessons Learned from HIV and Other Countries

The HIV sector has leveraged important gains surrounding previous HLMs and have galvanized around issues such as access to medicines and ensuring a focus on key populations. Following the HIV Declaration in 2001, a handful of groups took the commitments that Canada made and held Canada accountable for what it needed to do domestically. It led to very real changes within communities. How can we mirror this for TB? We can learn lessons and amplify our impact through TB-HIV intersections. We can explore examples of success from other countries. Identifying common elements in the responses from high burden countries and our communities within Canada with high incidence could be interesting and could lead to potential collaboration.

Potential actions:

- Expand ICAD's Digital Liaisons to include TB-HIV lessons learned and case studies of innovative approaches.
- Share lessons learned and support twinning strategies offering opportunities to communities within and outside Canada to empower one another.

12. Monitoring and Ensuring Accountability

We have a role to play in monitoring the accountability framework that emerges from the HLM as well as ensuring Canada respects the commitments it has made as part of the HLM and beyond. For example, First Nations are rights holders and there are specific jurisdictional and fiduciary responsibilities related to their health. We need strong accountability mechanisms and ways of working collectively. This process includes solidifying relationships between civil society and decision-makers, moving away from the impression that accountability means communities are 'out to shame' governments. We need to consider how we deal with HLM commitments in Canada, when the federal government signed the Declaration, but provinces and territories mostly run TB care in Canada, and they weren't involved at all in the HLM.

Potential actions:

- Leverage existing and new commitments and responsibilities (e.g., HLM commitments, rights held by First Nations, Inuit and Métis communities); hold our governments and ourselves accountable for meeting these commitments.
- Engage actively in the post-HLM accountability framework

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