



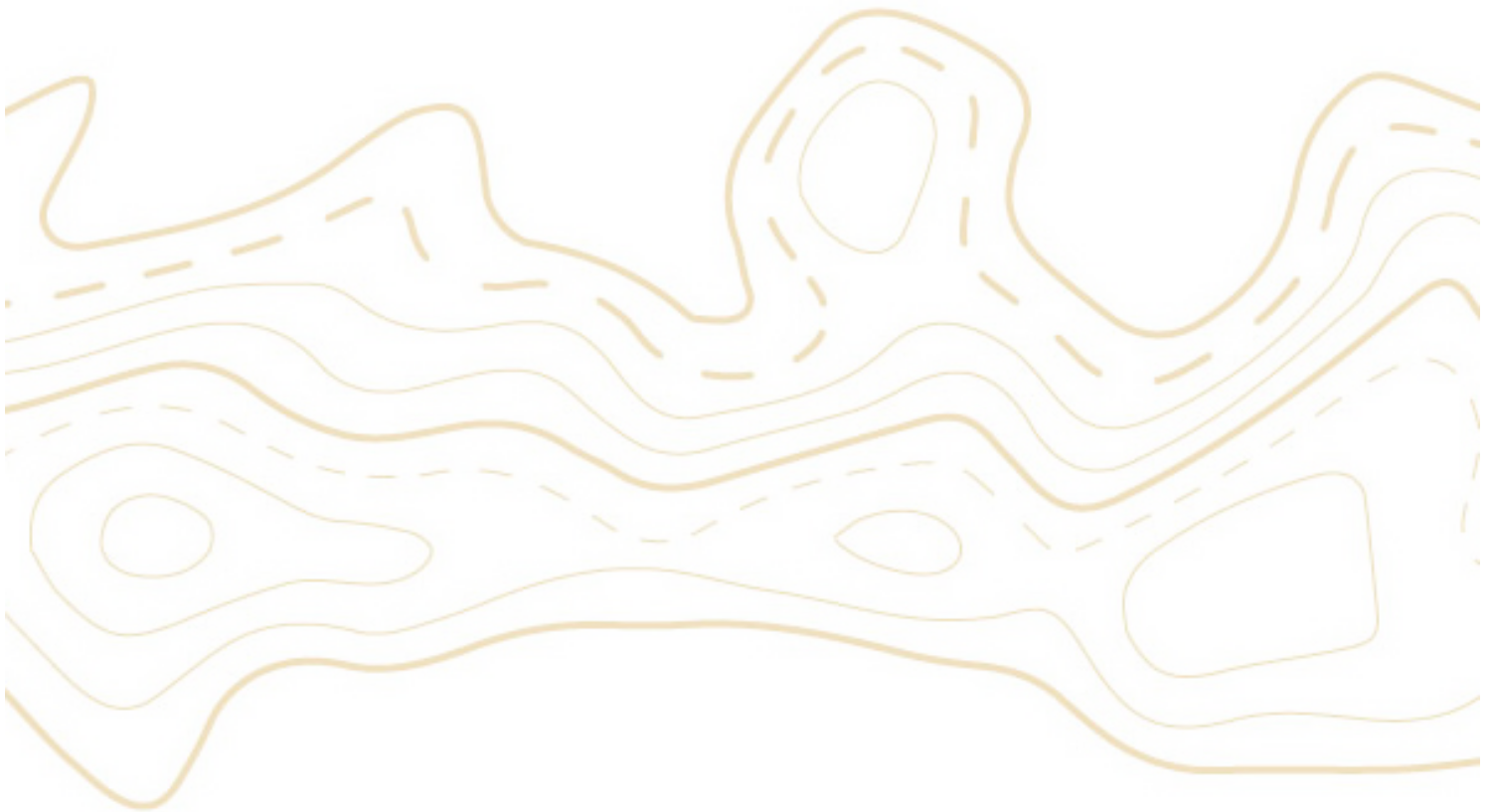
COMMUNITY REPORT

**Research to Action: Insights from the
Northern HIV Journey Mapping Project**

PREPARED JANUARY 2025



The Northern HIV Journey Mapping Research Project: 2019 - 2025



INTRODUCTION



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Research to Action: Insights from the Northern HIV Journey Mapping Project

HIV remains a significant health challenge in Manitoba, particularly among First Nations people in northern communities. Barriers such as geographic isolation, stigma, and systemic inequities hinder timely care and support access. Cultural strengths, community resilience, and innovative approaches can drive positive change despite these challenges. This study was created in response to community concerns about rising rates of HIV. A collaboration of researchers, health professionals, front-line workers and policy makers was formed to explore these concerns. (See list of Research and Working Group Teams).

This report shares insights from the **Northern HIV Journey Mapping Project (NHJMP)**¹, a community-driven study conducted between 2019 and 2025 funded by the Canadian Institutes of Health Research. There were two parts to the study:

1. Exploration of experiences of First Nations people living with HIV and the healthcare providers who supported them
2. The development of the First Nations Community Readiness Assessment for Creating Change: HIV Workbook

¹ Full title: *Mapping the journey: Developing culturally appropriate, geographically-responsive HIV care for northern Manitoba First Nations People.*

PART 1:

The study explored the experiences of First Nations people living with HIV and the healthcare providers who support them in Manitoba, Canada. First Nation people living in rural and remote Northern communities and those living in urban cities were interviewed. Guided by Two-Eyed Seeing and Ethical Space, the research prioritized First Nation and Western perspectives.

Data was gathered through in-depth interviews with 29 participants (18 First Nations individuals living with HIV and 11 healthcare providers) and a stakeholder workshop with over 40 participants. Recommendations for systems change are part of the research-to-action as a result of the study.



PART 2:

Based on identified needs from First Nation communities, a request was made to redesign the CAAN HIV Community Readiness Assessment Workbook.

With input from First Nation communities, we developed the **First Nation Community Readiness for Change: HIV Workbook**, was developed as part of the study, which was then pilot-studied with four First Nation communities and is ready to be scaled up. This was part of our research-to-action deliverable built into this study.



Why is this Study Important?

HIV rates continue to rise in Manitoba, with significant impacts on Indigenous populations. In 2023, the incidence rate of HIV reached 26.4 diagnoses per 100,000 people, reflecting a sharp increase over previous years. Among new diagnoses, 85.1% of females and 68.6% of males self-identified as Indigenous. These rates highlight systemic inequities in healthcare access and underscore the need for culturally safe and responsive solutions.

This is one of the first studies that focuses on understanding the barriers and facilitators for HIV care for First Nation people in Canada.



Approaches Woven Throughout the Study

ETHICAL SPACE AND TWO-EYED SEEING APPROACH

A two-eyed seeing and an ethical space approach was woven throughout the project. A *Two-Eyed Seeing* approach and the concept of *ethical space* were foundational to this project, fostering respect for both Indigenous and non-Indigenous worldviews.

The research team created Ethical Space, a concept introduced by Elder Willie Ermine, to ensure respectful and reciprocal engagement. Ethical Space serves as a neutral ground where Indigenous and Western knowledge systems meet to foster understanding and collaboration. This approach was complemented by Two-Eyed Seeing, which combines First Nation and Western ways of knowing to co-create solutions.

Key principles of Ethical Space in this study included:

- **Reciprocity:** Ensuring mutual benefit for researchers and communities.
- **Respect:** Valuing First Nation knowledge and lived experiences.
- **Relationality:** Building trust and sustained partnerships.

Dr. Albert McLeod, a First Nation Elder and Co-Principal Investigator, co-designed the research, participated in data analysis, and led the creation of an *Ethical Space Online Course* during the COVID-19 pandemic, equipping the research team with the tools to work within these principles. Ongoing guidance was provided by a *Two-Eyed Seeing Working Group*, comprising Indigenous and non-Indigenous health professionals, community members, and individuals with lived experience from northern Manitoba and Winnipeg.

Two First Nation community research associates with lived experience were integral to data collection, analysis, and knowledge sharing.

The project culminated in a facilitated data engagement and interpretation session (December 2023) involving the research team, the working group, and diverse stakeholders, including healthcare professionals, community representatives, and individuals with lived experience from across Manitoba-44 participants. This collaborative session validated the findings and ensured the data interpretations reflected the diverse voices and contexts of those involved.



A SYSTEMS CHANGE APPROACH

The NHJMP study adopted a systems change framework to address the root causes of inequities in HIV care. This approach examined the healthcare system's structural, relational, and cultural elements. This approach aligns with First Nation ecological systems theories, emphasizing interconnectedness and holistic care. First Nation people view health as deeply relational, influenced by family, community, and the natural world. The systems change framework respects this worldview, integrating it into actionable policy and practice.

Partnerships

This study included an essential partnership with Nine Circles Community Health Centre and the MB HIV-STBBI Collective Impact Network. In early 2023, we partnered with the MB HIV Program on a visit to Thompson to share information, share early study results, and seek assistance with participant recruitment.

During the Thompson visit, we met with 26 people, including 13 health professionals/ frontline workers who attended our joint workshop and 13 people who participated in the Manitoba Harm Reduction Network.



An abstract graphic composed of various orange lines, including solid, dashed, and dotted lines, forming a complex, organic shape that resembles a stylized map or a series of interconnected paths. The lines are of varying thickness and are set against a light beige background.

KEY FINDINGS

KEY FINDINGS

“

I was scared to go in [the community-based HIV clinic] because I thought people would see me and judge me. They'd look down on me and think less of me.

”

– First Nation person living with HIV

Barriers to Care

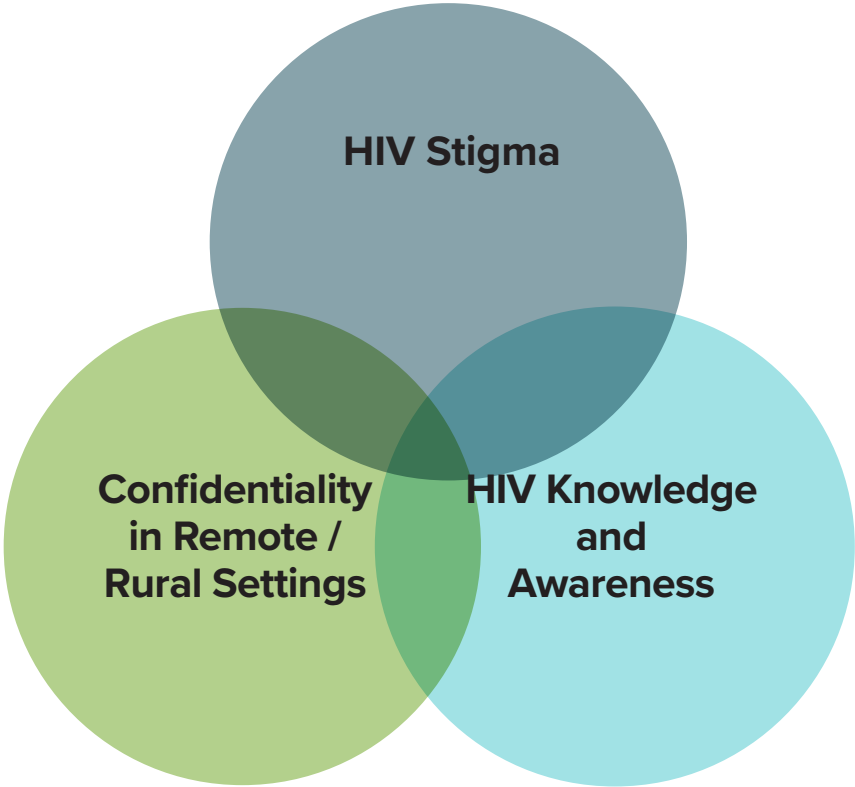
- **Lack of Access to Adequate Healthcare:** Many communities face significant barriers to accessing quality healthcare services.
- **Stigma and Discrimination:** Stigma and racism, both within communities and the healthcare system, discourage individuals from seeking care and contribute to disparities in health outcomes.
- **Lack of Opportunities for Accessing Up-To-Date Knowledge:** Limited understanding of HIV health-related information was reported by individuals when they were first diagnosed. Interviews also noted that the communities' lack of up-to-date information contributed to stigma.
- **Social and Environmental Factors:** Broader social determinants, such as poverty, housing insecurity, and environmental conditions, significantly impact health and well-being.
- **Geographic Remoteness:** Long travel distances and limited healthcare services create logistical challenges for individuals in remote and rural communities, hindering access to care. Confidentiality emerged as an important theme in rural and remote locations.
- **Cultural Safety:** Healthcare systems often fail to incorporate cultural safety, eroding trust and effectiveness in healthcare delivery.



Inter-related Barriers to Care

Three dominant interrelated themes emerged: **HIV Stigma**, **HIV Knowledge and Awareness**, and **Confidentiality**. In an ethical space of dialogue and reflection, the study team’s First Nation Elder situated these findings within the broader historical and current context of colonization and cultural genocide.

INTER-RELATED THEMES



**** IMPORTANT:**

The history of Colonization and Cultural Genocide in Canada and Manitoba impacts access to health services, including geographic location, housing, resources, and allocation of health services.

“

It’s hard to keep medications hidden when you live with multiple people. Privacy is not a luxury we have.

”

– First Nation person living with HIV

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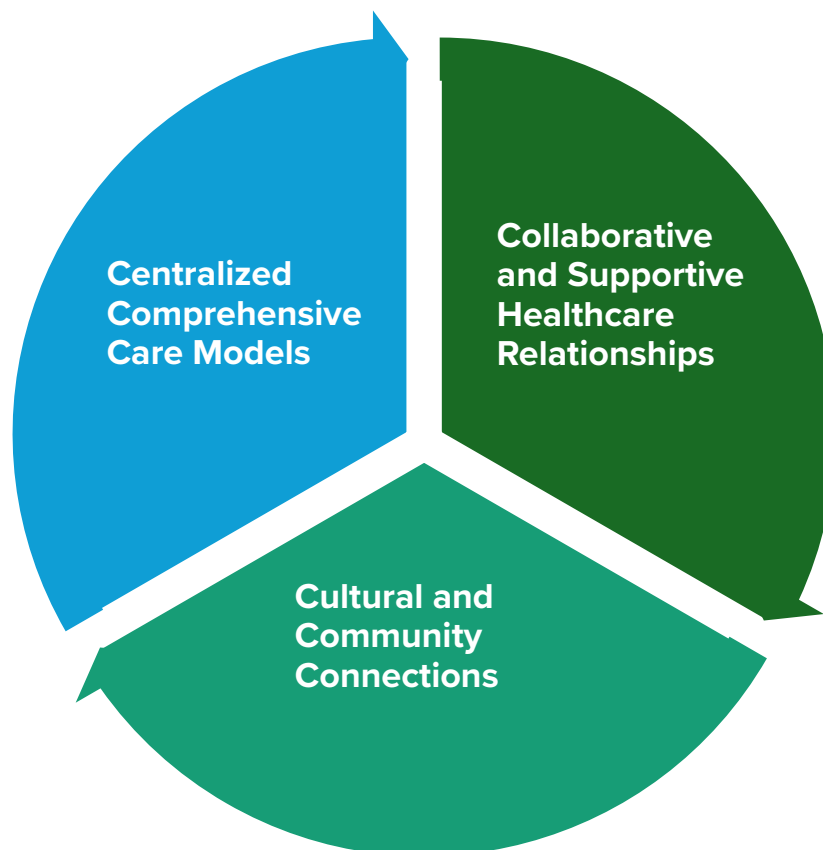
I knew I was Métis, but I never connected with my Métis heritage, and Nine Circles helped to introduce me to my culture.

”

– First Nation person living with HIV

Facilitators to Care

- **Collaborative and Supportive Healthcare Relationships:** Compassionate, culturally competent health care providers foster trust and improve health outcomes through collaborative and supportive care.
- **Cultural and Community Connections:** Incorporating practices such as traditional medicine, ceremonies, and connection to the land strengthens resilience and promotes holistic well-being.
- **Centralized Comprehensive Care Models:** Integrated hubs/programs that address medical, social, and cultural needs enhance overall health and quality of life.





RECOMMENDATIONS FOR CHANGE

Recommendations for Change

1. **Indigenous Leadership:** Develop regional, provincial, and federal policies to support Indigenous health leadership and establish Indigenous-led health authorities.
2. **Healthcare Access and Innovations:** Increase local healthcare services and transportation options to improve access for remote and underserved communities
3. **Changes to Resource Distribution:** Advocate for changes in resource allocation and create policies at federal, provincial, and regional levels to ensure equitable funding distribution.
4. **Community-Led Solutions and Novel Approaches:** Encourage novel and community-driven approaches to healthcare that prioritize Indigenous perspectives and leadership.
5. **Enhance HIV Education:** Enhance public education initiatives to reduce stigma and increase knowledge about HIV prevention and care.
6. **Culturally-Safe Care:** Train healthcare providers in culturally safe and trauma-informed practices to rebuild trust with Indigenous communities, supported by mandatory provincial training policies.



RECOMMENDATIONS FOR

Systems Changes

STRUCTURAL CHANGES

- **Policies:** Advocate for equitable healthcare policies that prioritize remote and First Nation communities.
- **Resource Flows:** Allocate funding to enhance local services, training, and infrastructure.
- **Practices:** Implement trauma-informed and culturally safe healthcare practices.

RELATIONAL CHANGES

- **Relationships:** Strengthen partnerships between First Nation communities and healthcare providers.
- **Power Dynamics:** Empower First Nation voices in decision-making processes.

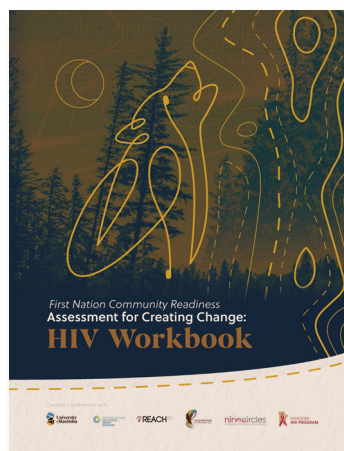
TRANSFORMATIVE CHANGES

- **Mental Models:** Challenge stigma and colonial perspectives by fostering greater cultural understanding.
- **Cultural Integration:** Embed First Nation ways of knowing into healthcare delivery and policy.

Path Forward-Research to Action

Improving health outcomes for First Nations living with HIV requires sustained, systemic efforts:

- **Address root causes:** Tackle social determinants of health, including poverty and housing.
- **Build on strengths:** Support community-led solutions, leverage traditional practices and community resilience.
- **Innovations:** Supporting new technologies that enhance rural and remote HIV testing and care.
- **Enhance collaborations:** Foster two-eyed seeing partnerships among policy makers, researchers and First Nation communities, healthcare providers, and policymakers.
- **Advocate:** Support equitable and culturally safe healthcare policies.
- **Preparedness:** Help reduce stigma by promoting awareness about HIV, leverage the First Nation Community Readiness for Change-HIV Workbook
- **Engage:** Partner with organizations that serve First Nation communities.



Together, these actions can pave the way for a healthier, more equitable future. Since the study began, there have been changes in Manitoba, including universal coverage of HIV treatment meds, new Manitoba HIV Programs, including the establishment of a Northern HIV Care HUB in Thompson, the expansion of HIV services to primary care physicians, and the establishment of the PATHs program with wraparound care beyond the central location in Winnipeg. There has also been an expansion of testing innovations, including self-testing, multiplex testing, and point-of-care testing innovations.

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ACKNOWLEDGEMENT & APPRECIATION

Acknowledgement and Appreciation

We acknowledge and express our respect for the study participants. We want to sincerely thank the 29 First Nations people living with HIV and the healthcare providers who agreed to be interviewed for this study. We also want to thank the two-eyed seeing group of 44 people who provided their input at our Data Engagement and Interpretation Session in December 2023 and the four First Nation communities (Little Saskatchewan, Wuskwi Sipihk First Nation, Lake Manitoba First Nation, and Pinaymootang Health Centre), who participated in the First Nation HIV Community Readiness Workbook pilot study.

We appreciate the project funding by the Canadian Institutes of Health Research (CIHR) (CIHR Operating Grant (Grant Number CBA-164022)).



Working Group Team

We acknowledge the two-eyed-seeing working group that we worked with throughout the years. In addition to our research team, these people included the following:

In some cases, their roles changed over the years. Many of these people participated in the December 2023 data integration session.

- Nancy Vystrcil (Former Northern Regional Health Authority Nurse)
- Agnes Denechezhe (Former Keewatin Tribal Council Nurse)
- Alex Bunn (Northern Regional Health Authority Nurse)
- Amber Mitchell (Northern Regional Health Authority Nurse)
- Dr. Barry Lavallee (CEO-Keewatinohk Inniniw Minoayawin)
- Dr. John Kim, (National Microbiology Lab)
- Kim Templeton (Program Director-MB HIV Program)
- Dr. Michael Isaac (Former Medical Officer of Health Northern Regional Health Authority and former Medical Officer of Health with-Indigenous Services Canada).

Research Team

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Publications

We have presented this study at several meetings and conferences, published several papers listed here, and are submitting more for publication.

- Larcombe, L., Mcleod, Payne, M, Samual S., Samuel J., Van Haute, S., Singer, M., Ringaert, L., Meyers, A., Kinew K., Keynan, Y., Macdonald, K., Antsanen J., Orr, P. (2019). **A Dene First Nation's community readiness assessment to take action against HIV/AIDS: a pilot project.** *International Journal of Circumpolar Health*, 78-1.
- Larcombe, L., Hydesmith, E., Restall, G., Ringaert, L., Singer, M., Souleymanov, R., Keynan, Y., Payne, M., Macdonald, K., Orr, P. & Mcleod, A. (2020). **Creating change using two-eyed seeing, believing and doing; responding to the journey of northern First Nations people with HIV.** *Journal of Indigenous HIV Research*, 22.
- Larcombe, L., Ringaert, L., Restall, G., Mcleod, A. Hydesmith, E, Favel, A., Morris M., Payne, M., Keynan, Y., Souleymanov, R., Macdonald, K., Singer, M., Star J., Orr, P. **"Because of COVID. . .": The impacts of COVID- 19 on First Nation people accessing the HIV cascade of care in Manitoba, Canada.** *PloS One*. August 8, 2023.
- Larcombe, L. and Ringaert, L. (2025). **Community Report-Research to Action: Insights from the Northern HIV Journey Mapping Project.**

We recommend that First Nation communities consider using the [First Nation Community Readiness Assessment for Creating Change: HIV Workbook](https://cinetwork.ca/projects/cinetwork-usability-studies-first-nation-community-readiness-for-change-hiv-workbook-study/) to guide their work on HIV. Available at <https://cinetwork.ca/projects/cinetwork-usability-studies-first-nation-community-readiness-for-change-hiv-workbook-study/>

Please visit the [CINetwork website](https://cinetwork.ca/) for updates on new publications.

Contact

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