MB HIV-STBBI Collective Impact Network

HIV Long-Term Survivors Action Group – Engagement Session Report

October 15, 2025 | Bill & Helen Norrie Library | 19 Participants

1. Introduction

The Manitoba HIV-STBBI Collective Impact Network (CINetwork) convened an **HIV Long-Term Survivors Action Group** engagement session on **October 15, 2025,** at the Bill and Helen Norrie Library in Winnipeg. The session brought together **15 people living with HIV**, primarily long-term survivors from Winnipeg and rural Manitoba, to share lived experiences, identify priority issues, and shape survivor-driven recommendations for systems change. **Four** health care providers and frontline service providers also attended.

The CINetwork is an initiative of Nine Circles Community Health Centre. The Public Health Agency of Canada-Community Action Fund provides funding for the CINetwork.

Purpose of the Session

The engagement session was designed to:

- Deepen understanding of the **unique issues facing HIV long-term survivors** in Manitoba.
- Gather **survivor-informed recommendations** for improving services, supports, and policies.
- Strengthen community connections and create space for **peer sharing, healing, and collective action**.
- Identify next steps for the **Long-Term Survivors Action Group** within the CINetwork.

Planning and Facilitation Team

The session was co-designed and co-facilitated by the CINetwork LTS Planning Team:
Ken Bristow, **Freda Woodhouse**, **Christine Bibeau**, **Jim Kane**, with staff **Gina Laliberte**, **Ella Rockar** and **Laurie Ringaert**.

2. Overview of the Session

The half-day gathering followed a **relationship-centred**, trauma-informed structure that blended storytelling, panel discussions, and sharing circles.

Key Components of the Session

Opening and Framing (11:00–11:30)

Ken welcomed participants and outlined objectives: understanding HIV long-term survivors' experiences and co-creating recommendations for change. He invited Jim and Freda to open the session.

Icebreaker & First Sharing Circle (11:30–12:00)

Led by Freda, participants introduced themselves, shared how long they had lived with HIV, what brings them joy, why they attended, and their hopes for the day.

Light Lunch and Art Engagement by Christine

Panel of Long-Term Survivors (12:45–1:45)

Four panelists—Christine, Jim, Freda, and Ken—shared personal stories, highlighting issues such as aging, stigma, disclosure, criminalization, and gaps in supports, as well as their visions for change.

Thematic Sharing Circles (2:00–3:30)

Led by Jim, participants chose from the five guiding questions:

1. What are the positives about being HIV-positive?
2. Tell us about your disclosure journey and what should change?
3. What issues are you facing as a long-term survivor?
4. What recommendations do you have for change?
5. Can you relate to issues faced by long-term survivors across Canada?

Closing Reflections, Evaluation, and Next Steps (3:30–4:00)

Led by Ken, key messages were summarized by Laurie, and closing reflections were provided by Mike Payne, Executive Director-Nine Circles Community Health Centre. Participants were asked whether the group should meet again, evaluation forms were completed, door prizes were awarded and Jim and Freda provided closing reflections.

3. Key Findings

The following findings integrate discussion themes, the October 15 event draft summary, and the **Top 5 Recommendations for Long-Term Survivors in Manitoba**. These findings have been developed into a one-pager for distribution.

1. Inadequate and Inaccessible Supports

Participants emphasized barriers to navigating the health system, a lack of coordinated survivor-specific supports, and major challenges for rural residents. Manitoba lags behind other provinces in drug coverage, peer programs, and survivor-focused services.

2. Persistent Stigma and Discrimination

Stigma remains present in health care, families, and dating contexts. Aging with HIV amplifies concerns about discrimination in personal care homes, long-term care, and urgent care settings.

3. Isolation and Mental Health Challenges

Many survivors live alone and struggle to form new connections—especially after the loss of peers or partners. Loneliness, depression, survivor guilt, and addiction remain ongoing concerns. Participants expressed a strong need for **peer-led spaces**, family supports, and culturally safe mental health resources.

4. Disclosure, Safety, and Criminalization

Disclosure remains one of the most traumatic aspects of living with HIV. Survivors described rejection, break-ups, and safety risks following disclosure. Criminalization policies continue to instill fear, reduce autonomy, and discourage openness in relationships and health care.

5. Lack of Public Education and Awareness

Participants described widespread misinformation in the public, among youth, and even among clinicians. Many felt Manitoba has insufficient HIV education campaigns—particularly outside Winnipeg—further reinforcing stigma and internalized shame.

Resilient Ways Identified by Survivors

Participants also shared strengths and sources of resilience, including:

- peer support and chosen family
- cultural identity and spiritual practices
- humour, creativity, and advocacy
- long-term relationships with trusted providers
- personal growth through survivorship

4. Recommendations

Across panel discussions and sharing circles, participants identified **priority areas for systems and community change**:

System-Level Recommendations

- Expand and streamline **drug coverage** and survivor-specific supports.
- Improve access to **culturally safe, trauma-informed** care—particularly in rural and remote areas.
- Address stigma in health care through mandatory **HIV education** for providers.
- Advocate for **legal reform** related to HIV non-disclosure and criminalization.
- Fund **survivor-led peer programs**, mentorship, and community gatherings.
- Increase public-facing, province-wide **education campaigns** on U=U, aging with HIV, and contemporary treatment realities.

Other Recommendations

- Continue hosting safe, peer-led long-term survivor gatherings on a regular basis.
- Create a resource guide for navigating Manitoba's HIV care and support landscape.
- Support survivor voices in research, policy, and planning tables.
- Support research studies on HIV long-term survival

5. Evaluation Results

Overall Satisfaction

Participants rated the session highly, noting:

- The space felt safe, respectful, and supportive.
- The sharing circles and panel were the most valued elements.
- Participants appreciated being heard, believed, and connected with others.

Participant-Reported Impacts

People reported:

- Increased sense of belonging
- Greater understanding of shared challenges
- Hopefulness about future advocacy
- Validation through hearing others' stories

Suggestions for improvement included:

- More time for small-group discussions
- Holding future sessions in community-based settings

6. Recommended Next Steps

Based on group discussions and evaluation feedback, the following next steps are recommended:

- Bring the findings from this meeting to the people who have the power to make system level changes
- Plan a follow-up meeting in early 2026 to advance the recommendations and grow the network of survivors.

Our Thanks!

Our gratitude to

- Ken Bristow, Freda Woodhouse, Christine Bibeau, and Jim Kane for their guidance, planning and co-facilitation of the session
- All of the people who attended the session
- To Marcie Wong, Nine Circles Community Health Centre Social Worker, for providing support as needed at the session.
- To the Public Health Agency of Canada, Community Action Fund, for funding the event.