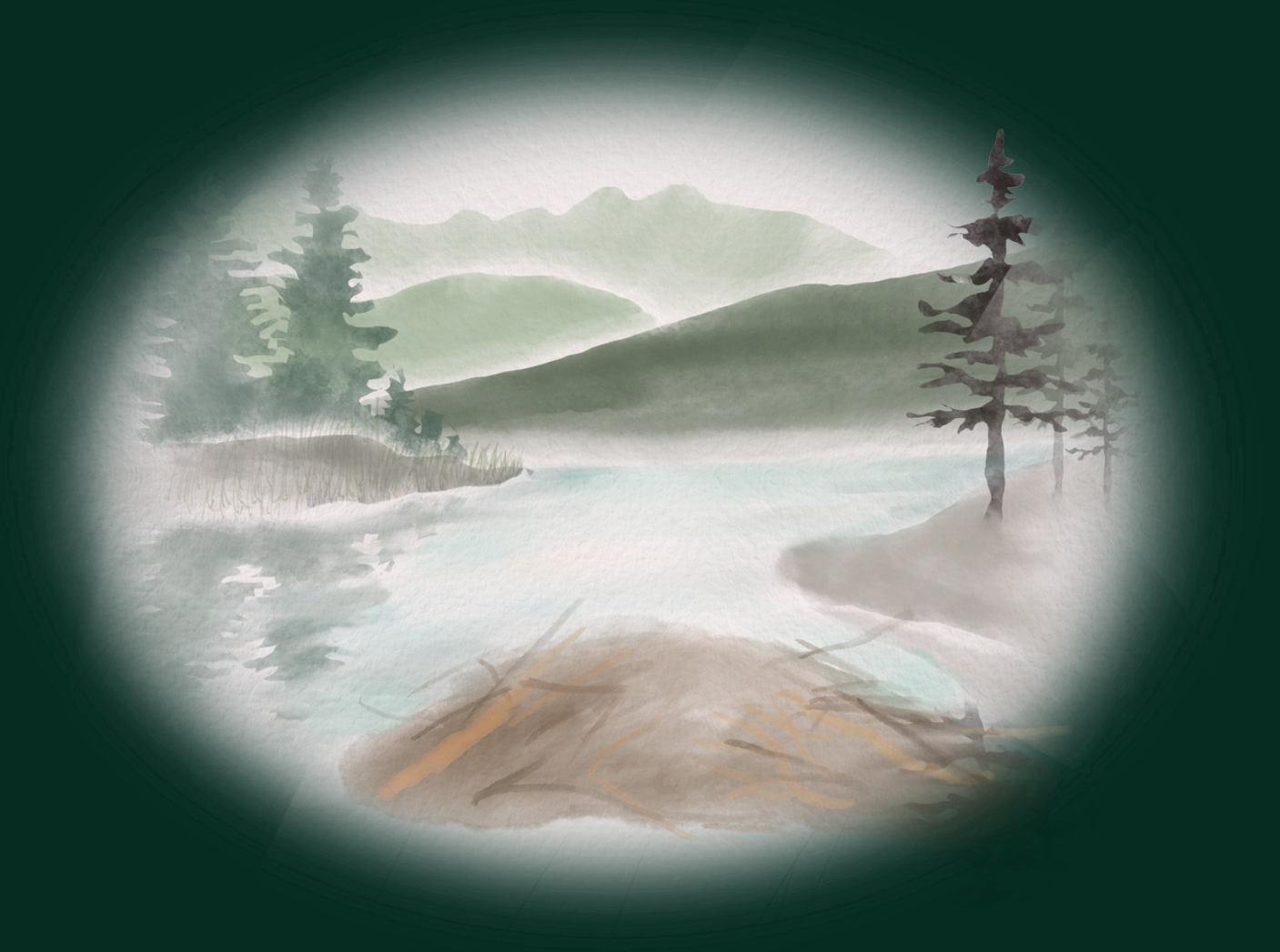
From Listening to Action:

First Nations Perspectives on Liver Wellness and Hepatitis C



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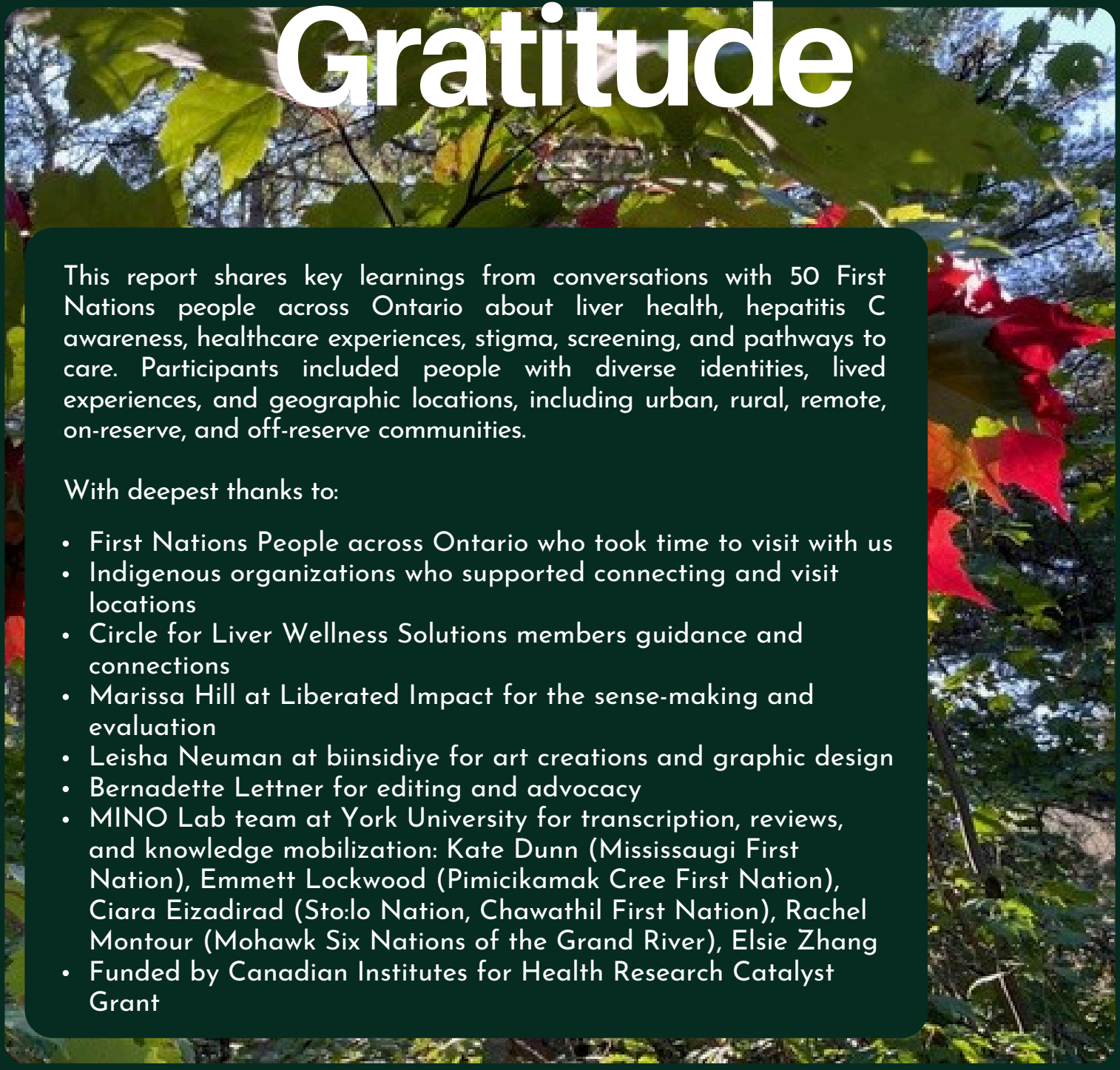

This report shares key learnings from conversations with 50 First Nations people across Ontario about liver health, hepatitis C awareness, healthcare experiences, stigma, screening, and pathways to care. Participants included people with diverse identities, lived experiences, and geographic locations, including urban, rural, remote, on-reserve, and off-reserve communities.

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Summary

Five themes emerged, highlighting that hepatitis C elimination cannot be achieved through clinical interventions alone. Success requires Indigenous-specific models of care that prioritize awareness, relationality, community leadership, cultural safety, and long-term investment in community capacity.

Five Main Themes

1. **Awareness is the Foundation of Change**
2. **Relationships, Trust, and Cultural Safety Matter**
3. **Stigma Continues to Limit Engagement**
4. **Community-Led Approaches Create Better Outcomes**
5. **System Change is Required to Support Equitable Care**

The strongest finding was that awareness of liver health and hepatitis C is extremely limited. Most participants knew little about the liver, hepatitis C transmission, treatment, or cure, highlighting awareness as the critical first step.

People who participated emphasized that awareness alone is not enough.

Trust, relationships, cultural safety, and respectful healthcare interactions strongly influence whether people seek testing, treatment, and ongoing care. Experiences of racism, stigma, and medical trauma continue to shape healthcare engagement and contribute to avoiding services.

Community members consistently called for approaches that are relational, culturally relevant, strengths-based, and community-led. Education, screening, and treatment must be integrated into broader conversations about wellness, family, culture, and community rather than focused solely on disease.

Awareness is the Foundation of Change

A lack of awareness about liver health and hepatitis C was the most consistent message across all conversations. This finding crossed age groups, locations, and life experiences. Many participants had never received information about liver health, while some people who had previously been treated for hepatitis C reported retaining little information after treatment about the virus or relevance of liver health.

Participants repeatedly emphasized that awareness should begin long before diagnosis. Discussions about the liver should be part of everyday conversations included with wellness, nutrition, prevention, family health, cancer screening and community wellbeing.



"Focusing on awareness and education through conversation fosters trust and hope and creates opportunities to talk and learn."



Why this Matters:

Without awareness, people are unlikely to pursue screening, understand risk factors, seek treatment, or support others in accessing care.

Awareness creates the foundation for informed decision-making and helps reduce stigma by normalizing conversations about liver health.

Information should be:

- Visual and engaging
- Easy to understand
- Relevant to First Nations experiences
- Connected to culture, community and land
- Focused on wellness, not fear
- Action-oriented and practical
- Accessible and visible in many places
- Shared in relational conversations



"Anyone with a liver can get hep C, and hep C testing is part of liver wellness for everyone."

Relationships, Trust, and Cultural Safety Matter

What we Heard:

Relationships are central to health and wellbeing. Trust is built through presence, respect, listening, and genuine human connection. We heard that healthcare engagement improves when providers take time to understand people's lives, experiences, and priorities.

On the other side, many people shared with us experiences of racism, judgment, stereotyping, or feeling invisible within healthcare settings. Several people stated they actively avoid healthcare because they do not feel safe, respected, or understood.

Many people could not recall a positive healthcare experience when asked. This finding emerged as one of the most concerning messages in the report.

"Do I see myself in that space? And if I don't see myself, if I don't feel safe in that health system, I'm not going there."





Why This Matters

Healthcare pathways are only effective when people feel safe accessing them.

Trust and cultural safety are prerequisites for engagement in screening, treatment, follow-up care, and prevention efforts.

“Respect can be felt.”



“I think being in community and being present is a really big part of it.”

“People are scared, so more positive feedback towards me, on the things [I’m] doing right.”

“I would trust this team here in this building with anything in my life.”

“Having those conversations, it really help, and it makes people more comfortable.”

Stigma Continues to Limit Engagement

What we Heard:

Stigma was one of the largest barriers to discussing hepatitis C, seeking screening, and engaging in treatment. Many people explained that stigma is reinforced by silence, misinformation, stereotypes, and associations between hepatitis C and substance use.

Many community members felt conversations focus too heavily on disease and risk rather than hope, wellness, and healing. Participants noted that stigma is often intensified when healthcare providers lack understanding or use judgmental language.

People wanted hepatitis C framed as a health issue that can affect anyone, rather than something associated with specific groups.

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"It's not a drug problem, it's a not understanding problem."



Why This Matters

Stigma discourages testing, limits conversations, and prevents people from seeking support. People consistently linked awareness, education, and open dialogue with stigma reduction.

"Awareness and education... I think that would end the stigma."

"Openly talk about it. We need to give it a human face."

"It's your auntie, it's your sister, it's your uncle, it's your brother."

"A big part of the stigma... [is that] people aren't having these conversations with anyone."



Community-Led and Culturally Relevant Approaches Work

What we Heard:

There is strong support for community-driven approaches to awareness and care. People want messaging that reflects First Nations experiences, values, cultures, and ways of learning.

Education was seen as most effective when delivered by trusted people including:

- Elders
- Knowledge Keepers
- Community ambassadors
- Peers
- People with lived experience
- Indigenous healthcare workers



Visual storytelling, art, humour, social media campaigns, youth programming, community events, and intergenerational community-wide learning opportunities are recommended as ways to build relationships to knowledge and awareness in a good way.

Awareness efforts should focus on whole-community wellness rather than individual risk.

Why This Matters

Stigma discourages testing, limits conversations, and prevents people from seeking support. People consistently linked awareness, education, and open dialogue with stigma reduction.

"We need community members to be that bridge, to build trust."



"Broad awareness is needed for all people and all ages in community."

"Building capacity in the community to do their own presentations and lead in their own community."

"When I was in active addiction, I wouldn't sit there and read the full pamphlet, I would read a card."

System Change is Required

- **What We Heard:**

Community members describe barriers that extend beyond individual healthcare encounters. They identified challenges within policies, healthcare systems, funding structures, staffing models, provider education, data systems, and access to services. They also emphasized the ongoing impacts of historical contexts creating spaces of mistrust.

Many community members reported receiving inconsistent information about hepatitis C from healthcare providers. Others described difficulty accessing screening, treatment, or follow-up support.

Healthcare providers themselves acknowledged gaps in awareness and capacity.

We were told to advocate for:

- Indigenous healthcare workforce development
- Community connector roles
- Healthcare team cultural awareness training
- Hepatitis C education for providers
- Flexible community-based care models
- Mobile services and screening options
- Sustainable funding and infrastructure

Why This Matters

Community engagement alone cannot overcome structural barriers. Sustainable progress requires healthcare systems that support culturally aware, accessible, and responsive care pathways.

"You deserve care. You deserve to be treated well."

"People are dying while we fight about money."

"Everyday doctors and healthcare professionals need to know the basics."

"Make access to knowledge and care available to people who need it, in ways that they need it."

"Care Providers need to deeply understand colonial history and medical trauma and what they might do to perpetuate them."



From Listening to Action:

We heard a consistent vision for the future: broaden awareness, reduce stigma, strengthen trust, support community specific screening/ care pathways, and build healthcare systems that are culturally responsive and relevant in First Nations realities.



Success will not come from treatment alone; it will come from relationships, awareness, and community-driven approaches that support wellness throughout the entire care journey.

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"You have one life to live.
Live it well. Liver it well."

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