PRINCIPLED RECOMMENDATIONS

Co-Designing Digital Health Evaluations with First Nations, Inuit & Métis Communities

The Canadian Network for Digital Health Evaluations, Women's College Hospital Institute for Health System Solutions & Virtual Care

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Table of Contents

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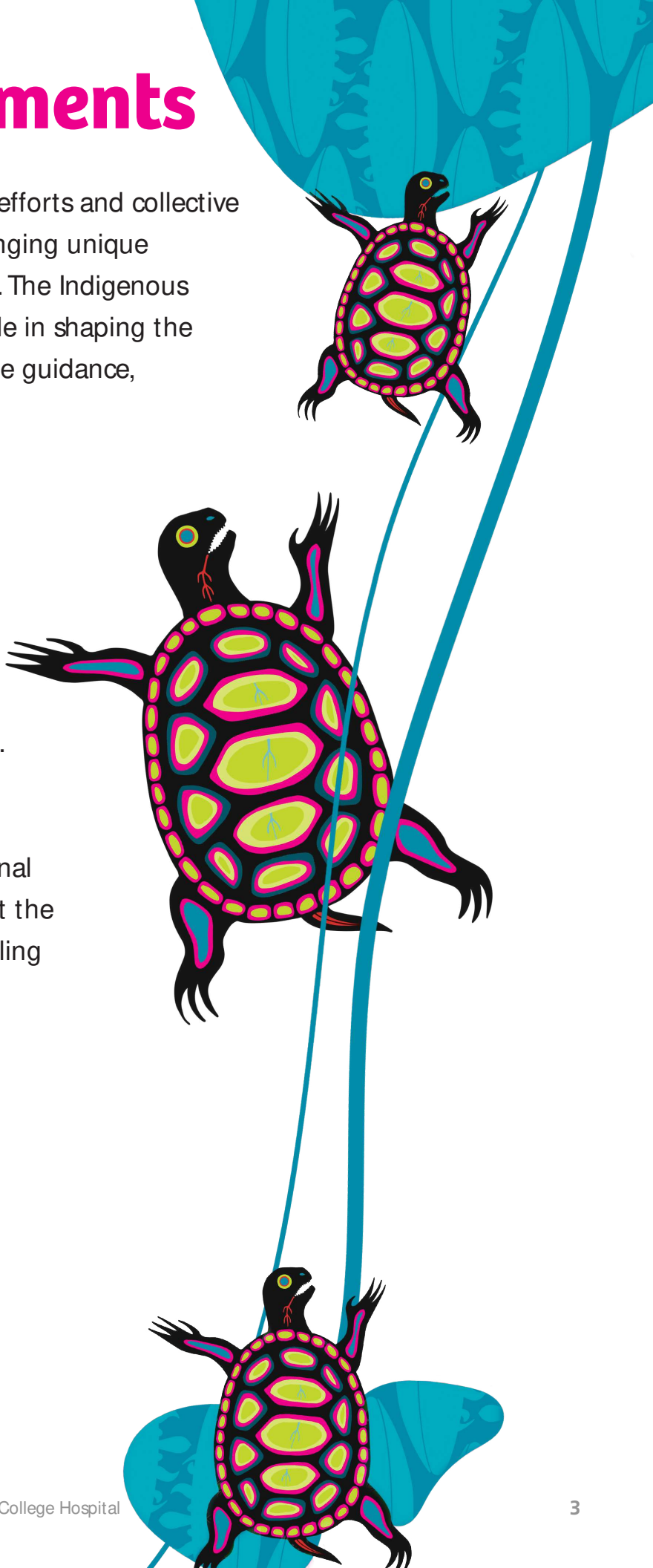
This document reflects the collaborative efforts and collective wisdom of several contributors, each bringing unique expertise and perspectives to the project. The Indigenous Circle of Experts (ICE) played a pivotal role in shaping the project's framework by offering invaluable guidance, technical expertise, cultural knowledge, and strategic insights.

The Project Co-Leads offered complementary expertise, steering the project's strategic direction and ensuring alignment with its objectives. The Author led the research and writing, ensuring the project's vision was realized.

Research Assistants supported essential data collection, analysis, and organizational tasks, while the Visual Storyteller brought the project's narrative to life through compelling design and storytelling.



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Acronyms

GGCWP-IH Ganawishkadawe Centre for Wise Practices in Indigenous Health
FNIHB First Nation Inuit Health Branch
ICE Indigenous Circle of Experts
ISC Indigenous Services Canada
TRC Truth and Reconciliation Commission
UNDRIP United Nations Declaration of Rights of Indigenous Peoples
WCH Women's College Hospital

What's New in Version 2.0

The original report was released on February 15, 2023. This updated version (Version 2.0) includes the following additions and enhancements:

Opening Reflection:
Remarks by Traditional Healer, Kahontakwas Diane Longboat, emphasizing the importance of relational accountability in transforming health and social systems.

Expanded Executive Summary:
Updated to summarize key barriers affecting the uptake and implementation of digital health solutions.

Refined and Expanded Recommendations Section:
Expanded focus on key areas, including pathways of accountability and the addition of broader considerations impacting the digital health landscape.

Expanded Conclusion:
Emphasizes the transformative potential of collaborative, community-driven evaluation approaches, highlighting their role in advancing equity, supporting Indigenous self-determination, and fostering sustainable health systems.

Visual Enhancements: Improved design elements and layouts to better align with the guiding principles of Indigenous collaboration and self-determination.

Opening Reflection: Transforming Systems Through Relational Accountability

“ Indigenous-specific racism and discrimination are systemic and continue to permeate every aspect of society—from housing and education to finance, social services, and the healthcare system. These remain among the greatest obstacles to addressing the health and wellness challenges faced within our communities and in urban centers as First Peoples of Turtle Island. The presence of structural inequities and chronic underfunding manifests in unequal access to care, culturally unsafe practices, and the erasure of First Nations, Inuit, and Métis governance and knowledge systems within health strategies and care practices. Racism and discrimination are foundational detriments to reconciliation.

Addressing and dismantling Indigenous (First Nations, Inuit, and Métis) specific racism and discrimination requires a willingness to engage in courageous collaboration. Collectively, we must remain intentional in avoiding the replication of the status quo, which serves only to maintain and perpetuate imbalances in power. This demands deep reflection on how policies, programs, and systems are designed, implemented, and evaluated, along with sustained accountability from institutions and individuals alike. Such undertakings should aim to repair, restore, and uplift connections across our Nations and communities—both urban and rural—while recognizing and respecting our roles and responsibilities in the shared stewardship of the health system. The cornerstone of this effort is a commitment to adopting an anti-racist approach that is deeply rooted in humility and affirms the citizens of First Nations, Métis, and Inuit as Rights Holders.

As members of sovereign nations, First Nations, Inuit, and Métis have the right to First Peoples-led health-care design and delivery. This principle affirms not only the inherent rights of First Peoples but also their ability to lead transformative change grounded in their governance systems and knowledge traditions. When efforts to pursue change fail to recognize the sovereignty of First Nations, Inuit, and Métis, they risk overlooking the historical and political contexts—including colonial modes of relating—that have produced and continue to perpetuate systemic marginalization. As a result, such efforts fall short of addressing root causes and combating racism.

A rights-based, community-centered approach to digital health evaluations underscores that First Peoples' worldviews and ways of being are not merely sources of data or information to be included. These worldviews offer transformative solutions that unsettle and challenge colonial paradigms by prioritizing holistic well-being. First Nations, Inuit, and Métis embody inherent, inalienable rights that, when exercised, support the wellness, health, and future of their communities. Respecting their sovereignty demands that First Peoples take the lead in shaping the use and governance of their data while ensuring that data practices reflect relational accountability to community leadership, priorities, and values.

Together, we must continue to find ways for all to heal from the wounds of the past, build and maintain mutually respectful relationships that honor and value each person's humanity and expertise, and foster trusting intergenerational relationships. If we are to be healthy today and into the future, we must challenge the boundaries of what is possible—not merely to improve the healthcare system but to transform it. This transformation requires bold commitments to equity, the dismantling of colonial structures, shared power, and the centering of First Peoples' leadership and sovereignty in shaping health futures."
~Kahontakwas Diane Longboat

Kahontakwas Diane Longboat, M.Ed., is Turtle Clan, a member of the Mohawk Nation, and a citizen of the Haudenosaunee Confederacy. A recognized ceremonial leader, teacher, and traditional healer, she is the founder of the Soul of the Mother Lodge in Six Nations of the Grand River. As a professional educator, she has taught nationally and internationally on Traditional Knowledge systems and the role of spirituality as a catalyst for innovation. Diane is the founder of the First Nations House—Office of Aboriginal Student Services and Programs—at the University of Toronto, where she served as its first Director. She currently serves as an Elder at CAMH and Senior Manager of Strategic Initiatives at Shkaabe Makwa, the Centre for First Nations, Inuit, and Métis Wellness.

Executive Summary

Background

The growing availability and adoption of digital health solutions are increasingly recognized as pivotal opportunities to drive innovation in community health governance and to address disparities in health outcomes across Indigenous communities. However, despite the broad acknowledgment of the need to engage users at multiple stages of development, implementation, and evaluation, many non-Indigenous decision-makers lack a nuanced understanding of the challenges faced by healthcare providers, program managers, and community leaders who rely on virtual care tools. These challenges include inconsistent internet connectivity, cultural and linguistic mismatches in digital tools, and insufficient training for healthcare providers in delivering culturally safe care. Addressing these barriers is essential to ensure that digital health solutions are both effective and equitable in supporting Indigenous communities.

Compounding these challenges are intersectional factors rooted in colonial legacies, such as geographic remoteness, socioeconomic disparities, and gendered experiences of health inequities, which necessitate tailored and multidimensional approaches to address the structural inequities perpetuated by colonial systems.

Developing effective, place- and nation-specific, culturally appropriate digital health solutions is essential to addressing these challenges. These solutions not only improve care delivery but also ensure that digital tools align with Indigenous priorities, languages, and knowledge systems. Achieving this requires moving beyond consultation to the genuine recognition of community needs and priorities, along with intentional efforts to create culturally responsive healthcare systems.

Despite this need, engagement at the policy level—particularly at the federal and provincial levels—remains primarily advisory. Indigenous leaders and experts are seldom afforded direct roles in decision-making processes, limiting their influence on policy. This lack of meaningful involvement undermines the credibility and effectiveness of evaluations used to inform policies that address the needs and priorities of Indigenous communities.

Embedding ethical principles into the design and implementation of digital health solutions requires centering Indigenous perspectives, upholding transparency, and fostering culturally informed, community-driven decision-making practices that respect sovereignty and self-determination.

To address these gaps, it is essential to establish mechanisms for equitable and sustained collaboration between Indigenous leaders and evaluators, improve digital infrastructure, and allocate funding to support community-driven innovation in health technologies. Respecting Indigenous data sovereignty is equally critical, ensuring that data is collected, managed, and utilized in alignment with community priorities and in ways that uphold self-determination.

Indigenous data sovereignty encompasses more than technical data management; it requires active collaboration in shaping data collection, analysis, and usage practices to ensure alignment with community values, priorities, and governance structures. Evaluations of digital health initiatives must include measurable outcomes defined by the community, such as improvements in culturally safe care delivery, health outcomes, and accountability within health systems.

Addressing disparities in digital infrastructure is essential for the success of digital health solutions. Investments should prioritize equitable access to reliable and affordable internet connectivity, particularly in rural and remote communities. Through meaningful engagement and structural reforms, digital health solutions can support Indigenous community health governance and contribute to more equitable health outcomes.

Objective

Recognizing these gaps, this report sets out several pragmatic and principled recommendations to guide the co-design of evaluations for digital health solutions, to enhance their credibility and usefulness while improving the health and well-being of Indigenous peoples. These recommendations aim to support agencies and individuals responsible for developing and implementing digital health strategies, policies, and programming that impact First Nations, Inuit, and Métis peoples in urban, rural, and remote settings. These recommendations address critical gaps, including the lack of culturally relevant evaluation frameworks, inadequate mechanisms for incorporating Indigenous perspectives, and the absence of long-term accountability in digital health policies.

The recommendations are guided by the recognition that many individuals and organizations undertaking evaluations require support to design and implement evaluations that align with locally defined priorities and needs, rather than focusing solely on meeting fiscal accountability requirements. This approach underscores the ethical responsibility of evaluators to engage with Indigenous communities in a manner that prioritizes respect, reciprocity, and accountability.

Furthermore, the recommendations affirm that First Nations, Inuit, and Métis Peoples are 'rights and title holders,' rather than 'stakeholders'—a principle reinforced by the Truth and Reconciliation Commission (TRC) of Canada's 94 Calls to Action and the Government of Canada's endorsement of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). These recommendations aim to bridge existing gaps in evaluation practices and provide actionable steps for creating culturally appropriate and community-centred digital health evaluations.

Methods

The recommendations were developed through a combination of an environmental scan, a review of relevant academic literature, and formal discussion circles with the Indigenous Circle of Experts (ICE). The environmental scan analyzed existing digital health initiatives, policies, and evaluation frameworks, identifying gaps and opportunities for culturally relevant approaches. The literature review incorporated qualitative and quantitative studies, focusing on Indigenous health governance, digital health strategies, and culturally safe practices.

The ICE is composed of Indigenous experts with diverse experience in health evaluation and digital health policies and programs at the provincial, regional, and local levels across urban, rural, and remote contexts. The ICE provided critical insights, drawing on lived experiences and professional expertise. Their contributions ensured that the recommendations are grounded in Indigenous governance principles and community-defined priorities. Facilitated by the Ganawishkadawe Centre for Wise Practices in Indigenous Health (GGCWP-IH), this approach honours the collective knowledge of Indigenous experts and the diversity of nations, place-based thought traditions, and communities.

Finally, the global term 'Indigenous' is used throughout this report. In the contexts discussed, it specifically refers to the governance structures and peoples of First Nations, Inuit, and Métis (FNIM).

Recommendations

Co-Define Priorities

Adopt an Indigenous-led or co-led approach to ensure the prioritization of Indigenous self-determination and establish evaluation priorities that address questions most relevant to Indigenous and non-Indigenous leaders and communities.

Commit to long-term partnerships that extend beyond the evaluation itself, ensuring continuous dialogue and collaboration to align evolving priorities with Indigenous aspirations.

Partner with relevant Indigenous community leaders, representatives, and experts who can identify pathways of accountability, community priorities, potential partnerships with other community experts, and appropriate evaluation approaches.

Establish Pathways of Accountability

Define the purposes of the evaluation, specifying which decision-making processes or activities the information gathered will be used to inform.

Appropriately budget and co-design the allocation of resources to ensure the initiative is well resourced and capable of supporting sustained community leadership and participation across all phases of work.

Ensure that evaluation practices, processes, and tools reflect local community contexts and respond to community-specific needs and environments, including the historical and-socio-political contexts in which a person, community, program, or policy operates.

Ensure all data gathered during the evaluation is owned, controlled, and managed by Indigenous communities, aligning with principles of Indigenous data sovereignty.

Work with Indigenous leaders to define success metrics that reflect their cultural, social, and economic priorities, rather than defaulting to standardized or external benchmarks.

Develop clear accountability mechanisms for monitoring the implementation of evaluation recommendations, ensuring that they lead to tangible changes in policy and practice.

Respect Indigenous Knowledge Systems

Ensure that evaluations adhere to local protocols, cultural practices, wisdom, and language systems, and that they suit the context of the policy or program.

Incorporate the expertise of Elders, Knowledge Keepers, and other local experts as co-creators of evaluation frameworks, ensuring that local ways of knowing are central to all phases of the work.

Embed culturally safe and trauma-informed approaches to ensure that evaluation processes are respectful, inclusive, and sensitive to historical injustices.

Co-identify methods, modes of analysis, knowledge exchange, and dissemination approaches that explicitly reflect the Indigenous contexts, skills, knowledge, and practicesof the communities where the evaluation occurs.

Broader Considerations

Invest in capacity-building initiatives that support Indigenous communities in leading evaluations and shaping governance structures in alignment with their sovereignty and priorities.

Co-design knowledge translation strategies with Indigenous communities to ensure findings are accessible, actionable, and tailored to specific community needs.

Ensure findings and recommendations from evaluations inform policy advocacy efforts aimed at advancing Indigenous rights, equity, and self-determination at local, provincial, and federal levels.

Align evaluation findings with existing policies and frameworks, such as the Truth and Reconciliation Commission's Calls to Action, to support systemic change.

Develop community-defined metrics for success that include qualitative and quantitative measures, such as improvements in cultural safety, community trust, and health outcomes.

1.0 Background

1.1 Indigenous Peoples Rights, Health Governance, and Reconciliation in Health Research and Evaluation in Canada

In 2008, the Truth and Reconciliation Commission (TRC) was established as part of the Indian Residential School Settlement Agreement. The Commission's mandate was to "reveal to Canadians the complex truth about the history and the ongoing legacy of church-run residential schools" and to "guide and inspire a process of truth and healing, leading toward reconciliation within Aboriginal families, and between Aboriginal peoples and non-Aboriginal communities, governments, and Canadians generally" (2015). The TRC's final report documents the widespread impact of systemic colonial assimilation policies and practices implemented by the Canadian government. These policies, both historical and ongoing, are identified as part of the colonial experience in Canada and as acts of cultural genocide against Indigenous Peoples, continuing to drive and reinforce social inequalities.

The establishment of the TRC reflects a growing acknowledgment of the profound harms caused by colonial policies and practices, including land dispossession, cultural genocide, and systemic discrimination. It marks a crucial step in the broader movement to address the long-standing impacts of settler-colonial structures on Indigenous communities.

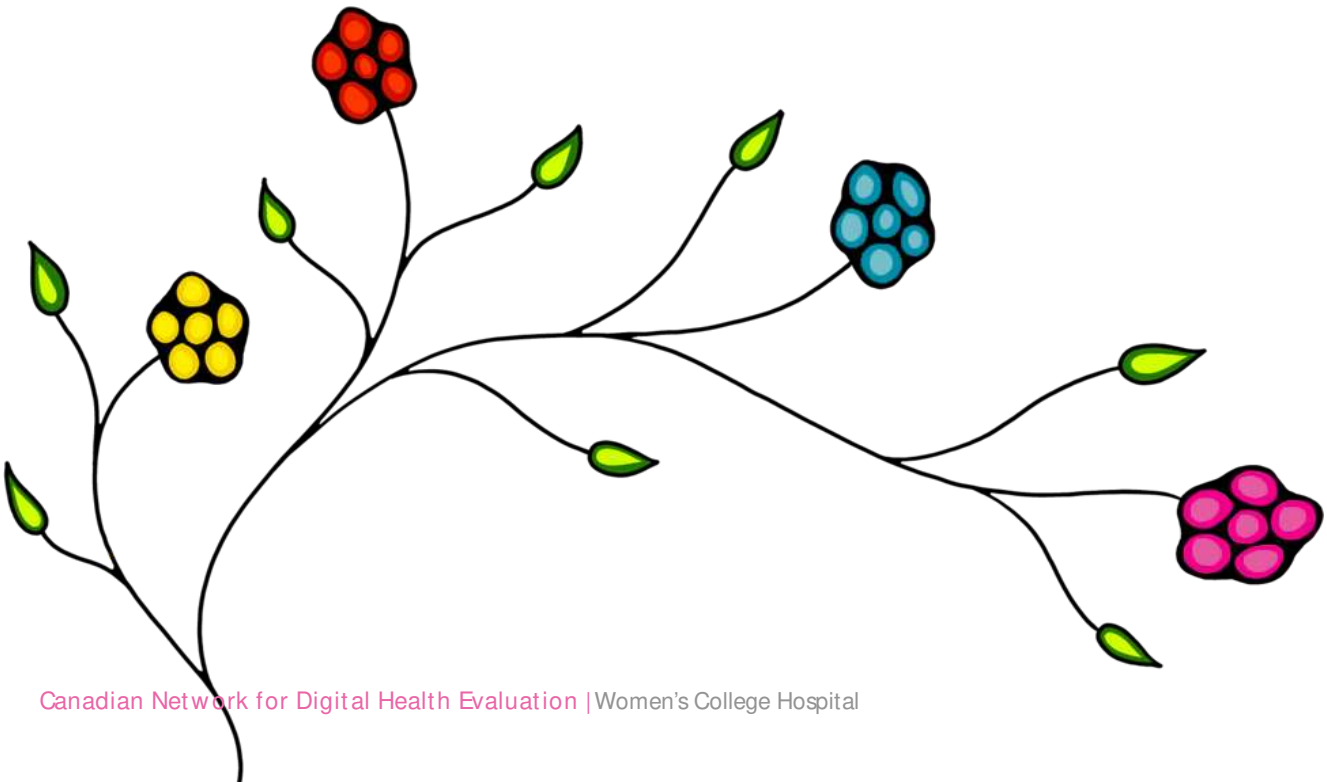
The TRC also released an executive summary with 94 recommendations, titled the "Calls to Action," covering broad themes such as justice, education, governance, and health. The Calls to Action aim to redress the legacy of residential schools and advance the process of Canadian reconciliation. Specific to health, recommendations 18-24 and 55 address systemic inequities, emphasizing the need for culturally safe health care, equitable access, and the inclusion of Indigenous perspectives in research and evaluation practices. These Calls to Action serve as a foundational step toward addressing structural inequities and ensuring that health systems are accountable to the needs and priorities of Indigenous Peoples. Many of these recommendations echoed the 440 recommendations outlined in the Report of the Royal Commission on Aboriginal Peoples (1996).

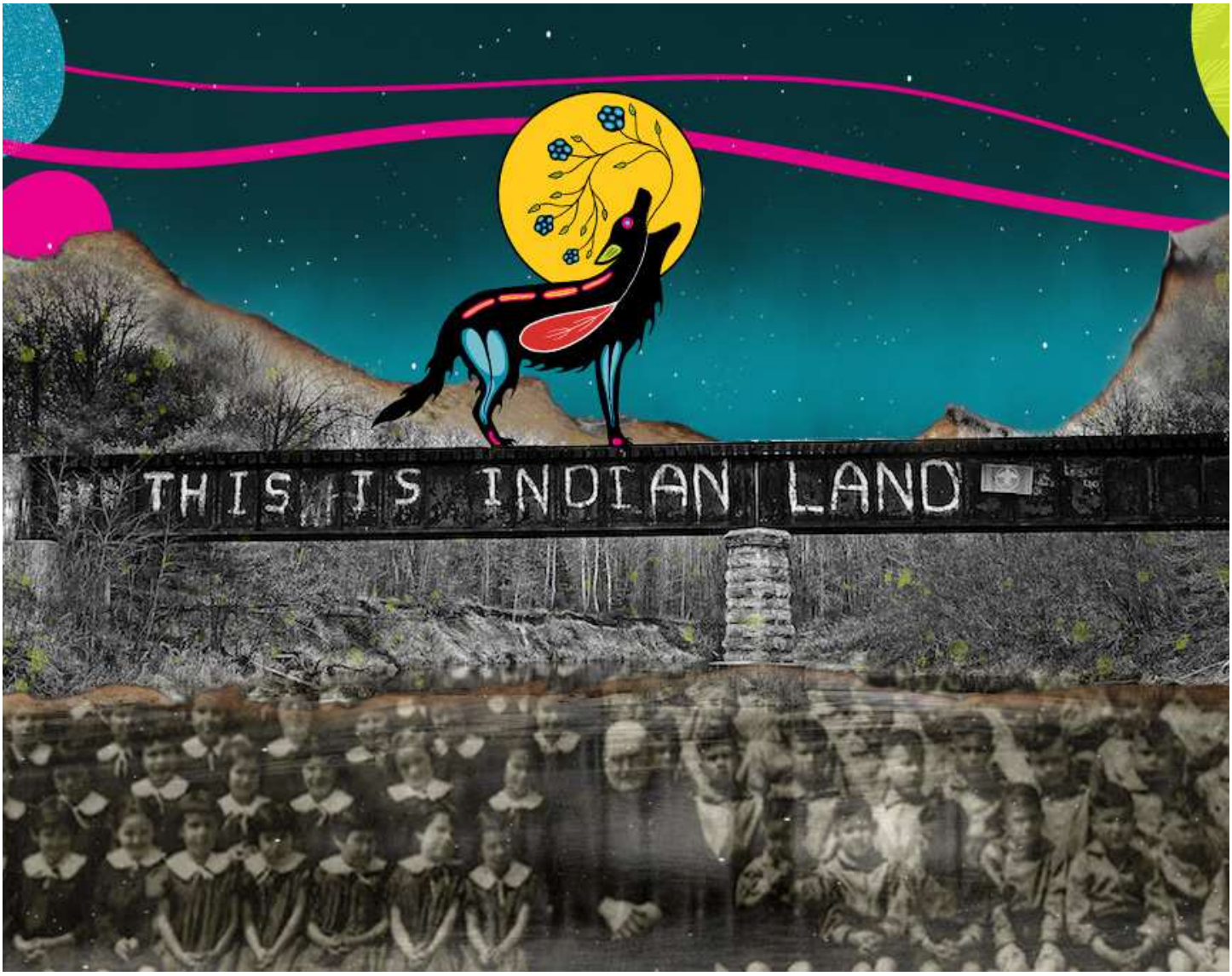
After decades of advocacy by Indigenous leadership and peoples, the Parliament of Canada passed the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) Act in 2021. The Act outlines Canada's obligation to uphold Indigenous Peoples' rights, including both Treaty and inherent rights, as affirmed by UNDRIP.

The declaration establishes an international standard for recognizing Indigenous Peoples' inherent rights, including their right to self-determine their own economic, social, cultural, and knowledge development. The Act acknowledges that the Canadian government has a responsibility to uphold Indigenous Peoples' individual and collective rights, including the right to design, implement, and maintain health institutions and systems. It also asserts their right to meaningful engagement in research and evaluations concerning these systems.

Despite their significance, the implementation of the TRC Calls to Action and the UNDRIP Act faces persistent challenges, including inadequate funding, fragmented accountability mechanisms, and resistance from institutions rooted in colonial systems. Addressing these barriers requires coordinated action and a long-term commitment. UNDRIP provides a critical framework to:

- **Inform the development of broader health care system policies that impact Indigenous nations and peoples**
- **Facilitate forums to advocate for strategic measures and resources to support community-led and culturally aligned health systems**
- **Generate innovation in health governance through respectful knowledge exchange**





The TRC's Calls to Action and the UNDRIP Act are complementary frameworks, jointly addressing the structural racism and systemic barriers that perpetuate health inequities across Indigenous communities. Both emphasize the centrality of Indigenous governance, leadership, and knowledge systems in developing solutions that reflect community-defined priorities. These frameworks also highlight the need to confront and redress the ongoing impacts of colonial violence, which continue to shape health systems and policies, reinforcing inequities and undermining Indigenous rights to self-determination and well-being.

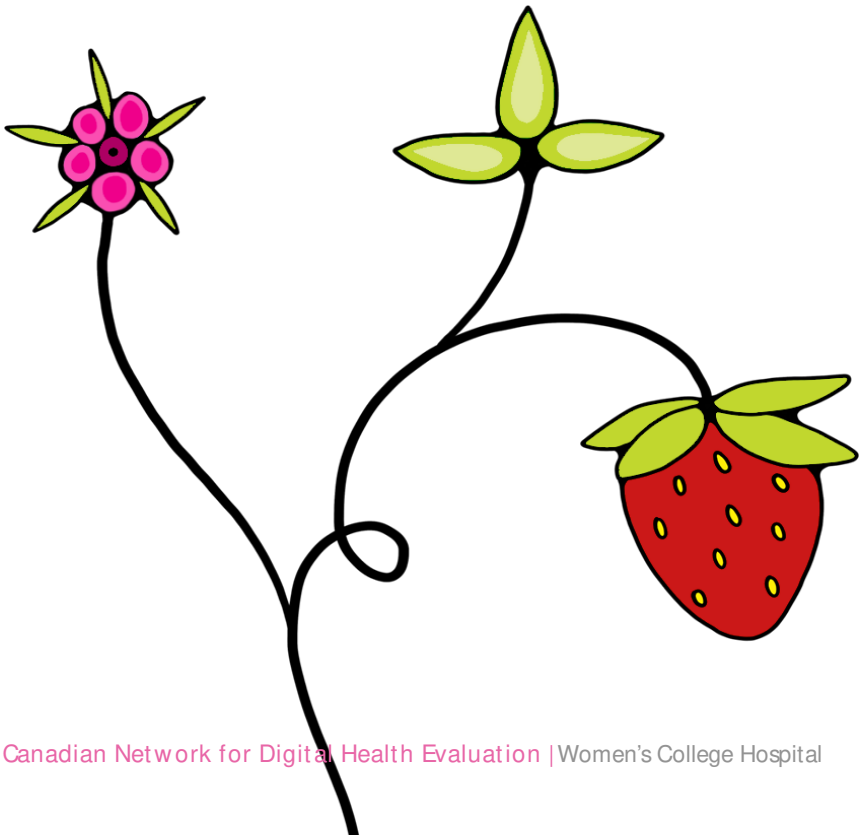
The UNDRIP Act reinforces that evaluation processes used to inform decision-making regarding programs and services tailored to or involving Indigenous Peoples must affirm Indigenous governance structures, center Indigenous priorities, and be treated as distinct from other forms of evaluation inquiry. The Act also underscores the importance of Indigenous governance in health systems, ensuring that policies, programs, and evaluations are developed in genuine partnership with Indigenous leaders. However, the successful implementation of these frameworks requires sustained effort, accountability, and resource allocation to ensure that the rights and priorities of Indigenous Peoples are respected and upheld.

1.2 Why Co-Design Health Evaluations?

Crucially, Indigenous experts—encompassing Elders, Knowledge Keepers, community leaders, health practitioners, researchers, and individuals with lived experience—have limited opportunities for meaningful participation in the planning, conducting, and reporting of digital health evaluations, particularly at the provincial and federal levels of governance. These experts bring diverse and invaluable cultural, historical, technical, and experiential knowledge that is essential for ensuring evaluations are culturally responsive, locally relevant, and methodologically robust.

Addressing this gap requires a shift toward a co-design approach to health evaluation. Unlike traditional evaluation methodologies, co-design emphasizes active collaboration and engagement throughout all phases of the evaluation cycle, including priority setting, design, implementation, and reporting. By grounding evaluations in processes that respect and reflect Indigenous governance structures, cultural protocols, and community-defined priorities, co-design offers a pathway for creating more equitable and impactful digital health solutions.

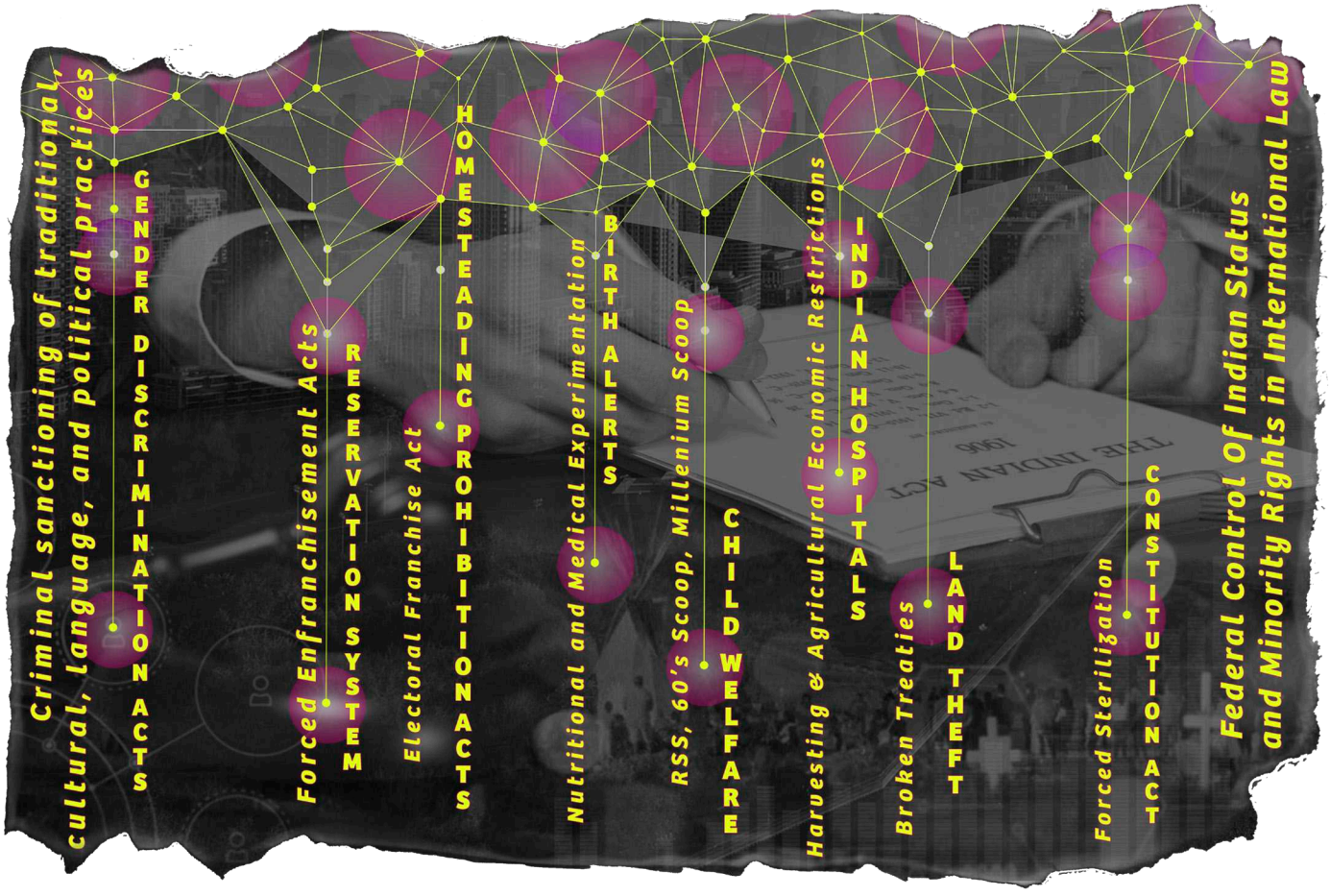
A co-design approach that respects and affirms Indigenous sovereignty also departs from conventional evaluation methodologies by prioritizing relationships, reciprocity, and mutual benefits over a narrow focus on outputs or fiscal accountabilities. By embedding community priorities into the evaluation process through genuine partnership, co-design promotes the development of frameworks that are both contextually relevant and culturally aligned. This shift is essential for producing data that holds shared value for both Indigenous and non-Indigenous decision-makers, fostering accountability, and supporting the development of policies and programs that contribute to equitable and sustainable health outcomes.



Embracing a co-design approach is not merely a methodological choice but an ethical imperative that recognizes the sovereignty, rights, and lived experiences of Indigenous Peoples. This approach aligns with broader policy commitments, including the Truth and Reconciliation Commission's Calls to Action and the UNDRIP Act, which emphasize the importance of Indigenous leadership and governance in health policy and evaluation. For example, co-design has been instrumental in initiatives focused on culturally safe telemedicine platforms and community-driven health data management systems, illustrating its potential for transformative impact.

However, the successful adoption of co-design requires addressing barriers such as limited funding, institutional resistance, and a lack of culturally competent evaluation frameworks, which often hinder meaningful collaboration. By fostering trust and building lasting partnerships, co-design not only improves the immediate relevance of digital health interventions but also strengthens the foundation for sustained systemic change and equity in health governance.

Ultimately, adopting a co-design approach to evaluating digital health solutions—one that affirms Indigenous sovereignty—has the potential to address systemic inequities, enhance the relevance and effectiveness of digital health interventions, and build stronger partnerships across the health system. This shift requires a sustained commitment to rethinking how evaluations are conceptualized, conducted, and utilized, challenging the status quo to ensure they become tools for accountability and meaningful change.



1.3 Addressing Systemic Barriers in Health Evaluation Frameworks

Partnering with First Nations, Inuit, and Métis (FNIM) communities in health research and policy requires recognizing the contested nature of jurisdictional authority in Canada. Governance, accountability, and decision-making structures remain shaped by colonial frameworks, historically excluding Indigenous governance systems from influencing health policies, research priorities, and evaluation methodologies. To build meaningful and reciprocal partnerships, it is essential to move beyond extractive consultation models and commit to co-governance structures that uphold Indigenous sovereignty and self-determination.

Jurisdictional negotiations directly impact Indigenous health and wellness, shaping evaluation processes and decision-making power over health programs, policies, and digital health innovations. Without a rights-based, equity-driven approach, evaluations risk perpetuating institutional power imbalances, reinforcing Western biomedical paradigms at the expense of Indigenous knowledge systems, healing practices, and governance priorities.

To ensure health evaluations are ethical and methodologically rigorous, partnerships with FNIM communities must be community-led, context-specific, and relational, rather than externally imposed. Across Canada, Indigenous-led health governance bodies demonstrate the effectiveness of self-determination models:

- **The First Nations Health Authority (FNHA) in British Columbia operates as the first province-wide, Indigenous-led health system, shifting governance from federal oversight to First Nations decision-making. FNHA integrates Indigenous knowledge into health programming and evaluation, setting a precedent for culturally relevant health assessments.**
- **The Inuit Tapiriit Kanatami (ITK) National Inuit Health Plan has developed policy frameworks reflecting Inuit-specific health priorities, ensuring evaluations measure community-defined health outcomes.**
- **The Nishnawbe Aski Nation (NAN) Health Transformation initiative in Northern Ontario advances Indigenous-led health policy, centering traditional healing practices and Indigenous knowledge in service delivery and program evaluation.**
- **The Métis Nation's health strategy initiatives focus on self-determined health policy, integrating Métis governance and culturally relevant health interventions into provincial and federal health programs.**
- **Regional FNIM-led health governance bodies, such as the Manitoba First Nations Health and Social Secretariat, lead health system transformation efforts, prioritizing Indigenous knowledge and data sovereignty.**

These initiatives underscore the necessity of shifting health governance and evaluation power to Indigenous authorities, ensuring assessments align with FNIM knowledge systems, health priorities, and data sovereignty principles.

This report provides guidance for health researchers, policymakers, and evaluation practitioners engaged in digital health strategy development, policy formation, and program evaluation affecting FNIM communities. By embedding FNIM governance principles and knowledge systems into health evaluation frameworks, partnerships can contribute to equitable, sustainable, and culturally responsive health outcomes.

The recommendations apply to external agencies, organizations, and individuals evaluating digital health strategies, policies, and programs affecting First Nations, Inuit, and Métis nations, communities, and peoples. While primarily designed for those developing, selecting, planning, conducting, and using evaluation frameworks, they are relevant to anyone evaluating digital health policies and programs focused on or serving Indigenous peoples, including:

Individuals who participate in interviews or surveys as part of an evaluation.

External evaluators conducting assessments in localized community contexts or programs designed to address the needs of Indigenous peoples.

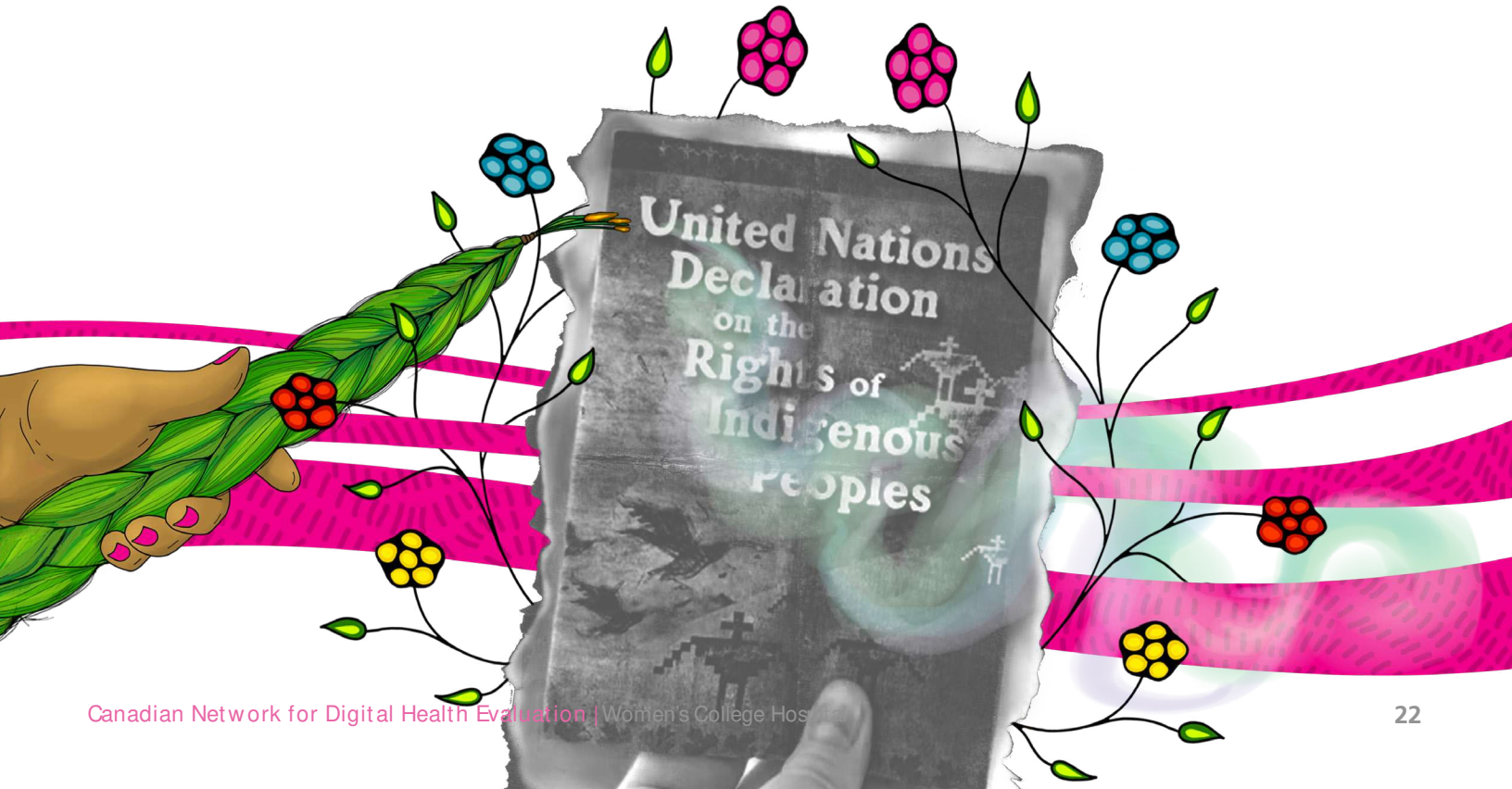
Service providers involved in delivering policies and programs, collecting data, identifying evaluation participants, or implementing recommendations from evaluations.

Evaluation users, such as decision-makers, policy and program administrators, and others responsible for designing and implementing policies and programs.

The recommendations align with broader frameworks, such as the Truth and Reconciliation Commission's Calls to Action and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) Act, emphasizing the importance of Indigenous leadership in decision-making. To ensure effective implementation, capacity-building initiatives are essential to equip evaluators, service providers, and policy administrators with the skills and knowledge to conduct evaluations that respect Indigenous governance and priorities.

Addressing systemic barriers—such as inadequate funding, institutional resistance, the devaluing of Indigenous wellness practices, and the lack of culturally competent evaluators—is critical for meaningful change. All evaluations should follow ethical guidelines that prioritize respect for Indigenous knowledge systems, cultural protocols, and data sovereignty. Adopting this approach ensures evaluations are conducted in culturally appropriate and respectful ways, fostering equitable outcomes for Indigenous communities.

Indigenous leadership must play a central role in defining scope, priorities, and methodologies of evaluations to ensure alignment with community-defined goals and governance structures. By embedding ethical principles, addressing systemic barriers, and prioritizing capacity-building efforts, evaluations can become powerful tools for accountability and transformative change.



1.4 Objectives

The principled recommendations seek to enhance the well-being of Indigenous peoples by ensuring that digital health solutions, policies, and program decisions are informed by robust, high-quality, authentic, and meaningful evaluation evidence that respects Indigenous sovereignty, nation-specific values, cultural practices, and knowledge systems. Evaluations of digital health solutions, policies, and programs, as well as the use of virtual care tools within community contexts and across Indigenous health programs, should contribute to a relevant and valuable body of evidence that both Indigenous leaders and non-Indigenous actors can confidently use to support decision-making and advance equitable health outcomes.

Evaluations must prioritize ethical integrity by adhering to cultural protocols, respecting Indigenous data sovereignty, and ensuring that processes are transparent, inclusive, and reciprocal. An Indigenous-led or co-designed partnered approach to evaluation can improve the effectiveness of digital health policies and programs, and the health and well-being of Indigenous peoples, by:

Centering place-based and nation-specific perspectives, priorities, and knowledge systems at all stages of evaluation and levels of governance.

Fostering a culture of evaluation that respects Indigenous worldviews and values.

Emphasizing the transformative potential of evaluation practices to drive meaningful and sustainable change across the health care system.

Promoting a rights-based, nation-specific approach to priority setting and evaluating digital health policies and programs affecting Indigenous peoples. By embedding nation-specific perspectives and Indigenous governance systems into evaluation practices, the findings can guide the development of long-term strategies that address systemic inequities and foster enduring health improvements. Capacity-building initiatives are essential to support Indigenous communities in leading evaluations, analyzing data, and using findings to inform their health governance strategies. Knowledge translation strategies must also be co-designed to ensure findings are accessible and actionable, with dissemination methods that reflect Indigenous cultural practices and communication preferences.

2.0 Methods

To develop the principled recommendations, the Ganawishkadawe Centre for Wise Practices in Indigenous Health (GCWP-IH), located at Women's College Hospital (WCH), engaged extensively and worked collaboratively with Indigenous leaders, experts, and community members involved in administering, delivering, and evaluating digital health policies and programs. This collaborative approach aimed to identify the strengths and weaknesses of current arrangements and determine how meaningful engagement could improve the evaluation of digital health policies and programs, enhancing the health and wellness of Indigenous peoples.

The principled recommendations are grounded in a comprehensive process of engagement, research, and collaboration, including:

Insights from Indigenous Experts and Stakeholders: Input from Indigenous experts, organizations, government agencies, and individuals involved in evaluations, focusing on their experiences, areas for improvement, and how assessment findings could be better utilized to enhance digital health policies and programs impacting Indigenous peoples.

Environmental Scan of Wise Practices: An analysis of Indigenous health evaluation approaches, ethics and research guidelines, evaluation strategies, and governance processes for digital health solution design and implementation. This scan informed the recommendations by highlighting effective practices and frameworks.

Discussion Circles with the Indigenous Circle of Experts (ICE): Discussions facilitated by the GCWP-IH to establish evaluation priorities for digital health, bringing together a diverse range of expertise. These collaborative dialogues emphasized the importance of Indigenous perspectives in shaping evaluation processes.

Through this process, the GCWP-IH developed recommendations that reflect the insights and expertise of Indigenous leaders and communities and aim to center their priorities while addressing systemic gaps in digital health evaluation. These recommendations seek to foster socio-political and culturally responsive digital health solutions that advance wellness and uphold the rights of Indigenous peoples.

3.0 Results

Overall, there is an expressed need for meaningful, sustained collaboration between relevant and representative Indigenous community leaders and non-Indigenous decision-makers at all levels of healthcare system governance. While there have been notable advancements in evaluation practices, including the increased inclusion of culturally responsive performance dimensions and holistic indicators, these improvements have yet to fully address the systemic challenges in health evaluation for Indigenous communities. Emphasizing the affirmation of Indigenous sovereignty helps ensure that evaluations are both methodologically sound and culturally aligned with the values and priorities of Indigenous communities.

Evaluations can sometimes lead to challenging experiences for Indigenous community leaders, representatives, and members when they prioritize Western methodologies and externally defined priorities over community-driven approaches. This misalignment with Indigenous ways of knowing may inadvertently overlook or misrepresent the experiences, priorities, and needs of Indigenous communities.

Additionally, many individuals involved in developing and administering evaluations may lack a comprehensive understanding of the governance landscape surrounding Indigenous-specific health programming. Limited awareness of jurisdictional complexities and varying levels of community control over healthcare delivery—shaped by transfer agreements with government bodies such as the First Nations and Inuit Health Branch (FNIHB) and Indigenous Services Canada (ISC)—can affect program implementation and outcomes. These factors may contribute to evaluation fatigue and risk producing results that fail to reflect community priorities, perpetuate systemic inequities, and reinforce deficit-based narratives about health outcomes.

Respect for Indigenous data sovereignty is critical to ensuring that data collected through evaluations is managed and controlled by Indigenous communities, aligning with their governance structures and cultural priorities. Capacity-building initiatives should also support Indigenous communities in developing the expertise and resources necessary to lead evaluations, analyze findings, and use data to inform their own governance and decision-making processes.

Determining the right questions to ask and identifying key dimensions to measure are critical steps for producing data that are actionable and meaningful to diverse decision-makers. Such data should support efforts to address persistent health disparities shaped by complex administrative processes and historical inequities. To ensure data quality and relevance, evaluation priorities should be systematically identified based on the needs and priorities of the communities involved, including the policy or program's ability to meet specific goals, as well as the timelines and resources available for evaluation.

Commission's Calls to Action and the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP), emphasizing Indigenous leadership and governance in health reform. Adopting these approaches fosters the transformation of health systems to be equitable, sustainable, and reflective of Indigenous knowledge and governance.

3.1 Centering Indigenous Knowledge and Expertise

Centering Indigenous perspectives, worldviews, and knowledge is fundamental to improving health and wellness outcomes for Indigenous peoples and ensuring evaluation practices are relevant and responsive to community priorities. This principle underpins the recommendations outlined in this report.

Indigenous values, knowledge, and lived experiences must inform both what is evaluated and how evaluations are conducted to ensure that digital health policies and programs address community-specific and localized needs.

This nation-based distinctions approach recognizes Indigenous governance structures, cultural diversity (including languages, knowledge systems, and histories), and the ongoing impacts of colonial policies on health and wellness. It emphasizes Indigenous self-determination and aligns with the UNDRIP Act and the TRC Calls to Action by urging agencies and organizations to engage meaningfully with Indigenous leadership and adapt to local contexts.

Indigenous-led health organizations, with their established research protocols and evaluation practices, are well-positioned to define mutual expectations, data governance, methodologies, resource requirements, and the roles of community members. By integrating localized needs, these evaluations can reflect community priorities and advance health and wellness in culturally aligned ways.

3.2 Using the Guiding Principles in Practice

In practice, this guiding principle means:

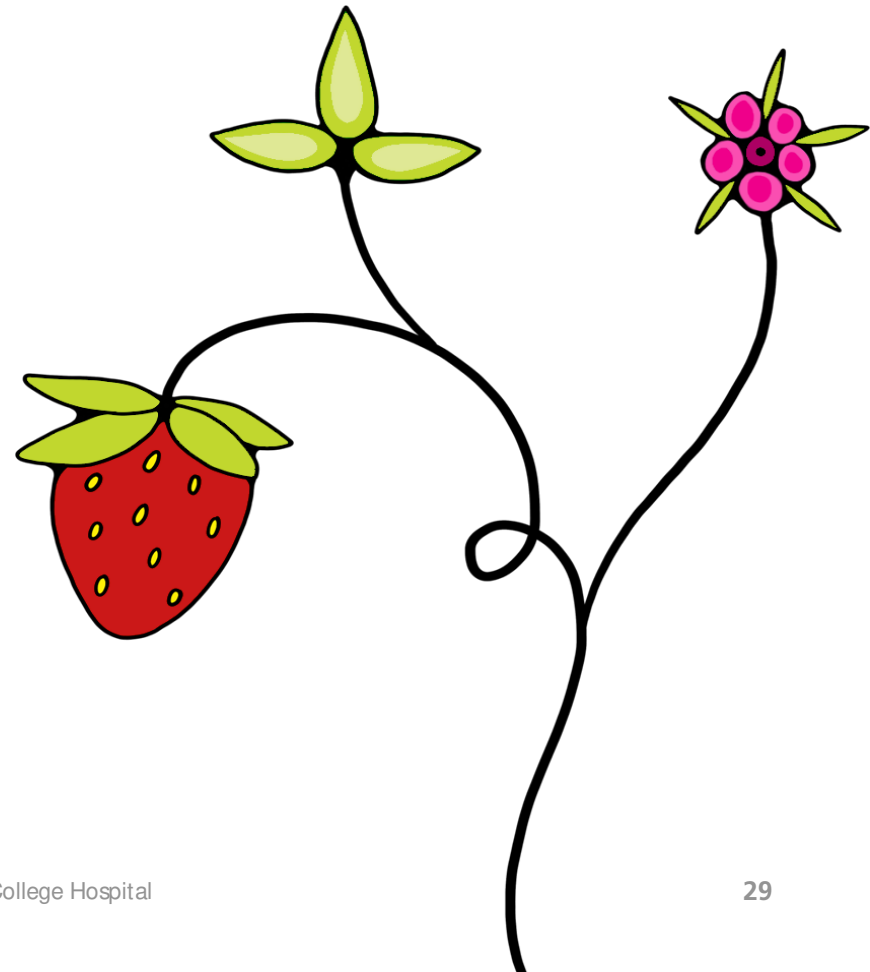
- Evaluations focus on the priorities identified by relevant Indigenous community leaders, representatives, and governance bodies.
- External agencies and experts engage meaningfully and consistently with Indigenous leaders and experts to assess the impacts of policies and programs on Indigenous peoples.
- Indigenous leaders, organizations, and community members define their roles and levels of involvement in evaluations.
- Evaluators complete accredited training to ensure they understand their responsibilities and accountabilities when collaborating with Indigenous communities.
- Evaluation practices align with the TRC's Calls to Action, support reconciliation, and uphold the principles of self-determination in the UNDRIP Act.
- Evaluation processes strengthen the capacities of Indigenous-led organizations at regional, territorial, and local levels to advance Indigenous health and wellness.

4.0 Discussion

4.1 Respecting Self-Determination: The Guiding Principle for Recommendations

The guiding principle aspires to define wise practices in action and provide considerations for all actors involved in evaluating digital health strategies, policies, and programs. It allows for flexibility to tailor evaluations to specific contexts, including policies, programs, Indigenous governance protocols, and community-defined priorities. Beyond evaluation, these principles can also guide priority setting, knowledge exchange, and translation, fostering a more responsive and equitable digital health ecosystem.

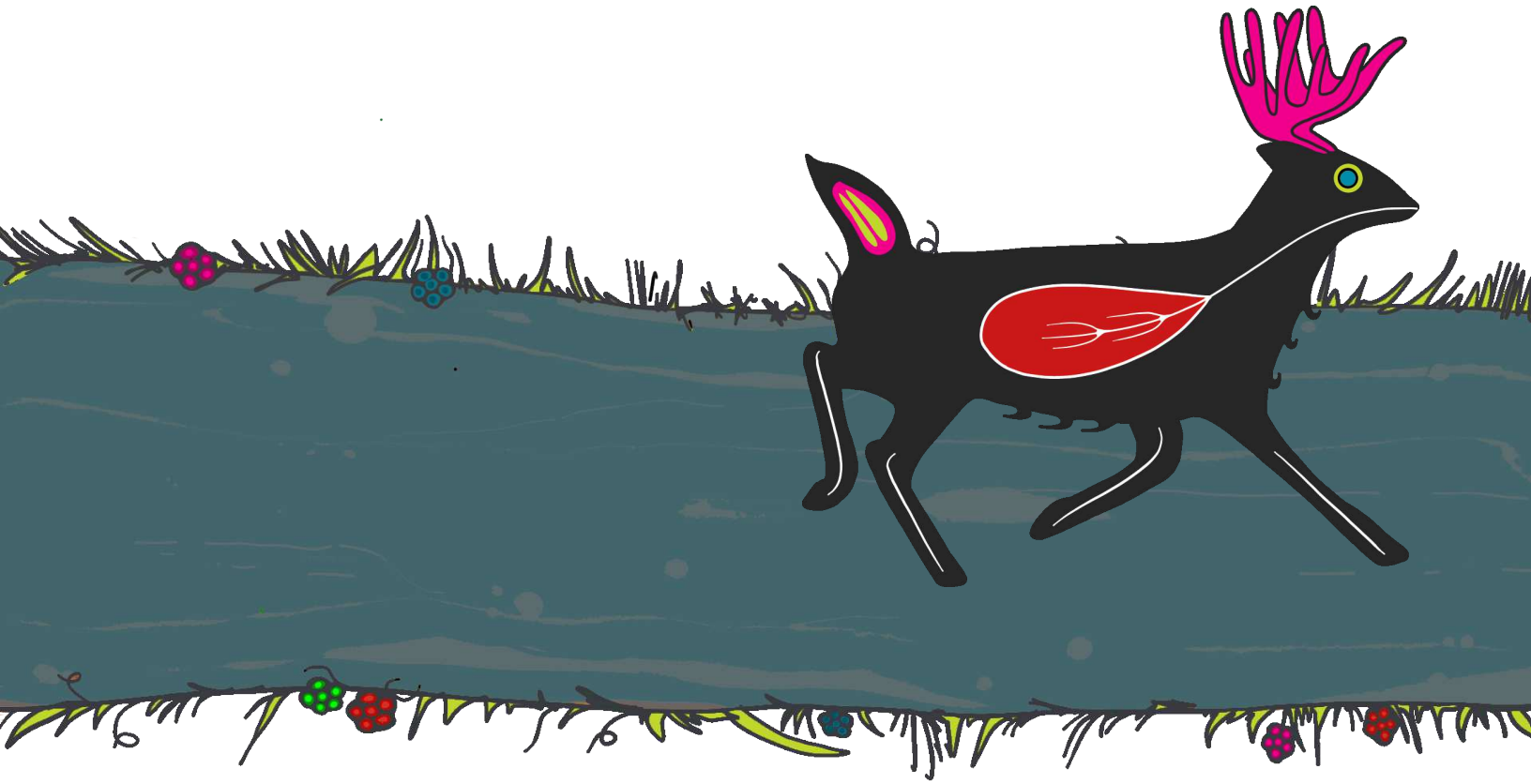
The overarching principle grounding these recommendations is a rights-based approach that centers the diversity of Indigenous perspectives, priorities, and knowledge systems. It acknowledges the strengths and diversity of Indigenous nations, community knowledge, and cultures while addressing the ongoing impacts of colonialism, including systemic exclusion of Indigenous governance structures and the undervaluing of community-based expertise. By foregrounding these realities, the principles aim to disrupt entrenched inequities and promote equitable practices in digital health evaluations.



At its core, this guiding principle emphasizes fostering meaningful partnerships with Indigenous decision-makers, leaders, and organizations. These partnerships collaboratively define strategies, set policy and program objectives, develop evaluation questions, determine methodologies, and establish processes for interpreting and sharing findings. They also build capacity within Indigenous communities, supporting leaders and organizations in driving evaluations aligned with their governance structures and cultural frameworks. This principle serves as a lens for interpreting other aims—commonly used in Western evaluation frameworks, such as improving health outcomes, enhancing experiences for patients and providers, managing costs, and promoting health equity.

By embedding Indigenous governance protocols and community-defined priorities into evaluation works, this approach offers a transformative model for inclusive and just health innovation. It emphasizes relational accountability, mutual learning, and shared decision-making, creating a foundation for sustainable digital health strategies that honour the rights and wisdom of Indigenous communities. Knowledge-sharing efforts should reflect Indigenous cultural practices, ensuring findings are accessible, relevant, and actionable.

Achieving these aspirations requires addressing systemic barriers, including fragmented jurisdictional authority, inadequate funding for Indigenous-led initiatives, and institutional resistance to culturally informed practices. Breaking down these barriers is critical to unlocking the transformative potential of this model, which benefits Indigenous communities and provides a blueprint for addressing systemic inequities in health systems more broadly. Community-driven innovations grounded in local solutions enhance cultural safety, improve health outcomes, and create stronger, more inclusive health systems for all.

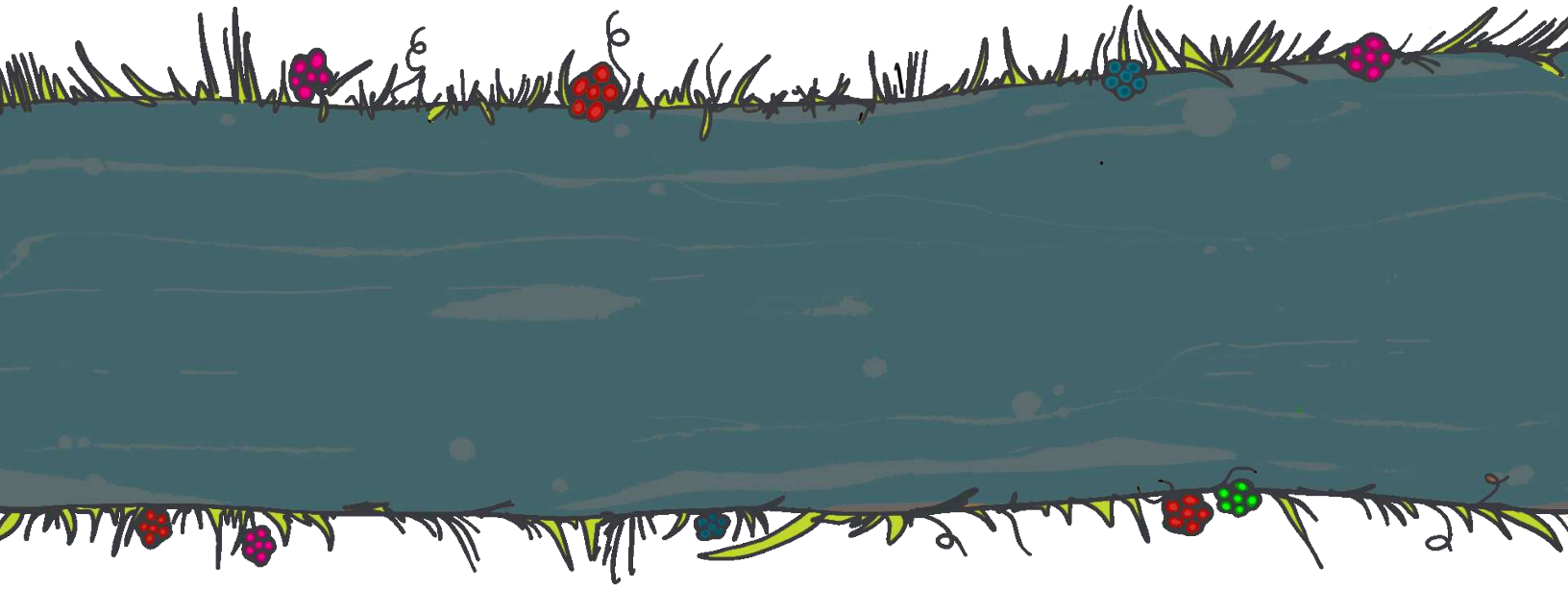


5.0 Recommendations

Engaging in meaningful partnerships for co-creating knowledge requires adequate resources, commitment, and effort. These recommendations outline practical components for building respectful working relationships, facilitating knowledge exchange, and advancing collaborative, community-driven approaches to evaluating digital health solutions. They emphasize shared accountability and reciprocity in developing policies and practices grounded in meaningful partnerships.

Effective partnerships must be rooted in an understanding of the cultural, historical, and socio-political contexts of the communities involved, ensuring evaluation processes are locally relevant and culturally aligned. Capacity-building initiatives should prioritize equipping Indigenous communities and organizations to lead evaluations, define priorities, and manage processes in alignment with their governance structures and cultural protocols. Grounded in ethical accountability to Indigenous Peoples, these recommendations also serve those relying on evaluations to guide evidence-based decisions about programming and services affecting Indigenous communities.

Overcoming systemic barriers—such as insufficient funding, resource limitations, and institutional resistance to culturally responsive methodologies—is essential. A co-designed approach ensures that evaluation findings are clear, practical, and aligned with the needs and priorities of the communities being served. This approach strengthens partnerships and supports the development of sustainable, transformative digital health solutions that reflect the rights, aspirations, and expertise of Indigenous Peoples.



Co-Define Priorities

Adopt an Indigenous-led or co-led approach to ensure the prioritization of Indigenous self-determination and establish evaluation priorities that address questions most relevant to Indigenous and non-Indigenous leaders and communities.

Commit to long-term partnerships that extend beyond the evaluation itself, ensuring continuous dialogue and collaboration to align evolving priorities with Indigenous aspirations.

Partner with relevant Indigenous community leaders, representatives, and experts who can identify pathways of accountability, community priorities, potential partnerships with other community experts, and appropriate evaluation approaches.

Establish Pathways of Accountability

Define the purposes of the evaluation, specifying which decision-making processes or activities the information gathered will be used to inform.

Appropriately budget and co-design the allocation of resources to ensure the initiative is well resourced and capable of supporting sustained community leadership and participation across all phases of work.

Ensure that evaluation practices, processes, and tools reflect local community contexts and respond to community-specific needs and environments, including the historical and-socio-political contexts in which a person, community, program, or policy operates.

Ensure all data gathered during the evaluation is owned, controlled, and managed by Indigenous communities, aligning with principles of Indigenous data sovereignty.

Work with Indigenous leaders to define success metrics that reflect their cultural, social, and economic priorities, rather than defaulting to standardized or external benchmarks.

Develop clear accountability mechanisms for monitoring the implementation of evaluation recommendations, ensuring that they lead to tangible changes in policy and practice.

Respect Indigenous Knowledge Systems

Ensure that evaluations adhere to local protocols, cultural practices, wisdom, and language systems, and that they suit the context of the policy or program.

Incorporate the expertise of Elders, Knowledge Keepers, and other local experts as co-creators of evaluation frameworks, ensuring that local ways of knowing are central to all phases of the work.

Embed culturally safe and trauma-informed approaches to ensure that evaluation processes are respectful, inclusive, and sensitive to historical injustices.

Co-identify methods, modes of analysis, knowledge exchange, and dissemination approaches that explicitly reflect the Indigenous contexts, skills, knowledge, and practicesof the communities where the evaluation occurs.

Broader Considerations

Invest in capacity-building initiatives that support Indigenous communities in leading evaluations and shaping governance structures in alignment with their sovereignty and priorities.

Co-design knowledge translation strategies with Indigenous communities to ensure findings are accessible, actionable, and tailored to specific community needs.

Ensure findings and recommendations from evaluations inform policy advocacy efforts aimed at advancing Indigenous rights, equity, and self-determination at local, provincial, and federal levels.

Align evaluation findings with existing policies and frameworks, such as the Truth and Reconciliation Commission's Calls to Action, to support systemic change.

Develop community-defined metrics for success that include qualitative and quantitative measures, such as improvements in cultural safety, community trust, and health outcomes.

6.0 Conclusion

This report provides principled recommendations for meaningfully engaging First Nations, Inuit, and Métis experts and representatives in the co-development of evaluations for digital health solutions. These recommendations aim to establish collaborative evaluation practices by respecting self-determination. Indigenous leadership is essential to ensuring that evaluations are not only methodologically sound but also reflective of the needs, priorities, and aspirations of Indigenous communities. By centering Indigenous leadership and perspectives, these practices strengthen the local relevance and effectiveness of digital health solutions while fostering respectful partnerships within the health system.

Building on this foundation, the recommendations also aim to address systemic inequities and ensure that digital health solutions align with the needs and goals of Indigenous communities. This approach represents an important step toward reconciliation by affirming self-determination. The recommendations align with the Truth and Reconciliation Commission's Calls to Action and the principles outlined in the United Nations Declaration on the Rights of Indigenous Peoples, highlighting the importance of systemic change within health systems.

Addressing systemic barriers—such as resource limitations, jurisdictional complexities, systemic anti-Indigenous racism, and institutional biases—requires acknowledging their colonial origins and confronting their impact on evaluation processes. This includes dismantling the pervasive naturalization and normalization of colonial deficit narratives that frame Indigenous communities through a lens of lack or failure. Reflecting and affirming Indigenous priorities, governance, and knowledge systems in evaluations requires shared effort and collaboration to support community-driven approaches and create equitable, culturally grounded health systems.