

# Integrating Indigenous Ways of Knowing Into Learning Health Systems: Moving From Learning Health Systems to Learning Communities

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## Keywords

Indigenous, youth, mental health, wellness, learning health system, learning community, integrated youth services

In Canada, various health organizations, research bodies and funders at the federal and provincial levels have been supporting learning health system (LHS) initiatives, including in youth mental health.<sup>1,2</sup> LHS are health networks that continuously self-study, adapt and improve health services by leveraging routinely collected clinical data and research data and engaging partners in identifying shared problems, co-designing solutions, and accelerating changes in practices and policy.<sup>3,4</sup> LHS continuously cycle from practice to data (services generate data for learning); data to knowledge (data is analyzed to generate insights); and knowledge to practice (knowledge is applied to enhance practice and policy). An important gap in the literature and in practice is the integration of Indigenous wisdom and ways of knowing in the LHS approach, which we begin addressing in this article. The authors are an Elder, a national Indigenous organization leader, and Indigenous and non-Indigenous researchers and clinician-scientists, who are part of the ACCESS Open Minds Indigenous Youth Mental Health and Wellness Network (a Canadian Institute of Health Research-funded national LHS network).

As we began conceptualizing what an LHS means, the Network's Indigenous Advisors immediately highlighted that, "our communities have forever been learning and sharing." Our discussions highlighted the need for LHS approaches to privilege and understand Indigenous ways of knowledge gathering and sharing through multi-generational perspective taking. Such a perspective emphasizes the importance of learning from the past and considers the effects of current decisions not only for the present but also for

generations to come. Network advisors reinforced a distinctions-based approach to data collection and governance that is rooted in, and celebrates the differences between and within First Nations, Inuit and Métis knowledge and community systems. It is important to recognize that each Nation or community holds unique ways of knowing and being, shaped by land, history and relationships. Building on this, a LHS in diverse Indigenous contexts (e.g., Indigenous communities, organizations and urban settings that serve Indigenous

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youths) may best be viewed instead as a Learning Community. For many Indigenous communities, the term “system” can be associated with previous and ongoing colonial structures that cause harm, and top-down approaches which impose decision-making. Learning Communities, on the other hand, centre communities and their right to self-determination. While the key focus of a youth mental health LHS is health service improvement, the focus of a Learning Community in Indigenous contexts is on youth wellness, recognizing youth as current and future leaders. Additionally, while many LHS require unity in terms of goals, defined outcomes and/or pathways to change, a Learning Community recognizes that different contexts may have different perspectives and values regarding their goals, outcomes and change.

Although our conceptualization aligns with that of “learning healthcare communities” which have more recently been proposed and which embed community engagement into the core LHS model to reduce inequities,<sup>5</sup> a fundamental difference is that it shifts the focus beyond formal health systems and even “health” narrowly defined. Our notion of Learning Community emphasizes the need for and value of community-wide and wholistic approaches to wellness, by integrating Indigenous culturally-based supports and identity-affirming approaches with clinical/formal services. Below we outline considerations for integrating Indigenous knowledge in co-creating Learning Communities with and for Indigenous communities, based on multiple exchanges among network members, the broader literature and practice. We use the metaphor of berry harvesting to illustrate how Indigenous communities have always engaged in exchanging knowledge and experiences. This metaphor extends Michell’s<sup>6</sup> use of gathering berries as a metaphor for community-based research with Indigenous Peoples. While berry harvesting is a significant cultural practice that contributes to wholistic wellness for many Indigenous Peoples and communities, we recognize and celebrate the diversity of practices in berry harvesting (and Indigenous communities).

### **Berry Harvesting as a Metaphor for an Indigenous Learning Community**

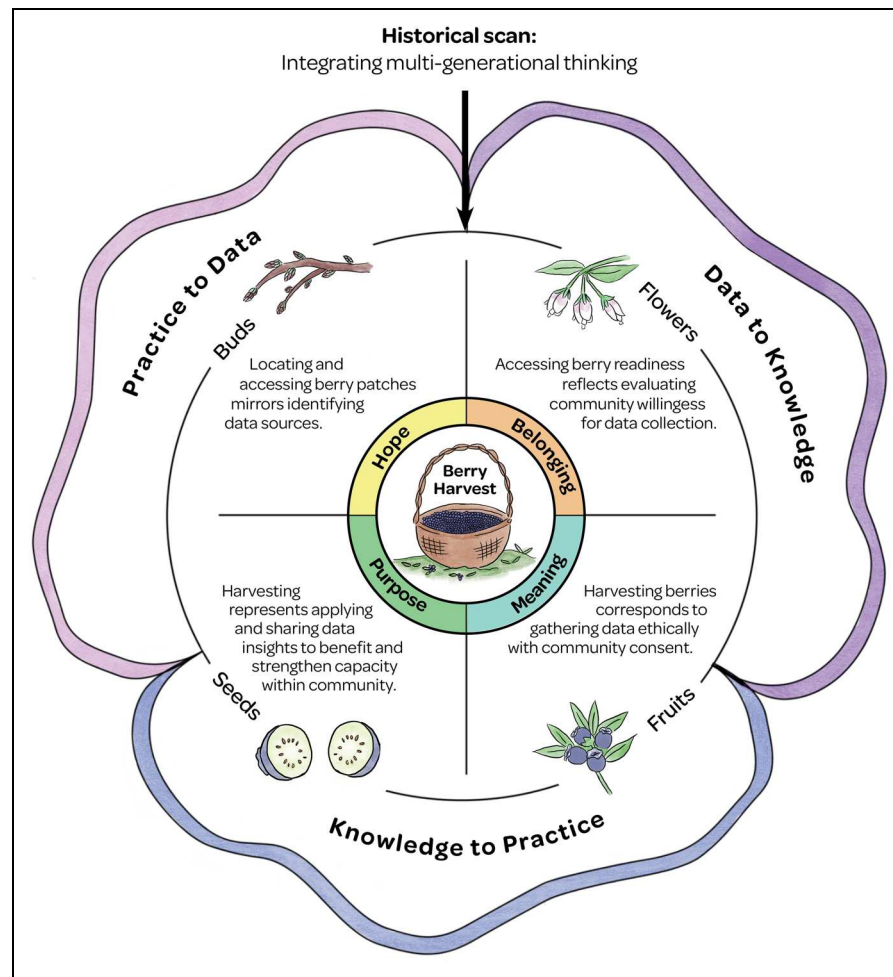
Harvesting reflects stewardship, reciprocity and the responsibility to gather and share resources in a sustainable, community-focused manner, principles central to ethical data governance with Indigenous communities. Berry harvesting, a specific medicine harvesting activity, parallels the stages of data collection and governance (Figure 1). Locating and accessing berry patches mirror identifying data sources. Like berries, data (or potential data) may be abundantly present. There are also different data sources (e.g., surveys, interviews, stories, photographs, artefacts), like there are different berry varieties. Regardless of presence, abundance or type, harvesting berries or using data should only be done when there is a purpose or a need:

*what are we going to do with this berry? How will this berry harvest be used or shared?* The location and condition of berries represent the diverse contextual and cultural factors to consider when partnering with Indigenous communities through a Learning Community approach. Like berry harvesting, data collection requires identifying and using data (berries) at the right time and thus begins with visiting and respectfully partnering with Indigenous communities. Assessing berry readiness reflects evaluating community readiness for data collection. Harvesting berries corresponds to gathering data ethically with community consent, ensuring one only takes what one needs. This emphasizes understanding the meaning behind why one is gathering data (berries) and that some learnings (berries) can be shared immediately, while other insights might ripen later into insights or inspire future growth. Sharing the harvest represents applying and sharing data insights to benefit the community. Throughout, we return to this metaphor.

### **Learning Communities That Integrate Multi-Generational Thinking**

Some core values that have been reported across LHS include accessibility, adaptability, cooperative and participatory leadership, shared accountability, inclusiveness and privacy.<sup>1</sup> While these values may be relevant across contexts, integrating LHS within Indigenous contexts requires further consideration. An environmental scan of LHS in Indigenous communities identified that community partnerships are critical, which entail time and resources to build relationships, co-create knowledge and respond to the priorities and values of Indigenous communities.<sup>7</sup> Our network has created a conceptual framework for fostering and maintaining trust with Indigenous youths and community partners that weaves in Indigenous research principles of self-determination, cultural humility, and respect, responsibility, relevancy, reciprocity and resources.<sup>8</sup> By using berry harvesting as a metaphor, we can appreciate the delicate and ongoing effort required to build and sustain trust, integral to building Learning Communities with and for Indigenous communities.

Guided by Indigenous teachings of multi-generational perspective-taking, we recognize the importance of considering the generational effects of our decisions. In planning and implementing the continuous LHS cycle (Figure 1), we encourage reflection on both the past and the future. We share reflective questions for decision-makers and mental health providers to consider as they develop and implement LHSs such as, “*How will the decisions we make now affect future generations?*”; and “*In what ways have past decisions shaped our present-day circumstances?*.” These questions not only integrate Indigenous wisdom and teachings but also guide us towards a sustainable and thoughtful future through equitable health system planning. Drawing on the Feather Carriers work,<sup>9</sup> a life promotion program to



**Figure 1.** Berry harvesting as a metaphor for a learning community approach.

prevent high suicide rates among Indigenous communities (of which author Elder Tecumseh is a co-lead), an important first step would be a “Historical Scan” whereby Indigenous (and non-Indigenous, if involved) partners will begin by listening and visually recording the history and turning points of the community and discussing how these could be integrated and measured in mental health service delivery and planning. Conducting such a scan will ensure that an LHS is planned not solely based on the current status quo regarding health needs, but also on deeper insights into what supports mental health and wellness, what hinders it, and the changes required to meet the needs of Indigenous youths in the past, present and future. Berry harvesting includes a set of knowledge (how to harvest, how to locate berry patches, how to use and share berries) that is often passed down generationally. Tending to berry patches is important to ensure they are available for future generations. LHS can also embrace this perspective of sharing knowledge, planning for the future, and knowing that both questions and lessons will evolve as the environment shifts.

### Wholistic Conceptions of Data, Practice, Knowledge, and Sharing

To promote self-determination, community engagement and capacity-bridging, LHS in Indigenous contexts should integrate local Indigenous perspectives for gathering data from practices (e.g., cultural teachings, stories, formal interventions); generating knowledge from data (e.g., using data to respond to a community question or priority), learning and sharing (e.g., sharing results or a collective story with communities); and adapting or changing practices guided by learnings (e.g., sharing circles about how to use knowledge for collective benefit). A broad definition of “data” is recommended. “Data” should include numbers, stories, experiences, histories, teaching, art, and ways of being, among others. It should be reflective of diverse voices, including youths, families/carers, Elders, Knowledge Holders, natural helpers, formal mental healthcare providers, decision-makers, and organizations. We similarly have a broader view of “practice.” While LHS are often seen as bridging evidence-practice gaps, this view may be too narrow

considering the limited inclusion of Indigenous communities in research (in terms of both participants and leadership) and the limited relevance of a rigidly bounded concept of “evidence” from a scientific perspective that might not encompass or fully appreciate Indigenous ways of knowing and healing. Indigenous health research and knowledge sharing have also been hindered by policies, practices, training and funding that do not prioritize local Indigenous Peoples’ contexts and priorities or their ways of sharing knowledge.<sup>7</sup>

We conceptualize a Learning Community as supporting the delivery of youth mental health care and programs that are guided by a Two-Eyed Seeing approach.<sup>10</sup> Two-Eyed Seeing is inclusive of traditional healing and Indigenous identity-affirming practices, as well as clinical approaches that contribute to health, recovery, healing and resilience (particularly when they have been adapted and shown to be acceptable and effective for Indigenous communities). We also see LHS approaches as having the potential for generating new data and knowledge about what constitutes “wise practices” for Indigenous contexts. In this way, a Learning Community can support the implementation of currently known and valued wise practices, as well as advance much-needed knowledge and research about additional and innovative strategies, interventions and practices that can address urgent challenges for youth mental health in Indigenous contexts, such as limited accessibility and resources, inadequately trained workforce, lack of culturally grounded/adapted interventions.<sup>2–11</sup>

The sharing of knowledge, or knowledge translation in Indigenous contexts has been defined as “Indigenously led sharing of culturally relevant and useful health information and practices to improve Indigenous health status, policy, services and programs,” and “sharing what we [referring to Indigenous Peoples] know about living a good life.”<sup>12</sup> Knowledge sharing (i.e., the LHS knowledge to practice process) should therefore embed traditional Indigenous knowledge, use local languages and engage Elders, Knowledge Holders and leaders. Beyond sharing knowledge to improve practice, knowledge can also be used to advocate for continued or additional funding for service delivery and culturally relevant and effective youth wellness supports, often a key priority for many Indigenous communities. Returning to the berry harvesting metaphor, stakeholders should view berries (data) as stories that emerge from and enrich Indigenous communities’ knowledge base and capacity for service delivery and advocacy.

### **Intentional, Ethical and Respectful Data Governance**

Given the key role that data play in LHS, LHS should carefully develop and implement an inclusive, ethical and respectful approach to data governance that respects

Indigenous communities’ self-determination in research and data sovereignty.<sup>13–16</sup> Indigenous data governance frameworks (see Supplemental Material) can guide these efforts as they were developed in response to historical and ongoing Indigenous data mismanagement and mistrust in research.<sup>7,8</sup> In berry harvesting, berry types and locations are diverse although they share commonalities. Not every berry patch will be appropriate for the same type of harvest, or at the same time. It is important, in stewarding the berries, to ensure that the harvest will return next season and communities have various practices that have emerged from the wisdom of their Elders and local knowledge and decisions for such stewardship. Extending this analogy, data governance in LHS for Indigenous contexts goes beyond following frameworks/principles in a checkbox fashion to deeper, intentional engagement with communities and their specific goals and aspirations for data and Learning Communities.

### **Centred on What Matters**

A priority for LHS is to arrive at core outcomes that matter to pertinent stakeholder groups and a set of measures and metrics associated with these outcomes that then become the focus of data collection, sharing and learning activities. Learning Communities must be led by and with Indigenous Peoples to focus on their priorities for present and future generations. Our network aims to support Learning Communities that foster hope, belonging, meaning and purpose among youths, the four key directions in the First Nations Mental Wellness Continuum Framework,<sup>17</sup> in which mental wellness encompasses mental, physical, spiritual and emotional dimensions. Inuit and Métis Peoples also see this framework as valuable for thinking of mental health and wellness. Integrating the perspectives of First Nations, Inuit and Métis Peoples—including Elders, Knowledge Holders, families, carers and youth—throughout, the Learning Community should honour traditional teachings while also applying culturally appropriate and acceptable contemporary methods (e.g., mobile apps, tablets) to support gathering and learning from data on culturally relevant health and wellness outcomes.

In terms of measures, a Learning Community could prioritize culturally grounded, Indigenous-developed tools to assess and support health and wellness. An ideal tool would be one that can be adapted to each Indigenous community’s worldviews, values and language, while still allowing communities to collect similar information so they can share with and learn from each other. A Learning Community would use tools and an associated data interface that provide immediate results to Indigenous communities and mental health and social service providers on how youth see their own well-being and supports them in identifying needs, supporting youth, tracking changes over time and

evaluating programs, while respecting Indigenous data sovereignty. An example of such a tool is the *Aaniish Naa Gegii*: the children's health and well-being measure.<sup>18</sup>

Considerations around data collection methods vary by context. In urban contexts, a relevant metric to track over time could be the number of First Nations, Inuit and Métis youths accessing and engaging with services. Youth services that are part of a province-wide LHS should carefully examine the cultural safety of common tools and measurement-based care practices for Indigenous youths.

In the next five years, our network plans to support a number of First Nations, Inuit and Métis communities in integrating a "Learning Community" approach whereby they collect data that they see as important for improving youth mental health and wellness, learn from such data to determine the steps to take, take those steps, collect data again and iteratively learn and share back with youth, community members, Elders, service providers and decision-makers. The network will also foster connections between participating Learning Communities so that they can come together to share with, learn from and support each other's learning journeys. In doing so, our Network will gain rich insights on integrating Indigenous ways of knowing, being, and doing into LHS processes, which we will share widely. By integrating Indigenous ways of knowing and embracing a wholistic perspective of health and wellness, Learning Communities can inform more effective and equitable health services and support Indigenous wellness.

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### Supplemental Material

Supplemental material for this article is available online.

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