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The SEEDS of Indigenous population health data linkage

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Abstract

Introduction
Globally, the ways that Indigenous data are collected, used, stored, shared, and analyzed are advancing through Indigenous data governance movements. However, these discussions do not always include the increasingly sensitive nature of linking Indigenous population health (IPH) data. During the International Population Data Linkage Network Conference in September of 2018, Indigenous people from three countries (Canada, New Zealand, and the United States) gathered and set the tone for discussions around Indigenous-driven IPH data linkage.

Objectives
Centering IPH data linkage and research priorities at the conference led to budding discussions from diverse Indigenous populations to share and build on current IPH data linkage themes. This paper provides a braided summary of those discussions which resulted in the SEEDS principles for use when linking IPH data.

Methods
During the Conference, two sessions and a keynote were Indigenous-led and hosted by international collaborators that focused on regional perspectives on IPH data linkage. A retrospective document analysis of notes, discussions, and artistic contributions gathered from the conference resulted in a summary of shared common approaches to the linkage of IPH data.

Results
The SEEDS Principles emerge as collective report that outlines a living and expanding set of guiding principles that: 1) prioritizes Indigenous Peoples' right to Self-determination; 2) makes space for Indigenous Peoples to Exercise sovereignty; 3) adheres to Ethical protocols; 4) acknowledges and respects Data stewardship and governance, and; 5) works to Support reconciliation between Indigenous nations and settler states.

Conclusion
Each of the elements of SEEDS need to be enacted together to create a positive data linkage environment. When implemented together, the SEEDS Principles can lead to more meaningful research and improved Indigenous data governance. The mindful implementation of SEEDS could lead to better measurements of health progress through linkages that are critical to enhancing health care policy and improving health and wellness outcomes for Indigenous nations.

Keywords
Indigenous; data governance; data linkage; data principles; data sovereignty; population health; IPH; SEEDS principles; CARE principles

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Introduction

Indigenous data and its applications such as transfer and linkage have the potential to further empower Indigenous nations by unsettling colonial, governmental, institutional, political, and legal systems that are historically designed to undermine Indigenous self-determination. This includes a historical and ongoing lack of Indigenous data infrastructure and support, data misuse, non-Indigenous control over Indigenous data, data that is not representative of Indigenous priorities, reliance on non-Indigenous data spaces, and a narrative driven by disparity, deprivation, disadvantage, dysfunction, and difference [1–3]. Acknowledging and finding ways to address this is one of the ways that Indigenous nations are actively developing mechanisms aimed at rebuilding self-determining Indigenous nations [3, 4]. Indigenous nations, leadership, governance organizations, scholars, practitioners, data users, and allies are advancing the diverse data rights and interests of Indigenous Peoples across the globe, through Indigenous data sovereignty (ID-Sov) [5–11]. Indigenous data, and the lens used to collect, analyze, link, and apply Indigenous data, have the power to impact decision-making, improve services and policies, drive innovation, enhance understanding, and influence resource allocation based on Indigenous values [12, 13]. Data linkage is a process that matches common elements across data files in order to combine information for a single individual [14]. Support for data linkage practices recognizes that these mechanisms are hugely beneficial to the monitoring, measurement, and evaluation of health systems and their outcomes [14–16]. For instance, health data linkage has the potential to expose service provision successes and challenges based on patient pathways in ways that, if used effectively, could lead to improved health policies, practices, and outcomes [17]. However, universal approaches to data linkage are often not oriented to benefit Indigenous nations; rather, they are structured to respond to research, government, or system priorities [17].

Uninformed Indigenous Population Health (IPH) data linkage is a violation of Indigenous Peoples' inherent rights. Tensions arise when Indigenous data are linked with other datasets, particularly when respectful Indigenous-based protocols and Indigenous ethics are not considered throughout the entire data life cycle, including the linkage process [17]. IPH data are routinely used and linked without the free, prior, and informed consent of the Indigenous people and communities who are represented in the data. Indigenous data include any information that can be digitized and that affect Indigenous lives at the individual or collective level [7]. Broadly, this includes primary, secondary, historical, oral, and traditional information. This can include information on Indigenous systems, land, resources, environments, people, and nations [18, 19]. Examples include data about health services, education outcomes, locations of trails, historic areas, spiritual sites and harvesting areas, traditional place names, membership lists and community stories [20]. Unfortunately, Indigenous nations are regularly excluded from decision-making processes and as a result, Indigenous data are often misused, misrepresented, or lack consistent, inclusive, and reliable information [3, 6, 21].

In 2018, leaders and advocates for Indigenous data governance (ID-Gov) from nations around the world gathered at the International Population Data Linkage Network Conference (IPDLN-2018). In the wake of historic and ongoing challenges within Indigenous data environments, particularly around IPH data linkage, speakers were invited to take part in a series of discussions at IPDLN 2018 around how successful Indigenous-led IPH data linkage approaches are being implemented in their respective regions. The gathering during IPDLN 2018 offered an internationally recognized population data linkage conference the opportunity to make space for diverse Indigenous voices from three countries (Canada, New Zealand, and the United States) and set the tone for positive discussions around IPH data linkage and research. During the conference, speakers shared their experiences working towards self-determination, autonomy, and sovereignty. Speakers spoke about imposed colonial systems and how these systems do not take into account Indigenous ways of knowing, being, and doing. Discussions also pointed towards mainstream data systems as sites where data dependency is reinforced, for example where Indigenous nations become dependent upon non-Indigenous data holders to respond to Indigenous-related health priorities.

The objectives of the conference included centering Indigenous-driven IPH data linkage and research. Following an analysis of conference event documents, notes, and artistic contributions, a set of high-level themes emerged. This paper presents a braided summary of the common knowledges and experiences that were shared at IPDLN 2018 and introduces *SEEDS* as a set of guiding Indigenous-led IPH data linkage principles.

The SEEDS of Indigenous Population Health Data Linkage are a set of aspirational principles that should be considered a starting point for discussions that pertain to IPH data. SEEDS offers a framework for IPH data that 1) prioritizes Indigenous Peoples' right to *S*elf-determination; 2) makes space for Indigenous Peoples to *E*xercise sovereignty; 3) adheres to *E*thical protocols; 4) acknowledges and respects *D*ata stewardship and governance, and; 5) works to *S*upport reconciliation between Indigenous Peoples and settler states. The SEEDS Principles reflect many Indigenous worldviews and are presented here with the intention of encouraging more critical and reflective approaches to IPH data linkage around the world. The SEEDS principles are designed to encourage an understanding of historical, cultural, linguistic, and traditional differences between Indigenous nations and to prioritize those differences when seeking to link IPH data.

International movements creating space for Indigenous data governance

Background

International, critical, Indigenous-led advancements are transforming the ways that Indigenous data are collected, used, stored, shared, linked, and analyzed [5, 22–25]. The collective rights of Indigenous nations to autonomy and sovereignty are being advanced by Indigenous nations around the world in accordance with international human rights instruments such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) [4, 25–29]. Global ID-GOV movements are rooted in the UNDRIP and are advancing ID-SOV initiatives and priorities. These movements are (re)affirming Indigenous

Peoples' ethical rights to free, prior, and informed consent as active participants in consultation processes that affect Indigenous lives- which includes Indigenous data [7, 26]. UNDRIP also provides an excellent vehicle with which to position IPH data linkage, which is far-too-often driven by disparity, inconsistencies, irrelevance, and unreliability for the Indigenous nations they are meant to represent [12, 18].

Born of similar discussions on the governance of Indigenous data, *the CARE Principles for Indigenous Data Governance* are another example of protocols developed by Indigenous Peoples at an international gathering. The CARE Principles underscore the importance of people and purpose within big data spaces [5, 28]. CARE stands for Collective benefit, Authority to Control, Responsibility, and Ethics [5]. Criteria outlined in the CARE Principles advocate for ID-Sov and stress the importance of Indigenous Peoples' rights to govern the collection, application, and ownership of Indigenous data and information [28]. The CARE Principles act as a conduit for the activation of ID-Gov, while advancing the position that Indigenous-driven data stewardship is about more than the *governance of data*, it is also about mobilizing *data for governance* [2, 28]. This process allows for the ongoing dismantling of settler-colonial structures in ways that acknowledge Indigenous rights, interests, and ways of knowing —including cultures, values, and principles— in the management and control of Indigenous data [2, 7, 15, 19]. The SEEDS Principles presented in this paper can be regarded as an extension of currently established Indigenous-led principles, such as CARE. Unlike the high-level governance priorities established within CARE Principles, SEEDS specifically addresses and creates a foundation for IPH data linkage.

Indigenous perspectives on IPH data linkage

Rationale

Too often, Indigenous data are created or derived and then linked with little focus or understanding of Indigenous histories, priorities, and worldviews. In fact, the way that Indigenous identity is conceptualized, collected and recorded in population-level datasets is often inconsistent or irrelevant to the nations to which they refer. For instance, definitions of Indigenous identity may be recorded based on self-identification, blood quantum, eligibility for Indigenous-specific services or recognized Indigenous status [19]. These types of identification vary in their relevance to Indigenous cultural and community identity and the uninformed and unethical use of them has the potential to further perpetuate systemic inequities and assimilation. Even once Indigenous data are identified in a dataset, the way that databases are linked and used must be reoriented to align with Indigenous worldviews, priorities, and methodologies. For Indigenous nations, priorities may include concepts of relationality, wholism (whole-health) and strengths-based inquiry.

To illustrate the diversity of data possibilities, an example that was shared during the conference spoke of how in Blackfoot culture there is a process called the *winter counts*, which includes symbolic drawings on animal hide that illustrate an important point in a year. Each year a new drawing is added to the hide resulting in an illustrated story that is kept as a historical data record for the nation. Further, a metaphor that was shared during the IPDLN 2018 keynote address expressed the need for non-Indigenous organizations to make the space for Indigenous nations to lead. An image was shared with the conference attendees of a river with rocks in it. The addressee pointed to the rocks as hurdles restricting the flow of the water. Within the metaphor the rocks were obstacles experienced by Indigenous Peoples and as part of the powerful keynote, the addressee looked to the room and asked that non-Indigenous organizations use their privilege to move the rocks out of the way so that the water could flow freely. More importantly, the addressee said, '*don't build a canal and tell the water where to go, allow that water to flow where it needs to.*' As Indigenous nations continue to advance efforts that lead to nation rebuilding through self-determination and self-government [19], mainstream organizations can contribute by working with Indigenous nations towards accomplishing those goals. By helping to move those proverbial rocks/obstacles and advocating for changes to oppressive systemic policies and practices, Indigenous Peoples will benefit from not having to continuously move or push those rocks away themselves.

Methods

The SEEDS of Indigenous population health data linkage

Cultivating and sowing SEEDS

The IPDLN 2018 conference was held in Banff, Alberta, Canada and provided a space for Indigenous Peoples to gather and empower one another on approaches to navigate the linkage of IPH data. Adding to the overall conference were three Indigenous events that included a pre-conference invitation-only workshop, a panel discussion, and a keynote address [22]. These discussions articulated common priorities and practices taking shape or being enacted in Canada (Alberta, British Columbia, and Ontario), in Aotearoa New Zealand, and in the United States. Missing from the in-person discussions were the expected contributions from Australia [22]. Indigenous panellists were asked questions on what Indigenous-led data linkage looks like in their respective regions and why it is important. Each of these events were illustrated by a graphic facilitator who was present during the conference (See Appendix).

In an effort to uncover and summarize key and common points around IPH data linkage that were shared during the gathering, initial themes were developed collaboratively using a conversational method by RR and JW following the conference in 2018. A qualitative, retrospective, manual document analysis of pre and post conference discussions, detailed notes, and artistic contributions that were created during the conference were compiled and thematically explored for commonalities. Grounded in an Indigenous methodology, the document analysis employed ongoing relational and conversational methods [23]. The final set of principles that emerged from this process were vetted through conference attendees, co-authors, and ID-Sov advocates over the course of two years. The final set of principles also took into consideration the revolutionary discussions and digital

expansions occurring through the work of global ID-Sov movements that occurred throughout that time.

Results

Planting the SEEDS of IPH data linkage

As visualized in Figure 1, the SEEDS Principles embrace international Indigenous perspectives and emerge as a living set of guiding principles for IPH data linkage. While SEEDS is presented here as a new framework, the principles within it are typical to discussions on ID-Gov. Their importance within the SEEDS frameworks stems from their direct affiliation to IPH data linkage.

The emergence of the SEEDS Principles further reinforces some of the governance mechanisms already being mobilized through the CARE Principles [27]. Activating SEEDS and CARE within IPH data linkage environments specifically, could contribute to greater improvements to the governance of data throughout data linkage lifecycles. As such, SEEDS should be included as supplementary guidelines for use specifically within environments where Indigenous population health data is being linked. This distinction is a necessary part of ensuring that the many elements that reinforce and promote Indigenous Peoples' data sovereignty are actively cultivated by users of Indigenous data. The elements of SEEDS are described in further detail below. The explanation provided for each element originates from the discussions had during the IPDLN 2018 conference.

Self-determination

Indigenous priorities around data linkage highlight the inherent rights of Indigenous Peoples to self-determination and autonomy. This includes Indigenous nations, leadership, and organizations identifying Indigenous health priorities and leading research and decision-making processes within that research. Self-determination strengthens Indigenous resurgence, reclamation, revitalization, and resilience and in doing so works to decolonize and transform data, data collection methods, and data environments. Self-determination respects that Indigenous Peoples have their own ways of knowing, being, and doing; and as such, incorporates diverse Indigenous knowledges, cultures, traditions, and languages throughout the entire research process. In this way, Indigenous definitions of health and wellness (which go beyond mainstream definitions of health) are prioritized. As a result, data relating to Indigenous health and identifiers used to classify Indigenous identity are decided upon by Indigenous collectives who the data are about. Through processes that decolonize data, space is made within Indigenous health data systems and research for Indigenous nations to: 1) define what Indigenous health data are; 2) decide on how diverse Indigenous nations will be identified within data; and 3) determine how to integrate Indigenous-defined and identified data into IPH data linkage environments and processes.

Exercise sovereignty

Enacting self-determination requires that the rights of Indigenous nations to exercise sovereignty be recognized.

This includes non-Indigenous groups respecting Indigenous data and research sovereignty while making the necessary space for Indigenous nations to lead research and exercise that sovereignty [4, 6, 13, 24]. It recognizes that Indigenous data are sacred, cultural, and economic assets [23] requiring processes that are respectful of distinctive Indigenous-based protocols, engagement, collective and community ownership, and collective and community control over Indigenous information. Exercising data sovereignty acknowledges the diversity of Indigenous nations. Approaches that link Indigenous data should appreciate and implement measures that ensure this diversity is respected.

Within supportive data spaces, Indigenous nations are actively exercising and advancing sovereignty. Non-Indigenous data stewards can contribute to advancements in ID-Sov by leveraging their privilege and supporting the dismantling of systems that do not prioritize Indigenous rights. This could be done by transforming and creating data environments that advocate for relationship-building, enhanced capacity, build-trust, and that make space for discussions that support Indigenous frameworks around data transfer and linkage. In this way, Indigenous nations will be further positioned to enhance internal capacity while continuing to act in ways that exercise sovereignty and improve infrastructure, leading to more meaningful results and improving health outcomes.

Ethics

Ethical approaches to IPH data linkage must begin by re-evaluating current ethical protocols through a lens that adapts distinctive Indigenous research methods and methodologies, and acknowledges Indigenous nations as rights holders throughout research processes. Ethical considerations that adhere to Indigenous priorities must also respect Indigenous diversity and Indigenous nations' rights to privacy and confidentiality. Indigenous ethics value the importance of meaningful partnerships, collaborations, trust, and relationship building and strengthening. More importantly when working with Indigenous data and linkage, data users must ensure that ongoing free, prior, and informed consent is obtained from the appropriate Indigenous nations who the data are about– before a research process begins. Ethical considerations should honour Indigenous data, including the ways that it is managed and linked, and should include ongoing processes of transparency motivated by *doing good* and *doing no harm*. As such, Indigenous-led discussions should foster relationships, respect, reciprocity, responsibility, and relevance [23] and also address future uses of linked IPH data including how data will be protected and used moving forward, and by whom.

An important ethical consideration when creating strategies and protocols around how to use and link Indigenous data is to understand that data collection and analysis about Indigenous lives affects Indigenous people. Non-consensual data linkage may be driven by non-Indigenous worldviews which are often grounded in disparity, deprivation, disadvantage, dysfunction, and difference [1]. As such, IPH linkage without Indigenous consent impacts Indigenous lives. Decisions around what data to collect, who to count and include in the data, and what to say or what stories to tell about the data needs to be decided upon by relevant

Figure 1: The SEEDS Principles for Indigenous Population Health Data Linkage

Designed by: Taynia Bedard, Missanabie Cree First Nation, Ontario, Canada.

Indigenous nations prior to the start of research. This includes an understanding that while individual consent is necessary, ongoing community-level consent is crucial to how Indigenous stories are told. Ultimately, ethics stresses that resulting Indigenous knowledges uncovered through IPH data linkage must only be used for the purposes that consent was provided, and be given back in an appropriate and predetermined manner to the nations with whom the data are about.

Data stewardship & governance

Meaningful partnerships that seek to link Indigenous data should be collaborative in nature, respect existing and varied ID-Gov principles, and highlight who makes decisions around Indigenous data about how data will be held, managed, used, stored, reused, linked, shared and for how long. This includes the integration of Indigenous-led mechanisms that enable the stewardship and governance of Indigenous data held by non-Indigenous governments, institutions, and agencies [2]. From this perspective, Indigenous data, regardless of where it resides in the world, must include processes that integrate applicable and Indigenous-accepted governance mechanisms or, be governed by appropriate Indigenous nations and used to further Indigenous governance [23]. This includes an understanding of any preexisting Indigenous data governance mechanisms. Globally, there are many, and they are often nation or region specific [4, 6, 13, 24]. Honouring data stewardship and governance may lead to contractual arrangements, privacy impact assessments, data sharing, and data transfer agreements between Indigenous nations

and non-Indigenous data holders or among non-Indigenous data holders in order to advance, empower, and inform Indigenous nation-based priorities. Advancing Indigenous data stewardship and governance includes careful and respectful consideration of the creation, collection, management, use, and linkage of Indigenous data. Expanding data stewardship and governance includes addressing the parameters around collective ownership and responsibilities that pertain to data and linkage; including the risks and benefits of linking datasets, and who the stewards of the data are. Parameters should also highlight: 1) Indigenous nations' expectations for the use of said data; 2) who makes decisions about the data; 3) who would have access and jurisdiction over the data; and 4) other predetermined conditions around the data including publication and authorship processes that are reflective of and led by Indigenous priorities.

Support reconciliation

Throughout all research and reporting processes, it is imperative that researchers and data holders recognize and support reconciliation with Indigenous Peoples through strength-based approaches that highlight Indigenous progress. Mobilizing this means that research processes that link IPH data must prioritize diverse Indigenous nation-based research initiatives that assert the rights and interests of Indigenous Peoples and work towards improved social, emotional, mental, and physical aspects of whole health. This process ensures that researchers know and understand the history of settler colonialism, its impact on Indigenous lives, and acknowledges the resilience of Indigenous nations.

In valuing Indigenous perspectives, research processes could include being on the land, and/or the involvement of Elders, Knowledge Keepers, and other traditional persons. Supporting reconciliation means making space within mainstream data environments for Indigenous Peoples to lead the way towards capacity building, infrastructure development, Indigenous data transfer and linkage, and ultimately, nation rebuilding.

Discussion

Growing S.E.E.D.S

Policies across major Anglo-colonizing nation states around the world, including Canada, Aotearoa New Zealand, the United States, and Australia boast diverse Indigenous policy frameworks and action plans that embrace collaboration and varying degrees of reconciliation and mobilization in accordance with the rights and interests of Indigenous nations [29–31]. In practice, however, systemically-rooted barriers limit the full implementation of ID-Sov and ID-Gov. IPH data linkage, for instance, is happening in many spaces that house Indigenous-identified health information without Indigenous consultation or authorization [16, 32]. More than ever, Indigenous data are being added to and Indigenous knowledges are being (re)produced, renewed, and revitalized [31]. As the availability of Indigenous data increases through digitization and linkage; researchers, funders, governments, and data stewards need to actively recognize diverse *Indigenous-led* IPH data linkage priorities in order to reflect the interests, values, and priorities of Indigenous nations.

SEEDS provides a clear and concise snapshot into nation-based processes and regional considerations around IPH data and linkage. Governments, institutions, and organizations that currently have power over IPH data, must actively work to dismantle the historically colonial systems and structures that are in place that impede Indigenous nations' ability to actively assert IPH data governance throughout the linkage process. Internally, this may involve cultural safety training leading to a deeper understanding of Indigenous nations' rights to govern Indigenous data and nation autonomy. What is clear is that within environments where Indigenous people are leading data advancements and linkage, processes that set collective priorities are being co-developed and decisions are coming from Indigenous nations and leadership [29–31]. This is leading to improved transparency and increased capacity, while furthering ID-Sov and ID-Gov. The SEEDS Principles enable IPH data linkage and the stories that come from that linkage to be reflective of the priorities that matter to Indigenous nations.

While each element of the SEEDS Principles when enacted together and in recognition of the CARE Principles can lead to improved approaches towards IPH data linkage; it is important to understand them as a living and ever-expanding set of guiding principles. When implemented together, the SEEDS principles can guide positive IPH data linkage processes and create more meaningful research for the nations that are represented in the data. The implementation of these principles can also lead to better measurements of health progress that

are critical to enhancing health care policy and improving health and wellness outcomes for Indigenous nations.

Conclusion

As part of global ID-Sov efforts, there is increasing prioritization and reaffirmation of Indigenous Peoples' rights to develop, maintain, control, and protect traditional knowledges, cultural expressions, and intellectual property [25]. This includes empowering Indigenous voices within research spaces. Amidst the global data revolution, Indigenous nations are further asserting their inherent rights over the collection, analyses, use, dissemination, and distribution of Indigenous data through governance mechanisms such as the CARE Principles. In recognition of the diversity of data environments, SEEDS is presented here as a new framework that offers a set of guiding principles for Indigenous-led IPH data linkage that also honours the CARE Principles' high-level approach to ID-Gov.

Improving IPH data linkage begins by prioritizing Indigenous nations' rights to self-determination, creating spaces where Indigenous nations can actively exercise sovereignty, advance Indigenous-based ethical protocols, and acknowledge and respect data stewardship and governance in ways that support reconciliation and nation rebuilding. Fundamental to this work is the ongoing development, redefining, and strengthening of trusting and meaningful relationships and collaborations between Indigenous nations and settler states. Advancing Indigenous data governance ultimately means the ongoing dismantling of mainstream data systems that Indigenous nations are historically dependent on. This includes *helping to move the rocks* and obstacles and advocating for changes to oppressive systemic policies and practices.

Supporting and adopting the SEEDS principles will lead to data environments where Indigenous nations are less reliant on non-Indigenous data holders. Doing this will contribute to Indigenous nations' asserting data governance while addressing nation-based health priorities through linkage. Looking ahead, Indigenous nations should be supported in order to develop the capacity to advance Indigenous priorities through Indigenous-based infrastructure that can collect, use, store, share, link, and analyze IPH data. Enacted together, the elements of the SEEDS Principles will ensure that IPH data linkage and data analyses support the goals and aspirations of Indigenous nations.

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Statement on Conflicts of Interest

The authors have no real or perceived conflicts of interests.

Ethics Statement

This is a collective report that explores documents and images collected during a public forum and did not apply any interventions, as such, ethics approval was not required.

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Abbreviations

CARE Principles:	Collective benefit
	Authority to Control
	Responsibility
	Ethics
ID-Gov:	Indigenous data governance
ID-Sov :	Indigenous data sovereignty
IPDLN 2018:	International Populations Data Linkage Network Conference 2018
IPH :	Indigenous Population Health
SEEDS principles:	**S**elf-determination;
	Exercise sovereignty;
	Ethics
	Data stewardship and governance, and;
	Support reconciliation
UNDRIP:	United Nations Declaration on the Rights of Indigenous Peoples

Supplementary Appendix 1: Pre-Conference Gathering
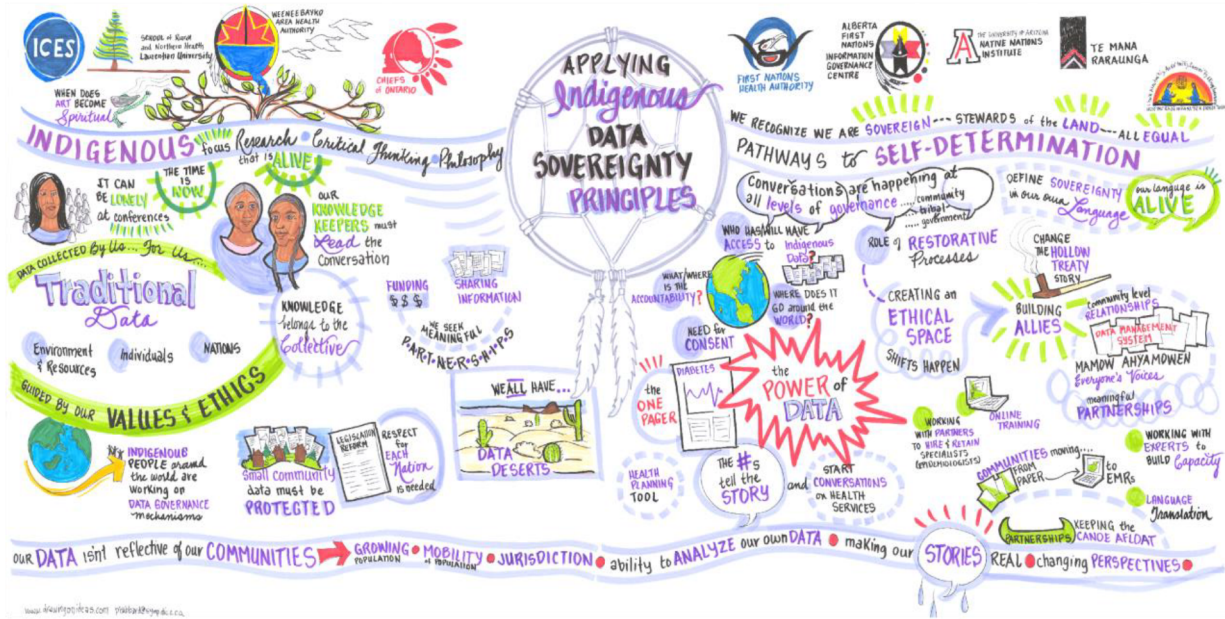
Supplementary Appendix 2: Keynote Address on Indigenous Health Data
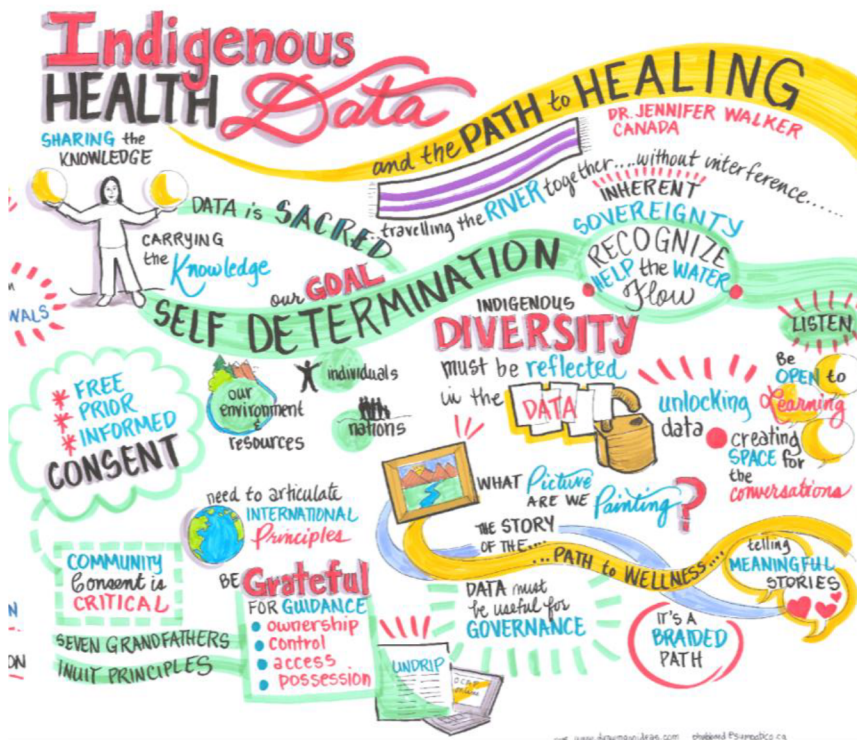
Supplementary Appendix 3: Indigenous Data Panel Discussion