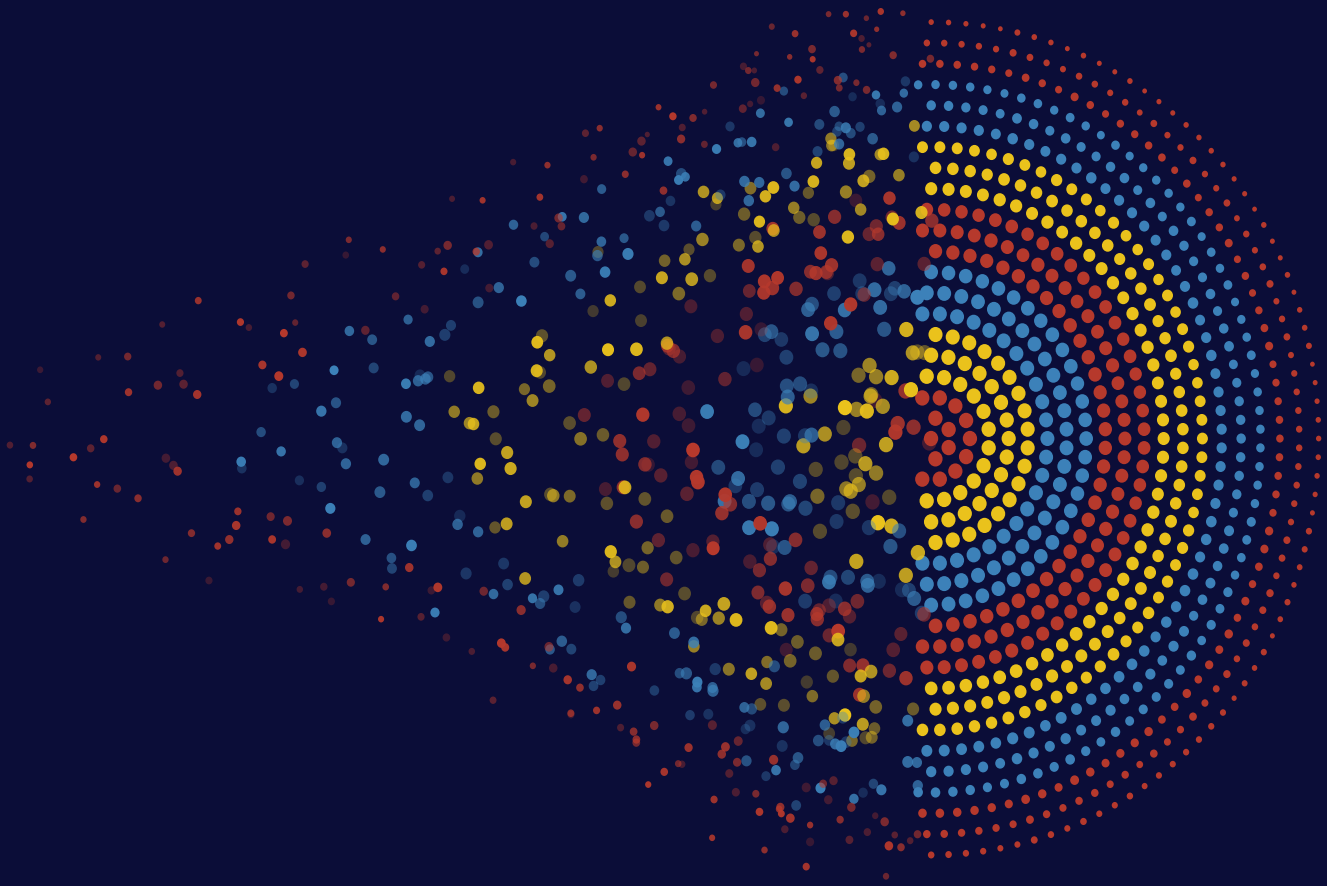


Indigenous Data Sovereignty



**Best practices research to inform
an Urban Indigenous partnership model
for the City of Vancouver**

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I would also like to acknowledge my position as an uninvited immigrant settler, which requires responsibility in addressing the enduring impacts of systemic racism and colonialism, with an ongoing commitment to reconciliation. My positionality as a non-Indigenous researcher limits my full understanding of the significance of Indigenous data sovereignty and my ability to make recommendations in this area.

While this research makes an effort to center Indigenous worldviews, values and voices, to maintain Indigenous self-determination, it needs to be complemented by an ongoing, direct engagement process with Urban Indigenous Communities, to gather their perspectives and foreground their priorities.

I would like to thank the City of Vancouver's Social Policy and Projects division for hosting this work. In particular, thank you to my mentors Jesse Bierman and Peter Marriott for their guidance and support throughout this project. I would also like to thank the Equity and Decolonization of Data Community of Practice for their insightful comments. Special thanks to Karen Taylor, UBC Sustainability Scholars Program Manager for her support.



About the author

Hilal Kina is completing her PhD in Social Anthropology at the University of British Columbia. Her research deals with the systematic dispossession, marginalization and resilience of the historical Armenian community in her country of origin, Turkey. Previously, she has been actively engaged in various projects involving social justice, memory, and decolonization in both Turkey and Canada.

Executive Summary

This report examines Indigenous data governance frameworks and partnerships to support the development of a City-wide model for community data governance that emphasizes accountability. This work supports the City's broader efforts to actively engage Urban Indigenous populations in shaping support for local governance and address distinct community needs and aspirations.

Background

As of 2021, more than half of all Indigenous people in Canada live in cities, with Metro Vancouver having the third-largest Indigenous population among census metropolitan areas in Canada (Statistics Canada, 2022). The Urban Indigenous population is diverse with the majority of the population considering cities as their home while maintaining varying connections to their communities of origin (Environics Institute, 2010).

Indigenous Peoples and their priorities remain under-represented in municipal government. Cities and municipal governments in Canada have been historically unwilling to actively engage with Indigenous relations, often leaving matters concerning Indigenous Peoples to be addressed by the federal and provincial governments.

This approach has fostered an environment where cities have operated without considering the needs and priorities of its

Urban Indigenous populations (Heritz 2018, Gosnell- Myers 2022).

The collection of accurate, relevant and accessible data is crucial for identifying current needs and service gaps in urban-based programming and ensuring appropriate allocation of funding for communities (Collier, 2020).

The City made a definitive declaration of support for Indigenous rights and self-determination by endorsing the UNDRIP, paving the way for a commitment to a model of Indigenous- municipal relationships that would prioritize increased power and representation to Indigenous Peoples and foster more equitable partnerships (City of Vancouver, 2022).

The City's implementation of the UNDRIP is rooted in a distinctions-based approach, which acknowledges that the Musqueam, Squamish, and Tsleil-Waututh Nations possess inherent rights to their lands. These rights are distinct from the rights of the large and diverse populations of Urban Indigenous people from other territories who have come to live on these lands.

While the UNDRIP Strategy currently has a focus on the priorities of Host Nations focusing on lands and economic resources and achieving Reconciliation through this lens, UNDRIP also represents the Urban Indigenous community, and their right to access services.

The City has initiated a consultation process with the UNDRIP Strategy to focus on and represent the Urban Indigenous populations through a distinctions-based approach that considers intersectionalities.

To promote the revitalization of Indigenous rights to self-determination, it is essential to further the process of decolonizing City processes and transfer power to Urban Indigenous communities. Collaborative data partnerships, are one way to facilitate this process.

Equitable and co-developed data partnerships carry the potential to foster equitable relationships towards Indigenous partners by improving transparency and accountability. They can work towards addressing the inherent power imbalances frequently found in the interactions between governments and communities, while contributing to the progress of Indigenous data governance and stewardship (Howard- Bobiwash et al., 2021; Love et al. 2022).

The efforts of the City to establish a data governance model should be recognized as part of this larger initiative to create new governance frameworks that uphold the rights of Indigenous People, by actively engaging Urban Indigenous communities as equal partners in City decision-making.

Research Approach

This report provides preliminary recommendations to support the City in the process of developing a collaborative data governance framework with Urban Indigenous communities.

This research is based on an environmental scan of academic literature, policies, reports and guidelines related to Indigenous data sovereignty. These documents and frameworks were reviewed and analyzed as references for the City, to guide its efforts towards establishing a collaborative data framework.

In this report, Urban Indigenous communities refers to: community members who self-identify as Indigenous (including First Nations, Métis, and Inuit), representatives from the Metro Vancouver Aboriginal Executive Council (MVAEC) and the Urban Indigenous Peoples' Advisory Committee (UIPAC), Indigenous service providers, and other community members who identify as Indigenous.

Opportunities

1. The City has made progress in using data in pursuit of equity and decolonization goals. Additional efforts are required to address the issues of accountability and the City's limited capacity concerning the collection and governance of data.
2. Existing relationships with UIPAC and the MVAEC provide a solid foundation for the City on which to envision a more decolonized and community-led approach in working with Indigenous data. Feedback from Urban Indigenous communities received through these two organizations, indicates that the communities require more support and access to space in cultural expression and are only considered in programs and services. The City can increase resources to these existing relationships to increase their capacity to govern data.
3. The City's facilitation of a data governance model that recognizes the distinct and sovereign rights of Indigenous people has the potential to establish a framework that could extend to greater data governance models for other equity-deserving communities.

Challenges

1. The absence of existing frameworks for equitable data collaboration between municipal-Urban Indigenous communities.
2. The vast diversity of the Urban Indigenous communities and the need to take a nuanced distinctions-based approach that will accommodate unique and intersecting data needs and priorities.
3. The lack of structures in place to create a community-led governance model with the MVAEC and UIPAC.
4. The need for capacity building and for additional resources, including the need to eliminate barriers related to funding, infrastructure, human resources, knowledge, training and technology.
5. A lack of high quality and relevant data due to issues such as community mistrust in data collection, and the insufficient collection of data that is culturally relevant and that reflects the assets and aspirations of distinct Urban Indigenous communities.



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Recommendations

Related to the process of establishing a data partnership:

1. Relationship building

- Acknowledge that the foundation of any respectful and sustainable partnership with Indigenous communities is based on fostering equitable relationships, meaningful consultation and ongoing accountability.
- Understand the various reasons why many Indigenous individuals harbor a deep-seated distrust towards data collection practices.
- Commit to overcome these challenges through a substantial investment of time and resources with a focus on fostering community engagement and actively seeking feedback throughout processes.
- Understand the evolving priorities of the Urban Indigenous communities on the data collection that they wish to see conducted.



2. Distinctions-based approach

- Maintain a distinctions-based approach in working with Urban Indigenous communities which acknowledges their rich diversity of Urban Indigenous People, their individual rights, unique experiences and distinct priorities.
- Create collaborative data governance processes by setting common goals and principles that foreground the distinct legal systems, languages, and traditions of all involved parties.
- Understand that diverse Indigenous communities will have different approaches and priorities around data sovereignty.



3. Capacity building and training

- Provide capacity building and training assistance to all partners. This could include trainings on data sovereignty, data governance, privacy, security, relevant legislation, as well as on the OCAP® and UNDRIP.
- Consider local needs and issues such as the diverse levels of experience among Indigenous partners, challenges in information technology capabilities, human resource capacity or funding support.
- In order to address power imbalances in partnerships and to equitably incorporate Indigenous perspectives in City services and programs, learn from and respect relevant Indigenous knowledge and models, acknowledging the inherent rights and sovereign powers of Indigenous communities regarding their data.
- Collaborate on approaches, resources, and best practices.



Recommendations

Related to preparing an Urban Indigenous data governance framework:

1. Collaboration

Clearly define the shared values and principles, vision and objectives, roles and responsibilities, available resources, and timelines for collaboration with all partners involved in the agreement. Ensure that a feedback mechanism is created for individual community members to report on any concerns about the use of data.



2. Data jurisdiction

Address the management and stewardship of data. Determine who has legal control of data and identify a suitable signatory or data steward for the process. Recognize that this may be challenge when establishing a data partnership with diverse Urban Indigenous communities.



3. Data collection

Ensure that culturally relevant and ethical data collection takes place with the insights and guidance of Urban Indigenous partners, incorporating Indigenous data governance principles.



4. Data ownership

Recognize the rights and interests of Urban Indigenous communities in their data, and their authority to exercise control over data. Confirm that a data partnership aims to *shift power to* Urban Indigenous communities, and that Indigenous communities are not *stakeholders* but have *the right to control* their data.



5. Data storage

Establish policies and procedures on how data will be stored, how it will comply with storage regulations and how storage practices will be integrated with the City and with Urban Indigenous goals and objectives.



6. Data security and privacy

Specify proactive policies and procedures on the commitment of partners to protect data from misuse, that describe how confidentiality and security of data will be protected, and that ensure compliance with regulatory standards, guidelines, and Indigenous protocols in case of unauthorized access.



7. Access to data

Address authorized access, analysis, use and disclosure of data and the effective dissemination of findings. Ensure that Urban Indigenous communities have access to their own data and can



determine access permissions based on their distinct cultural requirements and protocols. Discuss issues related to individual and collective rights on data.

8. Analysis and interpretation of data

Address accountability around the use of data, implement measures to ensure that data is used in a way that minimizes harm with the goal of creating actionable information that aims to enhance community well-being. Establish guidelines for the collection of data based on continuous input from the community.



9. Evaluation of data processes

Conduct regular assessments of data collection and sharing processes to ensure that community priorities are met, and that data aids in improving outcomes and enhancing urban-based service delivery and programs.



10. Termination of data agreement and destruction of data.

Clearly specify data life cycles including the duration of the data collaboration, and whether the data relates to a specific program or project. Determine how the data partnership can be terminated and the protocols for data destruction or archiving.





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Introduction

Contemporary Data Landscapes

In the present global context, the utilization, processing, and management of data have emerged as pivotal concerns. Data has the capacity to enhance planning and decision-making processes, and when contextualized and of high quality, it can serve as a fundamental building block for effective governance. (Bruhn 2014; Carroll et al. 2019)

Contemporary data practices are a continuation of processes and understandings of colonial extraction, exploitation, accumulation and dispossession (Couldry & Mejias 2019; Daly, Devitt & Mann 2019). Indigenous communities continue to face challenges arising from detrimental data practices.

As a consequence of its legacy of colonization, Canada has a social policy framework that fails to deliver effective Indigenous policy outcomes. The social policy around recent data collection has served to reinforce Indigenous marginalization (Walter et al. 2021).

This is particularly evident in the lack of consistent health data collection on Urban Indigenous communities (NAFC, 2022). Policies geared towards Indigenous communities have largely been deficiency-based. A strength-based approach would require decolonizing methodologies to produce determinants of wellness and data processes that support Indigenous self-determination (Newhouse & McGuire-Adams 2012; Quinless, 2022).

Some ways in which harmful data practices have historically been perpetuated:

1. The collection of extensive amounts of data on Indigenous communities by settler states to produce statistics as 'evidence' for policy interventions and for **monitoring populations** (Kukutai & Walter 2015).
2. The deployment of colonial strategies to **standardize and enumerate** diverse Indigenous Peoples into 'populations', constraining their wellbeing within quantitative datasets which reflect colonial preoccupations and values (Smith, 2016).
3. The **appropriation** of knowledge and information about Indigenous Peoples and its use in non-Indigenous contexts without consent and the use of data for individual benefit, with a lack of reciprocity and transparency (Reardon & Tallbear, 2012).
4. The conducting of research that has **no relevance** to community members and the **over-researching** of social inequalities with little follow-up action (Boilevin et al. 2019).
5. Exploitative data collection and research processes, triggering **collective and generational traumas**, leading to a lack of trust in researchers and government agencies collecting information (Boilevin et al. 2019).



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More recent issues involving harmful data practices:

1. A lack of **respectful relationships** with Indigenous peoples resulting in a **disregard of community priorities** in data collection and use (Indigenous Innovation Initiative, 2021).
2. The use of **data and indicators** which focus on Western concepts and exclude Indigenous perspectives on well-being, leading to the misrepresentation of the health status of Indigenous Peoples and reducing the ability of Indigenous Peoples to make informed decisions regarding their own communities. (Indigenous Innovation Initiative 2021; Wilson, 2004)
3. The **exclusion** and lack of representation of Indigenous Peoples in datasets, despite **persistent calls** for governments to establish comprehensive disaggregated data collection regarding essential service delivery (Metallic et al. 2019; NAFC 2022; Walter et al. 2021).
4. Data processes have described Indigenous Peoples and their lifeways with a **deficit lens**, representing Indigenous identity and issues through a narrative of negativity, deficiency and failure. (Fforde et al. 2013, Fogarty et al. 2018). This lens has impacted data collection and representation, as well as the choice of indicators and visual representations of Indigenous Peoples. (Wuttunee, 2019)

5. Data has been **decontextualized**, leaving insufficient information for readers to understand facts highlighted. This has obscured the reality that the challenges and disparities faced by Indigenous Peoples is a matter of systematic barriers resulting from an ongoing legacy of colonialism. (4, Allan & Smylie, 2016).

6. The lack of context in the presentation of data also leads to the **misrepresentation** of Indigenous communities, leaving Indigenous communities and individuals with **no chance to respond to or contest** research findings (Boilevin et al., 2019).

7. Data collections, excluding Indigenous knowledges and paradigms, often using language and statistics that is **irrelevant and inconsiderate** of Indigenous Peoples. Data has been shared in **inaccessible** to readers, such as through formats and the use of graphs, charts and maps which do not include an explanation on how to read them (Wuttunee, 2019).

8. Data infrastructures which do not carry the aim of addressing **systemic inequality** reinforce the notion that the defined categories being measured are biological and perpetuate **scientific racism and sexism**, rather than highlighting them as social, political and historical constructions (Rogers & Bowman, 2005).

9. Widespread **inconsistencies** in data collection due to the absence of Indigenous identifiers in datasets (Smylie & Lana, 2012). Insufficient regard of **diversity and intersectionality** of identities in Indigenous

communities, with existing models providing no standards for the appropriate identity categories in data collection (BCOHRC, 2020).

10. The lack of collection of relevant, accurate and consistent disaggregated data on Indigenous Peoples, making Indigenous knowledges and data available only in an **aggregate** way leading to the **misclassification or essentializing** of Indigenous Peoples. Existing categories used to describe diverse Indigenous communities function to make communities 'seeable' by the state, hiding ways of life, urbanity and the differing impacts of colonization (Indigenous Innovation Initiative 2021; Walter et al. 2021).

11. The **accuracy** of datasets, such as concerns regarding the accuracy of Census data, considering the effects of high mobility and migration (in and out of urban areas) of Indigenous people. (NAFC, 2022)

12. Policies of assimilation and dispossession have created a context of **data dependency** and a lack of **capacity** where communities are forced to rely on external sources of information regarding their economic, environmental and health status (Carroll et al. 2019).

13. The tension between individual and collective understandings on **privacy**, where dominant Eurocentric data perspectives have prioritized individual rights and safeguards in place of communal rights, and discussions over data sovereignty on a communal level. (Ongomiizwin, 2022).

Despite a considerable reluctance to modify data processes and relevant policies that are inaccurate and irrelevant for Indigenous people, (Kukutai & Walter, 2015) there has also been strong advocacy for data collection that recognizes distinctions and differences, such as those by the MMIWG2S calls for justice (NIMMIWG, 2019) and the the BC Human Rights Commissioner (BCOHR, 2020).

Parallel to these calls is the strong Indigenous-led movement for inherent rights and interests of

Indigenous data sovereignty, asserting the inherent rights and interests of the Indigenous Peoples in the collection, ownership and application of data about their people, lifeways and territories (Kukutai & Taylor 2016; Rainie et al. 2017). It is a movement to disrupt a data divide, based on data dependency and the erasure of Indigenous knowledge systems, replacing them with data systems that have reshaped power dynamics and that foreground Indigenous communities' goals and priorities (Carroll et al. 2021).



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Memorial on Robson Square to honour the MMIWG2S.

Open data

The global trend towards Open Data advocates for the promotion of unrestricted sharing and usage of data (ODC 2020). The International Open Data Charter (ODC) advocates for data that are: open by default; timely and comprehensive, accessible and usable, comparable and interoperable, for improved governance and citizen's engagement; and for inclusive development and innovation (ODC 2020).

A number of Indigenous scholars have highlighted the tension between prevailing notions of universal Open Data access and the principles of Indigenous data sovereignty, which call for Indigenous communities to control and govern their own data and to make decisions regarding its external access (CSD brief 2021; Rainie et al. 2019). They have argued that in the absence of Indigenous data protocols, Open Data operates in a manner that increasingly disconnects the significance of social data from lived social and cultural realities (Walter et al, 2022).

Current discussions around Open Data have assumed a number of binaries including framing the needs and interests of nation-states as single government actors, seeing data as open or not, and assuming that Open Data necessarily equates to useful data, disregarding potential biases and complexities around the relevance of data (Kukutai et. al 2019)

Some suggestions have been made by Indigenous scholars on how Open Data infrastructures can work in alignment with Indigenous data principles.

Some of these suggestions are:

1. The engagement of Indigenous peoples as equal partners and knowledge holders informing the stewardship of data within this Open Data infrastructure. (Rainie et al. 2019)
2. Incorporation of Indigenous Data Sovereignty principles into existing data systems that requires agencies to adopt and implement principles and which could include an accreditation scheme (Walter et al. 2020)
2. Engagement with Indigenous Peoples through Indigenous Data Sovereignty networks, utilizing existing and established connections and pathways for collaboration with non-Indigenous data actors. (Rainie et al. 2019)
3. The collaborative establishment of principles and protocols related to governing and stewarding Indigenous data (Rainie et al. 2019)
- 4 The development of an Indigenous data infrastructure and authority with Indigenous governance. (Walter et al. 2020)
5. Balancing of data access with data protection in collaborative protocols, including an acknowledgment of the risks



'Bright Futures' by Musqueam artist Brent Sparrow.

of opening data to external access while establishing mechanisms for the institutional supervision of data procedures (Open North and BCFNDGI, 2017).

One step to ensure the balance between open data and Indigenous data principles is to form policies on restrictions around data access and its re-use. The Māori Te Mana o te Raraunga Framework from Aotearoa New Zealand, offers a roadmap for establishing levels of control and access around the use of secondary data.

Data which is established as highly sensitive by Māori is subject to direct control of data or partnerships to control data, while data considered less sensitive by Māori is used through consultation or notification

processes, or may involve lesser control mechanisms and may be part of a data commons or Open Data (Hudson et al. 2017).

Technical tools such as those used to de-identify and anonymize data can incorporate different levels of privacy into datasets before it is released as Open Data. Further steps to balance the need for accountability and privacy involves procedures, such as conducting a purpose assessment to establish the privacy implications of a certain dataset and to ensure that the release of this data as Open Data carries specified objectives and benefits. (Geothink, n.d).

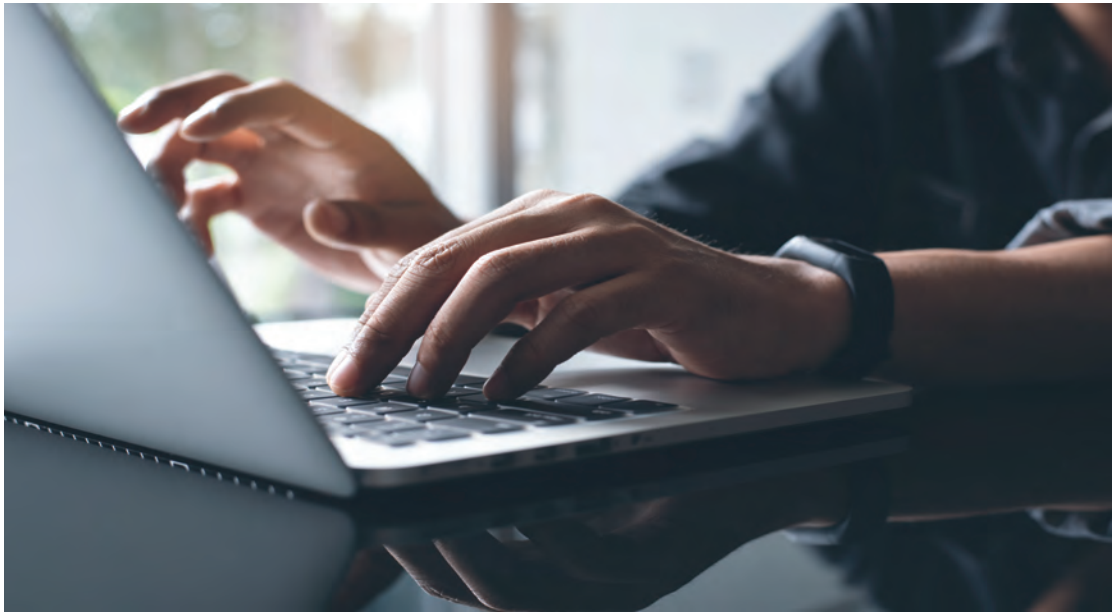


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Indigenous data sovereignty

Background

In an era characterized by dynamic shifts in data collection, storage, utilization, and dissemination, the concept of data sovereignty has become a subject of considerable interest (Open North & BCFNDGI, 2017).

In this context, Indigenous communities are increasingly advocating for greater control and ownership over their data. They are challenging the traditional approaches adopted by governments in utilizing Indigenous data for policy and program development in ways that fail to center Indigenous aspirations and priorities.

Indigenous data can be defined as “any information that is from or about any Indigenous person or their community, territory or nation, including but not limited to their languages, Knowledges, customs or traditions, intellectual property and ideas” (Indigenous Innovation Initiative 2021).

This includes data and knowledge collected and held both by Indigenous communities, Nations and organizations, as well data collected by external data agents (Kukutai & Taylor 2016; Carroll et al., 2019, 2022). Notwithstanding these broad definitions, the parameters of Indigenous data can solely be determined by the Indigenous communities themselves.

“At the heart of Indigenous Peoples’ demands for change are the enduring aspirations of self-determination over their institutions, resources, knowledge and information systems.” (Walter et al. 2021)

As custodians of their lands, and through direct engagement with the environment, Indigenous Peoples have accumulated a dynamic pool of knowledge that has evolved over hundreds or thousands of years. The principles of Indigenous land stewardship which are predominantly rooted in a deep familiarity with the surrounding ecosystems are referred to as Traditional Ecological Knowledge (TEK) (Robinson et. al 2021; Tengö et. al. 2014) .

Intergenerational data collection has been used by numerous Indigenous communities to inform distinct Indigenous practices, protocols and to support collective rights and interests (NCAI 2018; Rodriguez- Lonebear 2016).

Current data practices highlight the crucial need to center Indigenous worldviews in data collection that is relevant for Indigenous Peoples and that goes beyond the documentation of data on Indigenous Peoples’

social, economic, and demographic conditions. This involves using rights-based indicators that measure issues that are vital for the development and rights of Indigenous Peoples such as land and resource ownership, equitable involvement in decision-making processes, and autonomy in shaping their own developmental trajectories. It also involves collecting data on cultural dimensions, Indigenous ecological values, and the distinct connection between Indigenous Peoples and the natural environment (Kukulai & Walter 2015; United Nations 2004; Yap & Yu 2016).

Indigenous data sovereignty has been the response of Indigenous nations, communities and data activists towards their exclusion and lack of representation in data terrains (Lovett et al., 2019; Smith 2016).

The Indigenous data sovereignty movement has evolved into a global network driven by the objective of safeguarding Indigenous data from misappropriation, empowering Indigenous Peoples as the primary beneficiaries of their data and drawing attention to the power dynamics in current data practices (Carol et. al 2019, Daly et al., 2019; Lovett et al. 2019).

As a global, Indigenous-led movement, based on Indigenous understandings of sovereignty, Indigenous data sovereignty seeks to transform current approaches to data, by ensuring that Indigenous Peoples are the main beneficiaries of their data.

It also seeks to fill the requirement for disaggregated and contextualized Indigenous data that is relevant to Indigenous lived realities and differences and that is available for effective Indigenous governance (Lovett et al. 2019; Smith 2016).

Indigenous data sovereignty as a concept is supported by International Indigenous rights frameworks such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Indigenous data sovereignty offers an alternative vision for existing approaches to data, with potential benefits for both Indigenous and non-Indigenous communities (Pendergrast, 2019).

Indigenous data governance

Data governance involves the practice of making decisions and exerting authority over matters related to data. It establishes a structured framework of rights and responsibilities for processes involving information, determining which individuals are empowered to perform specific actions with particular data, when these actions can be taken, the contextual conditions under which they are permissible, and the methods to be employed (Plotkin 2021, p. 1).

Data governance encompasses a range of processes involving the activities of states, international organizations, local authorities and private entities concerning the

management, transmission, sharing, and overall utilization practices of data. Mechanisms involved for data governance may include legislation, common standards or terms of service agreements (Obendiek 2023, p. 4). Some issues involving data governance include the ownership, accessibility, and control of data (Bruhn, 2014).

The governance of Indigenous data involves the ability of Indigenous communities to internally steward and externally influence the use of data and be able to challenge and replace prevailing data narratives that disregard Indigenous perspectives. This is possible by adopting data that offers nuanced levels of disaggregation and reflects the ways that diverse Indigenous Peoples would like to tell their own stories (Carroll et al. 2019; Hudson et. al 2023; Walter et al. 2021).

The boundaries between data, information, and knowledge in Indigenous contexts are often more fluid compared to its sharp delineations in Western contexts. As a result, the governance of data for many Indigenous communities, includes both the governance of digital data as well as data arising from knowledge, language, and information (De Beer, 2016).

The status of Indigenous Peoples as political entities holding rights and interests in data regarding their peoples, lands, and resources, makes the relationship of Indigenous Peoples and Nations with Indigenous data distinct to the relationship held between racial or ethnic groups and data about their populations. (Caroll et. al 2019; Rainie et al. 2019; United Nations 2018).

Indigenous data governance refers to the structures, systems and policies through which Indigenous Peoples own, control and govern their data. Indigenous governments and communities require access to quality data to manage investments and outcomes related to community well-being (FNIGC, 2020). Access to data is a key mechanism for self-government, as it allows for measurement of progress towards specific objectives and evidence-based policy and program planning (BCFNDGI, 2018).

Indigenous jurisdiction over data involves a number of issues, which include the right to have meaningful participation in decisions around the collection, storage, access, dissemination and stewardship of data about Indigenous Peoples. It also entails establishing mechanisms to enhance communities capacity in gathering and utilizing data, with the aim of fostering their complete and active engagement in self-governance and development planning (Kukutai & Taylor 2016).

Indigenous Peoples exercise Indigenous data sovereignty through the intertwined processes of Indigenous data governance and decolonizing data. (Caroll et. al 2019). Decolonizing data involves Indigenous actors replacing external data norms with Indigenous systems that articulate the collection, access and use of data (Caroll et. al 2019). Some strategies toward decolonizing data systems include engaging in community-based initiatives to rebuild trust in research processes, enhancing the relevance, availability, quality, and accuracy of data collection, and producing data with the aim of advancing Indigenous self-determination (Rainie et al. 2017).

Smith (2016) suggests that many Indigenous Peoples are looking for 'culture-smart' data, which is information that "can be produced locally, captures local social units, conditions, priorities and concerns and is culturally informed and meaningful" (Smith 2016, p. 129). Culture-smart data leverages pre-existing Indigenous capacities and wisdom, possesses immediate real-world utility, and embodies collective identities, rights and concerns (Smith, 2016).



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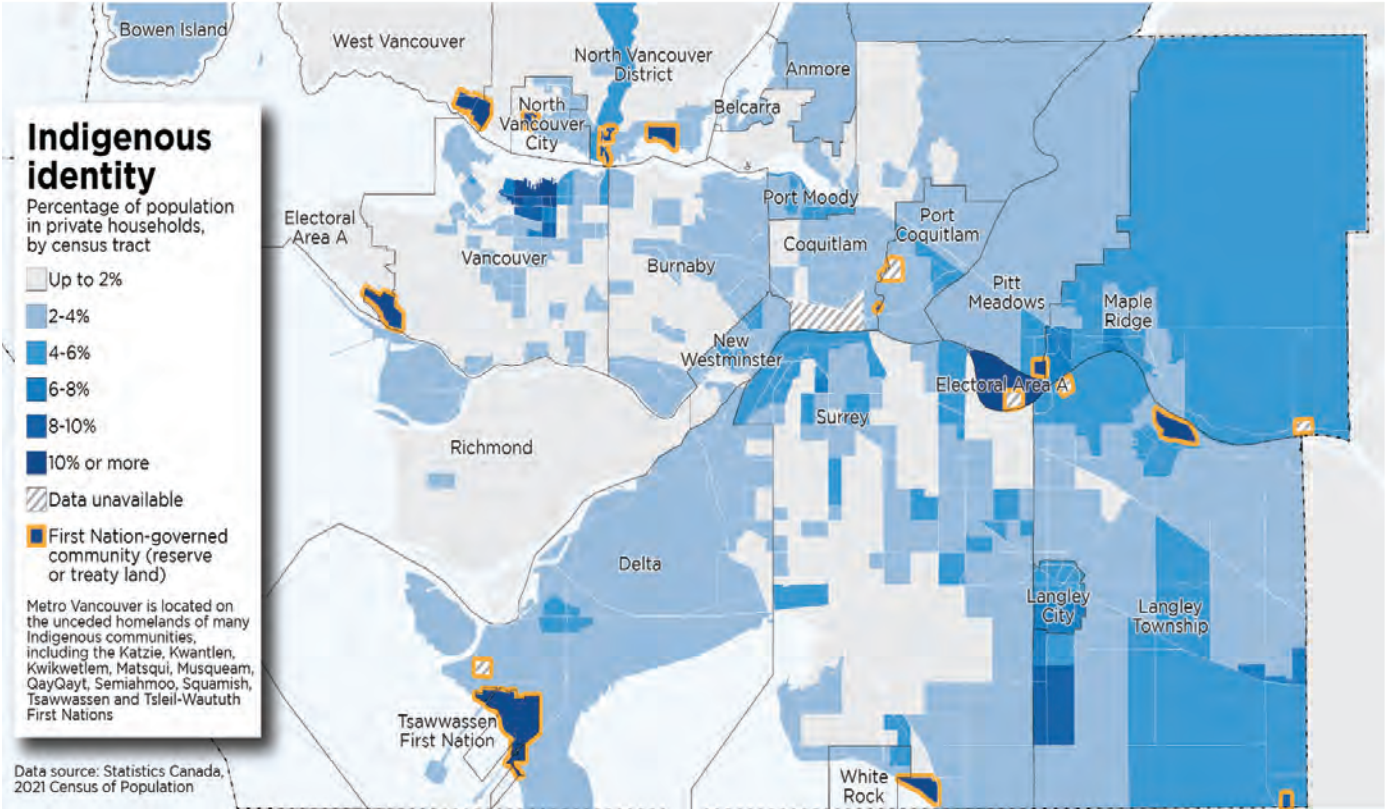


Figure 2: Map of the population with Indigenous identity across Metro Vancouver by census tract, 2021. (City of Vancouver, 2022)

Urban Indigenous communities in Vancouver

According to the 2021 Census, at least 14,660 people with Indigenous identity live in Vancouver. The Indigenous population is predominantly younger than the non-Indigenous population, and is expected to grow. (Statistics Canada, 2021) Urban Indigenous communities are resilient, dynamic and culturally diverse (MMIWG2S 2021; NAFC 2022). Urban Indigenous peoples often maintain ties to their communities of origin while seeking to become a significant and visible part of the urban landscape, and the majority feel they can make a positive difference in their urban homes. (Environics Institute , 2010)

Urban Indigenous individuals often carry multiple Indigenous ancestries and share experiences that traverse these identities. (MMIWG2S, 2021)

Notwithstanding these facts, Urban Indigenous communities and their priorities remain underrepresented in municipal government. Cities and municipal governments in Canada have exhibited a lack of active engagement and willingness when it comes to Indigenous community relations, often leaving matters regarding Indigenous Peoples to be addressed by the federal and provincial governments. This approach

has fostered an environment where cities have operated without considering the needs and concerns of its Urban Indigenous populations. (Heritz 2018; Gosnell-Myers 2022)

The location of cities on Indigenous lands, has frequently been overlooked in policy-making, disregarding government responsibility towards Indigenous Peoples who do not live on reserves and that require urban-based programming (Andrew & Graham 2014). All tiers of governance persist in evading the clarification of jurisdictional responsibility for Urban Indigenous populations, and fail to provide sufficient services for the overwhelming majority of Indigenous Peoples (Collier 2020; NAFC 2022; Snyder et al. 2015).

State policies have persisted in the notion that by leaving reserves and becoming city dwellers, Urban Indigenous communities have relinquished their rights to existing or future Indigenous rights, and to their identities and cultural heritage (Belanger 2011, 2013, Congress of Aboriginal Peoples 2019).

This has perpetuated the notion that Indigenous identity and urban environments are fundamentally incompatible, reinforced by the continuing belief that Indigenous Peoples are solely defined by their connection to the land, often idealized as a non-urban and romanticized space existing solely in pre-colonial history (Neale 2017).

These historical processes of state control over Indigenous self-determination have persisted today and continue to unfold.

The fact that Indigenous rights are not recognized and implemented in non-reserve and urban areas, has worked to keep Indigenous title, jurisdiction and rights as distinct from urban areas (Tomiak, 2018).

Federal policy has established a reserve-urban binary by recognizing First Nations as political communities while making no provisions for Urban Indigenous peoples. (Belanger 2013). Policies have often disregarded government responsibility towards Indigenous Peoples who do not live on reserves and that require urban-based programming (Andrew & Graham 2014).

The limited representation of political organizations has led to Urban Indigenous communities encountering difficulties in having their funding-related concerns addressed or in securing proper attention during the development of provincial and federal programs and policies (Peters, 2012).

Belanger (2013) argues regarding Indigenous community-making processes in cities: "Such processes reflect a spirit of self-determination historically advocated by Indigenous leaders and that reinforces ties to traditional lands, even those covered in concrete. Canadian policy has yet to catch up to this way of thinking, and federal officials have yet to reconcile themselves to the notion of Urban Aboriginal self-determination or, in this instance, the right of Aboriginals to self-administer appropriate programs in the city" (p. 79).



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“The tendency to ignore the political status of urban Indigenous peoples has created the impression that Canadian cities and towns are ‘off-limits’ when thinking about the meaning of Indigenous jurisdiction, nationhood, and self-determination.” (Horn, 2022)

Irrespective of the circumstances surrounding their relocation to urban areas, Urban Indigenous individuals retain their constitutional rights and Indigenous identities. In line with this, policies should address the specific needs and contributions of Urban Indigenous communities people while acknowledging their connections to the broader Indigenous communities across Canada (Andrew & Graham, 2014).



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UNDRIP and Urban Indigenous communities

The endorsement and implementation of UNDRIP presents an opportunity to envision new forms of Indigenous governance that transcend the traditional settler colonial framework of the "reserve-city" binary. UNDRIP offers Urban Indigenous communities a platform and structure to exert increased political influence within urban settings, aligning with their inherent right to self-determination (Horn, 2022).

The pressing needs of Urban Indigenous communities have led to demands for novel governance frameworks, and discussions regarding alternative organizational structures, programs, projects, and policies which consider the diversity of the Urban Indigenous population in Vancouver, and envisions self-governing systems that are not constrained by territorial boundaries but that focus on community and social organization (Todd, 2003).

Currently there still exists a significant disparity between the provision of services and the ease of access to these services for Urban Indigenous community members (NAFC, 2021). In response to inadequate public policy and services, urban Indigenous groups have established numerous Indigenous service delivery organizations, along with essential infrastructure such as educational authorities and shelters. These organizations and communities have developed culturally

informed operating standards around service provision and co-created solutions, as a collective response to community needs (MMIWG2S, 2021). Friendship Centers have particularly played a crucial role as self-determined, non-political Indigenous organizations that emerged in response to the need to support Indigenous communities in urban settings. (NAFC, n.d).

Establishing an Urban Indigenous data governance framework should be recognized as part of the municipal responsibility to create co-developed governance frameworks that embed and uphold the rights of Urban Indigenous communities.

In 2021, Vancouver became the first municipality in Canada to adopt and commit to implementing the UNDRIP. The City asserts that in this process, it is essential to take a distinctions-based approach that reflects the full diversity of Indigenous Peoples and their intersectional identities (City of Vancouver, 2022, p 10)

In implementing the UNDRIP, it is necessary to address the concerns of Urban Indigenous communities on the implications of the existing distinctions-based approach for diverse Urban Indigenous Peoples' representation and self-determination (ALIVE, 2020, 7). In order to meaningfully protect rights and address the challenges faced by communities, it is imperative for governments to transcend a purely distinctions-based



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categorization of First Nations, Inuit, and Métis, and take a more comprehensive inclusive and intersectional approach, addressing the distinct needs of the members of diverse Indigenous communities, taking into account multiple factors, including but not limited to, self-identification, residency on-reserve and off-reserve, and gender (ALIVE, 2020; MMIWG2S 2021; NAFC 2021).

A significant portion of UNDRIP's provisions relate to municipal actions. Adopting UNDRIP requires genuine efforts to actualize its principles. This includes meaningful consultation with Urban Indigenous groups as part of a commitment to establish a mutually beneficial governance partnership with Indigenous Peoples (Flynn & Alexander, 2021)

To promote the revitalization of Indigenous rights to self-determination, self-governance, land stewardship, service, and data sovereignty, it is essential to undertake the process of decolonizing City processes and transferring power to Indigenous communities.

The City is taking positive steps in this direction. In 2015, the City approved the first four-year Healthy City Strategy Action Plan. The Healthy City goals and targets promote safety, a sense of inclusion, and build connections between communities communities and individuals and align with the City of Reconciliation objectives (City of Vancouver, 2019).

The City is also partnering with Urban Indigenous organizations, namely the UIPAC and MVAEC, to increase the City’s engagement with the Urban Indigenous communities.

The Vancouver’s Urban Indigenous Peoples’ Advisory Committee (UIPAC) is an advisory body appointed to formally advise Council and staff on enhancing access and inclusion for Urban Indigenous Peoples to fully participate in City services and civic life. Included in the mandate of the UIPAC is to advise Council and City staff on the implementation of the City of Reconciliation Framework and the UNDRIP and to facilitate effective communication and consultation between the City and Urban Indigenous communities in Vancouver (City of Vancouver, n.d).

In 2022, the Task Force submitted the “Update Report of the UNDRIP Task Force to the City of Vancouver Mayor and Council” endorsed by the UIPAC. The report made a recommendation for Council to support six early actions which the Task Force considered to be high priority and that would help to create a path forward for further work to implement UNDRIP at the City, while also acknowledging that further engagement with the Urban Indigenous communities is needed (UNDRIP Task Force, 2022).

The Metro Vancouver Aboriginal Executive Council (MVAEC) is an umbrella organization serving 22 Indigenous service providers with policy development, advocacy and

“...UNDRIP in its entirety can be read as an expression of what the right to self-determination means in practical terms for Indigenous peoples” (Davis, 2016).

organizational leadership for Urban Indigenous Peoples. MVAEC has signed a Memorandum of understanding with the City, which emphasizes the need for a better model of collaborative governance and serves as a mechanism for the City to partner with Urban Indigenous service agencies and increase coordination, alignment and ability to address the priorities of communities (City of Vancouver, 2017).



Senákw development project

Decolonizing data at the City of Vancouver

Data on Indigenous communities intersects with issues of sovereignty, rights, and title, making it crucial for the City to develop datasets, methods and governance frameworks which support a more decolonized equitable and community-led approach to working with Indigenous data.

Among the initiatives of the City in the past few years to explore opportunities for this is the Interdepartmental Community of Practice for data equity and decolonization, which carries the objective of exploring these questions around decolonizing the City's methodology around data collection and governance as well as building capacity and relationships among City staff.

The Healthy City Strategy (HCS) was approved by City Council as Vancouver's overall social sustainability plan in 2014. The Healthy City Dashboard was created in engagement with Urban Indigenous groups as a tool to help people use data to work together to meet the goals of the HCS. The Dashboard aims to enhance data systems and to make existing population datasets accessible to more communities in the city, and highlights the importance of developing systems, methods, concepts, and indicators for understanding inequities through the lens of Indigenous knowledges and perspectives.

The Dashboard introduces a blueprint for collecting community-generated disaggregated data and establishing an Urban Indigenous

perspective on the characteristics of a healthy city. (KTCL, 2021)

The Healthy City Strategy continues to be implemented through parallel initiatives of community engagement, literature review and organizational support.

Concurrent to this Sustainability Scholars research, is a community engagement process, **PlanH**, underway through the BC Healthy Communities Society, which prioritizes the forging of relationships, engagements with Indigenous organizations and facilitates the development of partnerships by providing "learning opportunities, resources, and leading-edge practices for collaborative local action" (PlanH, n.d).

An parallel **engagement process** with the Urban Indigenous communities has been initiated by the City, through tabling at community events, key informant interviews with Indigenous community leaders, and data governance workshops in the community with Indigenous residents.

This process aims to further enhance an understanding of community perspectives on adapting and putting into practice principles and guidelines from existing data governance models with First Nations to meet the unique needs of Urban Indigenous communities.

It also aims to shift the City's position from an authoritative role to that of a collaborative partner in Indigenous relations and to decolonize its data processes.

The City has made progress in decolonizing its data processes with these initiatives. However there are certain issues which still need to be addressed. One of these involves the question of what sovereignty looks like in the particular context of non-identifying population-level data. The City carries a responsibility to use this data towards achieving its equity and decolonization goals but has a lesser capacity to control its collection and governance.

Continued engagement is needed with diverse Urban Indigenous groups and communities to co-develop data accountability frameworks that take a distinctions-based, cross-Indigenous, intersectional, and gender-based analysis plus (GBA plus) approach.

The formation of a governance framework which respects the distinct priorities and representatives of Urban Indigenous communities in Vancouver is essential to implementing the self-determination mandates of the UNDRIP. The City's efforts to facilitate greater data sovereignty for Urban Indigenous communities also paves the way for future opportunities to empower other equity-deserving communities and their control of data.



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UNDRIP

Articles relevant to Indigenous Self-determination and data governance

Article 3

Indigenous peoples have the right to self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.

Article 4

Indigenous peoples, in exercising their right to self-determination, have the right to autonomy or self-government in matters relating to their internal and local affairs, as well as ways and means for financing their autonomous functions.

Article 5

Indigenous peoples have the right to maintain and strengthen their distinct political, legal, economic, social and cultural institutions, while retaining their right to participate fully, if they so choose, in the political, economic, social and cultural life of the State.

Article 11

1. Indigenous peoples have the right to practise and revitalize their cultural traditions and customs. This includes the right to maintain, protect and develop the past, present and future manifestations of their cultures, such as archaeological and historical sites, artefacts, designs, ceremonies, technologies and visual and performing arts and literature.
2. States shall provide redress through effective mechanisms, which may include restitution, developed in conjunction with indigenous peoples, with respect to their cultural, intellectual, religious and spiritual property taken without their free, prior and informed consent or in violation of their laws, traditions and customs.

Article 15

1. Indigenous peoples have the right to the dignity and diversity of their cultures, traditions, histories and aspirations which shall be appropriately reflected in education and public information.

Article 18

Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own indigenous decision making institutions

Articles relevant to Indigenous Self-determination and data governance

Article 19

States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free, prior and informed consent before adopting and implementing legislative or administrative measures that may affect them.

Article 20

1. Indigenous peoples have the right to maintain and develop their political, economic and social systems or institutions, to be secure in the enjoyment of their own means of subsistence and development, and to engage freely in all their traditional and other economic activities.

Article 23

Indigenous peoples have the right to determine and develop priorities and strategies for exercising their right to development. In particular, indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them and, as far as possible, to administer such programmes through their own institutions.

Article 24

1. Indigenous peoples have the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals. Indigenous individuals also have the right to access, without any discrimination, to all social and health services.

2. Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.

Article 31

1. Indigenous peoples have the right to maintain, control, protect and develop their cultural heritage, traditional knowledge and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games and visual and performing arts. They also have the right to maintain, control, protect and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional cultural expressions.

2. In conjunction with Indigenous peoples, States shall take effective measures to recognize and protect the exercise of these rights.

Articles relevant to Indigenous Self-determination and data governance

Article 32

1. Indigenous peoples have the right to determine and develop priorities and strategies for the development or use of their lands or territories and other resources.
2. States shall consult and cooperate in good faith with the indigenous peoples concerned through their own representative institutions in order to obtain their free and informed consent prior to the approval of any project affecting their lands or territories and other resources, particularly in connection with the development, utilization or exploitation of mineral, water or other resources.
3. States shall provide effective mechanisms for just and fair redress for any such activities, and appropriate measures shall be taken to mitigate adverse environmental, economic, social, cultural or spiritual impact.

Article 33

1. Indigenous peoples have the right to determine their own identity or membership in accordance with their customs and traditions. This does not impair the right of indigenous individuals to obtain citizenship of the States in which they live.
2. Indigenous peoples have the right to determine the structures and to select the membership of their institutions in accordance with their own procedures.

Article 37

1. Indigenous peoples have the right to the recognition, observance and enforcement of treaties, agreements and other constructive arrangements concluded with States or their successors and to have States honour and respect such treaties, agreements and other constructive arrangements.
2. Nothing in this Declaration may be interpreted as diminishing or eliminating the rights of indigenous peoples contained in treaties, agreements and other constructive arrangements.

Article 38

States, in consultation and cooperation with indigenous peoples, shall take the appropriate measures, including legislative measures, to achieve the ends of this Declaration.

Article 42

The United Nations, its bodies, including the Permanent Forum on Indigenous Issues, and specialized agencies, including at the country level, and States shall promote respect for and full application of the provisions of this Declaration and follow up the effectiveness of this Declaration.

Directives for **Indigenous Data Sovereignty**

<p>UN Permanent Forum on Indigenous Issues (UNPFII)</p>	<p>In 2014, in the Outcome document of the World Conference on Indigenous Peoples, member states were called on to: “Commit themselves to working with Indigenous peoples to disaggregate data, as appropriate, or conduct surveys and to utilizing holistic indicators of Indigenous peoples’ well-being to address the situation and needs of indigenous peoples and individuals, in particular older persons, women, youth, children and persons with disabilities”</p>
<p>The Mataatua Declaration on Cultural and Intellectual Property</p>	<p>“Indigenous Peoples of the world have the right to self-determination and in exercising that right must be recognized as the exclusive owners of their cultural and intellectual property.”</p>
<p>The Report of the Royal Commission on Aboriginal Peoples (RCAP)</p>	<p>“The gathering of information and its subsequent use are inherently political. In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. The information gathered may or may not have been relevant to the questions, priorities and concerns of Aboriginal peoples. Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters.”</p>
<p>The Truth and Reconciliation Commission (TRC)</p>	<p>Article 19: “We call upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long term trends. Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services.”</p>
<p>The Declaration on the Rights of Indigenous Peoples Act (DRIPA)</p>	<p>“The purposes of this Act are as follows: a) to affirm the application of the Declaration [United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)] to the laws of British Columbia; b) to contribute to the implementation of the Declaration; c) to support the affirmation of, and develop relationships with, Indigenous governing bodies.”</p>
<p>Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls. MMIWG Calls for Justice</p>	<p>Goal 7, “Establish a culturally appropriate Indigenous data infrastructure reflective of Indigenous and 2SLGBTQQIA+ people, based on Indigenous data sovereignty and culturally rooted and distinctions-based indicators”</p> <p>5.24 “We call upon the federal government to amend data collection and intake-screening processes to gather distinctions-based and intersectional data about Indigenous women, girls, and 2SLGBTQQIA people”</p>


Indigenous Data Governance Principles




Figure 2: Indigenous Data Sovereignty Principles, based on the core principles of various Frameworks listed in Appendix DO

**Indigenous
Data
Governance
Frameworks**

Principles

<p>OCAP[®]</p> <p>First Nations Information Governance Centre (FNIGC)</p>	<ol style="list-style-type: none"> 1. Ownership 2. Control 3. Access 4. Possession 
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<p>Six Principles of Ethical Métis Research</p> <p>Métis Centre of the National Aboriginal Health Organization (NAHO)</p>	<ol style="list-style-type: none"> 1. Reciprocal Relationships 2. "Respect For" 3. Safe and Inclusive Environments: 4. Diversity: 5. "Research Should" 6. Métis Context 7. Evolving Principles 
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<p>National Inuit Strategy on Research (NISR)</p> <p>Inuit Tapiriit Kanatami Canada</p>	<ol style="list-style-type: none"> 1. Advance Inuit governance in research; 2. Enhance the ethical conduct of research; 3. Align funding with Inuit research priorities; 4. Ensure Inuit access, ownership, and control over data and information; 5. Build capacity in Inuit Nunangat research 
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Indigenous Data Governance	<h1>Principles</h1>
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<p style="color: #800000;">MaiaM Nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective (IDSC) Principles</p> <p style="color: #800000;">Australia</p>	<p>In Australia, Indigenous peoples have the right to:</p> <ol style="list-style-type: none"> 1.Exercise control of the data ecosystem including creation, development, stewardship, analysis, dissemination and infrastructure. 2.Data that is contextual and disaggregated (available and accessible at individual, community and First Nations levels). 3.Data that is relevant and empowers sustainable self-determination and effective self-governance. 4. Data structures that are accountable to Indigenous peoples and First Nations. 5. Data that is protective and respects our individual and collective interests. <div style="text-align: right; margin-top: 20px;">  <p><i>MaiaM nayri Wingara</i></p> </div>
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<p style="color: #800000;">Te Mana Raraunga (TMR) Māori Data Sovereignty</p> <p style="color: #800000;">Aotearoa New Zealand</p>	<ol style="list-style-type: none"> 1. Rangatiratanga (Authority) 2. Whakapapa (Relationships) 3. Whanaungatanga(Obligations) 4. Kotahitanga: (Collective benefit) 5. Manaakitanga (Reciprocity) 6. Kaitiakitanga Mahi (Guardianship) <div style="text-align: right; margin-top: 20px;">  </div>
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Indigenous Data Governance	Principles
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<p>US Indigenous Data Sovereignty Network (USIDSN)</p> <p>United States</p>	<ol style="list-style-type: none"> 1. Collective wellbeing, past & future oriented, across generation, equitable outcomes 2. Protection, ethics, responsibility, equal explanatory power, equitable outcomes 3. Inherent Sovereignty, self-determination, control, access 4. Relationships, responsibility, reciprocity, between nations and governments 5. Indigenous knowledge (honoring), reflexive of the people, relationship to the non-human world
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<p>CARE principles</p> <p>The Interntional Indigenous data sovereignty Interest Group</p> <p>The Research Data Alliance (RDA)</p>	<ol style="list-style-type: none"> 1. Collective Benefit 2. Authority to Control 3. Responsibility 4. Ethics 
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<p>SEEDS principles</p> <p>Collaboratory for Indigenous Data Governance</p>	<p>Offers a guiding framework for Indigenous Population Health data that:</p> <ol style="list-style-type: none"> 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 Peoples and settler states.
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**Indigenous
Data
Governance**

Principles

<p>Global Indigenous Data Alliance (GIDA) Initiative</p> <p>The Oñati Indigenous Data Sovereignty Communique</p>	<p>Findings:</p> <ol style="list-style-type: none"> 1. UNDRIP provides a necessary but insufficient foundation for the realization of Indigenous rights and interests in data. Indigenous Peoples also require Indigenous-designed legal and regulatory approaches founded on Indigenous Data Sovereignty principles. 2. While national Indigenous Data Sovereignty networks are best placed to respond to and progress data sovereignty for their peoples and communities, a global alliance is needed to advocate for and advance a shared vision for Indigenous Data Sovereignty. 3. The international focus on the protection of personal data and privacy rights is inadequate for Indigenous Peoples. There is an urgent need for the development and implementation of collective Indigenous privacy laws, regulations and standards.
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<p>GIDA- SÁPMI SÁMI Research governance network</p> <p>Norway</p>	<p>Objectives:</p> <ol style="list-style-type: none"> 1. to promote, adapt, and operationalise the CARE principles to the Nordic Sámi context; 2. to make the Nordic research community, memory and archival institutions aware of the Indigenous CARE principles; 3. to advance the discussion on Sámi data governance principles. 4. to strengthen Sámi data governance and Sámi research data for the needs of contemporary Sámi society.
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APPENDIX E

Mainstream
Data

Principles

FAIR Principles
for Data
Management
and
Stewardship

1. Findable
2. Accessible
3. Interoperable
4. Reusable

Open Data
Charter
Principles

1. Open by default
2. Timely and Comprehensive
3. Accessible and Usable
4. Comparable and Interoperable
5. For improved governance and citizen engagement
6. For inclusive development and innovation

STREAM
properties for
Industrial and
Commoditized
data

1. Sovereign
2. Trusted
3. Reusable
4. Exchangable
5. Actionable
6. Measurable

APPENDIX F

First Nations

Indigenous Data Governance Frameworks in Canada

<p>Alberta First Nations Information Governance Center (AFNIGC)</p>	<p>Background: "Since 2010, The Alberta First Nations Information Governance Centre has worked to promote ownership, control, access, and possession (OCAP®) of First Nations information for First Nation people"</p>
<p>Document: Framework for a Data Sharing Agreement. (n.d)</p>	<p>Goals: "To help determine First Nation priorities in data governance while working in partnership with government, universities, researchers, and other organizations. Outlines guidelines for a data partnership with First Nations, takes a community centered approach to information governance, data repatriation efforts, and fighting information poverty."</p>
<p>Mustimuhw Information Solutions Inc. (Through the BCFNDGI)</p>	<p>Background: "A data governance framework was created by and for First Nation communities that can be used in implementing and developing data governance capacities. Outlines the governance structures; accountability mechanisms; and governance, privacy, and security policies that work to prevent issues and protect individuals and their data. The document is accompanied by two policy manuals that can be updated and customized to meet the needs of individual Nations."</p>
<p>Document: Data Governance Framework (2015)</p>	<p>Goals: "A collection of strategy, structure, legislation and policy and related tools" that will "evolve and grow in iterative cycles of expansion and refinement" depending on the changing needs and capacities of First Nations."</p>
<p>First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC)</p>	<p>Background: "Designed to support the First Nations of Quebec as they take control of their information and give them tools to strengthen and organize it. Provides a key to defining the strategies to be adopted on how First Nations information should be gathered, preserved, protected, used, managed, accessed and shared"</p>
<p>Document: Quebec First Nations Information Governance Framework (2019)</p>	<p>Goals: "To raise awareness among First Nations about the issues related to information governance and changes in the environment that may hamper such governance. To have common First nations standards to protect information assets collectively and to act as a counterbalance to values imposed unilaterally by the State and public institutions. To identify the roles and responsibilities of each of the stakeholders in information governance by and for First nations. To support First nations in the development of mechanisms or in the adaptation of existing mechanisms to structure their information assets. To raise awareness among the partners of the First Nations about the principles of information governance by and for First Nations"</p>

First Nations

Indigenous Data Governance Frameworks in Canada

Manitoba First Nations Education Resource Centre	"A framework for First Nations and/or researchers contemplating research in First Nation communities in Manitoba"
Document: Guidelines for Ethical Research in Manitoba First Nations	Template for a data-sharing protocol (pg 35)
First Nations in Quebec and Labrador	Data-sharing agreement template (pg 76)
Document: First Nations in Quebec and Labrador's Research Protocol	" highlights three fundamental values to implement a collaborative research project between a First Nations community and researchers. These values are: Respect, Equity and Reciprocity. They must coexist and pave the way to any collaboration agreement for research projects, regardless of the discipline. These values have been inherent for First Nations from yesterday to today"
National Aboriginal Health Organisation (NAHO)	"provides practical guidance to communities interested in developing their own research policies and protocols. The most useful feature of this guide is its three templates to assist First Nations in the development of research policies and agreements."
Document: Considerations and templates for ethical research practices	
The Government of Yukon	" provides guidance for public bodies and organizations that are interested or required to share personal information."
Document: Information sharing agreement guidance and information sharing agreement template	

APPENDIX G


First Nations Data-sharing Agreements

Agreement	Partners	Background
First Nations in BC Tripartite Data Quality and Sharing Agreement (TDQSA)	First Nations Health Authority (FNHA), and The Province of British Columbia, The Government of Canada (ISC)	"A central aim of this agreement is to improve the quality of First Nations health data, to facilitate data sharing, and to ensure that these data are appropriately compiled, used and shared by the Parties. The agreement allowed for the creation of a First Nations Client File using an annual extraction of Indian Registry data held by AANDC and transferred to the BC Ministry of Health, which would act as the data custodian. Terms of the data transfer and custodianship are set out in a memorandum of understanding between the BC Ministry of Health and AANDC"
Tui'kn health partnership Strength In Numbers Project	The Eskasoni, Membertou, Potlotek, Wagmatcook, and Waycobah First Nations of Cape Breton, Nova	"As part of the Tui'kn partnership, the First Nations of Nova Scotia are working with provincial and federal partners to improve their access to reliable health information through the Strength in Numbers Project. This initiative has led to the creation of the Nova Scotia First Nations Client Linkage Registry, a registry of the First Nations population in Nova Scotia directly linked to provincial health data. This allows First Nations to better track a set of health indicators for their population. One of the key outcomes of this project is a data-sharing agreement between the First Nations and the Government of Nova Scotia"
Common Surveillance Plan Initiative	First Nations of Quebec and Labrador Health and Social Services Commission (FNQLHSSC, Quebec, Canada)	"The health surveillance framework is based in part on the common plan developed by the ministère de la Santé et des Services sociaux du Québec (MSSS). Although it lacks the specific indicators to develop it, the plan also draws on the health measurement framework of the EAGLE (Effects on Aboriginals from the Great Lakes Environment) project, which identified health indicators specific to First Nation communities and focused on holistic quality of life measures rather than health determinants. The inventory developed by the FNQLHSSC focuses on selected indicators that can be compared with other jurisdictions, but are also consistent with the cultural and historical background as well as data and reporting needs of Quebec First Nations."
The Institute for Clinical Evaluative Sciences (ICES) Indigenous Portfolio	ICES and the Chiefs of Ontario (COO)	"to ensure that First Nations' data sovereignty is upheld in decisions regarding the use of First Nations identifiers in data held at ICES".
	ICES and the Métis Nation of Ontario (MNO)	"a data governance and data sharing agreement that has enabled linkage to an updated version of the MNO Citizenship Registry and ensures that any use of data identifying Métis people aligns with the collective priorities of the MNO."
	ICES and Tungasuvvingat Inuit	"to formalize a partnership through a shared statement of values, to enable Inuit-specific research in Ontario in a manner that is grounded in Inuit Qaujimajatuqangit, a body of knowledge which encompasses Inuit worldviews and is guided by six principles"

APPENDIX H


**Urban
Indigenous
Communities**
Data-sharing Agreements

In comparison to other contexts, Canada exhibits a noticeable absence of a well-established culture and consistent practice of collecting race and ethnicity data. This deficiency was highlighted during the COVID-19 pandemic (McKenzie, 2020; Sheikh et al, 2023). This lack of data collection is also evident in the absence of comprehensive municipal disaggregated data strategies in Canada. The Data for Equity Strategy of the City of Toronto exemplifies one strategy to collect, share and use socio-demographic data to inform program planning and service delivery that addresses Municipal lack of disaggregated data in Canada in a way that is accountable to equity-seeking groups. The report provides a good roadmap for the City of Vancouver as a municipal approach that prioritizes Indigenous data governance in its Indigenous data collection processes, facilitating meaningful Indigenous involvement and leadership in data collection, protection, utilization, and sharing.

Initiative	Organisation	Aims	Summary
<p>Data for Equity Strategy</p> 	The City of Toronto	<p>“To support the collection of sociodemographic data and use of disaggregated data, to Inform program planning, policy development and service delivery that is inclusive of and responsive to the needs of all Torontonians, particularly Indigenous, Black and equity-seeking groups and to support equitable, evidence-based and accountable decision-making”</p>	<p>“Processes to collect socio-demographic data and analyze and report on disaggregated data will consider principles of:</p> <ul style="list-style-type: none"> ▪ OCAP® as a model. ▪ the importance of relationship building and collaboration ▪ reciprocity and accountability. ▪ Data to benefit not harm ▪ The need for community consultation and a need to mitigate distrust around data collection due to colonial harms <p>“The establishment of a First Nations Inuit and Metis Data and Research Circle to provide support, guidance and advice to City divisions and partners on collecting and using Indigenous data. The Circle will be established with collaboration and advice from the Aboriginal Affairs Advisory Committee.”</p>

Urban Indigenous Communities

Data-sharing Agreements




Initiative	Organisation	Aims	Summary
<p>Our Health Counts, Urban Indigenous Health Database Project</p>  <p>Well Living House</p>	<p>Well Living House</p>	<p>Well Living House is an action research center for Indigenous infants, children, and their families' health and well-being</p>	<p>"Partnerships: Several urban communities are part of this multi-phased project. To date, the urban centers included in this project are Ottawa, Hamilton, Toronto, London, and Kenora. Since the inception of this project, an urban Indigenous health information, knowledge, and evaluation (HIKE) network has formed. The HIKE network includes influential representatives from each urban community and members of the research team to share ideas, findings, tools, and resources"</p>

A study by the Our Health Counts project (Rotondi et al., 2017) implemented a community-based, respondent-driven method to point to a severe undercount of the Indigenous population in Toronto and demonstrated that the Indigenous population may have been two to four times larger than census estimates.

The study points that:
 "alternative sampling strategies such as RDS (respondent driven sampling) in conjunction with community-based partnerships may be added to the other tools used to ensure that individuals are accurately enumerated across all subgroups and jurisdictions, thereby improving healthcare access and equity for these marginalized communities" (p.7)

APPENDIX I

Other
Data Initiatives

Initiative	Objectives
 <p>RDA RESEARCH DATA ALLIANCE</p>	<p>“building the social and technical infrastructure to enable open sharing and re-use of data.”</p> <p>“RDA has a grass-roots, inclusive approach covering all data lifecycle stages, engaging data producers, users and stewards, addressing data exchange, processing, and storage. It has succeeded in creating the neutral social platform where international research data experts meet to exchange” views and to agree on topics including social hurdles on data sharing, education and training challenges, data management plans and certification of data repositories, disciplinary and interdisciplinary interoperability, as well as technological aspects.</p>
<p>The International Indigenous Data Sovereignty Interest Group (at the RDA)</p>	<p>“Through more effective collaboration, we seek to provide a highly visible international platform for ID-Sov that integrates and leverages existing ID-sov groups to create new opportunities for research and outreach. We also seek to attract new stakeholders beyond our current networks, including researchers, data users and indigenous communities. To that end all three existing ID-Sov networks have developed strong relationships with Indigenous stakeholders including tribes, Non Governmental Organisations, and Indigenous policy institutes, and researchers.”</p>
<p>Collaboratory for Indigenous data governance</p>	<p>“Develops research, policy, and practice innovations for Indigenous data sovereignty. Indigenous data sovereignty draws on the UN Declaration on the Rights of Indigenous Peoples that reaffirms the rights of Indigenous nations to control data about their peoples, lands, and resources.”</p>
 <p>WE ALL COUNT project for equity in data science</p>	<p>“A systematic process that provides you with a set of tools, checklists, and practices that allow you to identify and understand each place in your work where you are embedding a worldview or prioritizing a lived experience. It equips you and your team to make those choices intentionally in a way that achieves the equity goals you have identified for your work.”</p> <div style="text-align: center;">  <p>SEVEN STEP FRAMEWORK</p> </div>

APPENDIX J

Two cases

Of Indigenous data misuse

1. Research conducted with the Nuu-chah-nulth First Nation (B.C,Canada)

This case involves the collection of blood samples by Dr. Richard Ward between 1982 and 1985 under the guise of a \$330,000 Health Canada funded study of arthritis amongst Nuu-chah-nulth people, to conduct the then largest-ever genetic study of a First Nations population in Canada. After he failed to find any genetic markers in the DNA, Ward shelved the study, took on different positions at universities, used the blood himself, loaned it to other researchers. The samples were used to produce hundreds of academic papers on diverse (non-arthritis) related papers. Ward was eventually awarded a Chair at Oxford University as a direct result of this research.

University officials and researchers, worked with the community to recover the blood samples in 2004. During the return of the samples, the Nuu-chah-nulth established an independent research ethics panel to evaluate research protocols and played a role in shaping the Canadian Institutes for Health Research's Guidelines for Health Research Involving Aboriginal People (2007-2010). These guidelines introduced the notion of "DNA on loan," ensuring that participatory research with Indigenous peoples also includes the handling, storage, and use of biological samples. (Garrison et al. 2019; Wiwch ar, 2004)

2. Research conducted with the Havasupai Tribe (Arizona,USA)

In 1990, more than 400 members of the Havasupai Tribe gave consent for the collection of their DNA samples by an Arizona State University researcher, in the hope that they might provide genetic clues to the Tribe's devastating rate of diabetes. The study failed to find a genetic link to diabetes. However, the samples were used to study other issues including mental illness and theories of the tribe's geographical origins that contradict their traditional stories.

The Tribe filed a lawsuit in 2004 for a lack of informed consent and the misuse of genetic materials. The case settled in April 2010, and the university agreed to provide financial compensation, scholarships and assistance to obtain funds for a clinic and school, and the return of the DNA samples. (Harmon, 2010; Garrison et al. 2019)

APPENDIX K

(HCD) **Healthy City Dashboard**



Figure 3: City of Vancouver, Healthy City Strategy with Indigenous Lens based on medicine wheel.