# The Need for First Nations Collaboration and Co-development in Digital Research Infrastructure (DRI)

#### Introduction

As Canada further establishes its Digital Research Infrastructure (DRI) and continues to develop research data management (RDM) policy, it is integral to the vitality of these systems that they are co-developed with First Nations. This paper will outline the case for First Nations active collaboration and inclusion to help the New Digital Research Infrastructure Organization (NDRIO) meet its requirements to establish an accountable and sustainable research ecosystem for all users [1], including First Nations.

The First Nations Information Governance Centre (FNIGC) is an incorporated non-profit organization operating with a special mandate from the Assembly of First Nations (Resolution #48, December 2009). Our vision is that every First Nation will achieve data sovereignty in alignment with its distinct world view. With First Nations, we assert data sovereignty and support the development of First Nations information governance and management at the community level through regional and national partnerships. We are strictly apolitical and technical and serve as a tool wielded by First Nations through our governance.

FNIGC holds the trademark for the First Nations Principles of OCAP®, which stand for ownership, control, access, and possession of First Nations data by First Nations. 'First Nation data' means information in any form:

- About First Nations people like health, jobs, and housing;
- From First Nations like languages, patterns, songs, dances; and
- About First Nations reserve and traditional lands, waters, resources, and the environment

First Nations data sovereignty is the inherent right of First Nations to exert authority over First Nations information and means this data is subject to the laws of the First Nation. First Nations rights to data sovereignty extend to their citizens as individuals as well as their collective rights as nations and governments. First Nations data sovereignty is an integral part of rights to self-determination and self-government outlined in the *United Nations Declaration on the Rights of Indigenous Peoples*.

The Canadian data regime holds massive amounts of First Nations data. Non-First Nation governments, academics, and the private sector engage with this data every day. In light of First Nations data sovereignty, it is critical that First Nations are not only consulted in the development and implementation of new open data and open government policies and procedures, but are brought in as co-developers. It is essential, not only for the assertion of First Nations data sovereignty but for the efficacy of the policies that Canada is currently trying to develop, that First Nations are given the opportunity to actively participate in this work.

The Government of Canada is currently undergoing transformation towards an Open Data and Open Government approach. This is a significant backdrop to NDRIO's mandate in establishing a DRI ecosystem that is accountable, agile, strategic, and sustainable [1]. NDRIO will wield considerable power as it develops policy, distributes funds, and supports research data

management tools and standards that will facilitate an easy transition toward Open Data <sup>[2]</sup>. In so doing, NDRIO must ensure to establish a DRI ecosystem that:

- 1. Respects First Nations data sovereignty and the First Nations Principles of OCAP®;
- 2. Meets Canada's stated commitment to co-development [3];
- 3. Is responsive to the unique context surrounding First Nations data; and
- 4. Allows for strategic and sustainable growth of Canadian and First Nations data systems.

#### Current Issues

Historically First Nations people and communities have been mined for their data and information usually without compensation, benefit, or recognition from researchers or the Canadian state. This knowledge has been used to settle First Nations lands, foster a non-Indigenous economy, and build the wealth of the country. It has permitted the growth of the Canadian state and the wellbeing of its citizens, while Canada simultaneously worked to impoverish First Nations and dismantle First Nation political and economic systems. This disruption has resulted in the current data context in Canada. The Canadian data regime has had centuries to develop a foundation of legislation and policy to inform the collection and use of data and First Nations have no option but to subscribe to this system. Lack of equitable funding and opportunity to engage in this space has restricted First Nations ability to develop their own technical capacity and data infrastructure.

With the rapid development of RDM and DRI policies and tools, yet again First Nations are at risk of being left behind, despite federal commitments for co-development and engagement [4]. Canadian research data management has largely been overseen by non-Indigenous academic circles, non-governmental organizations, and professional networks. Collectively these entities wield the power to dictate how RDM will be implemented in Canada, especially as the state moves towards an Open Government and Open Data approach. First Nations leadership and experts have not had the opportunity to actively participate in this dialogue nor have they been given sufficient support in the development of data regimes of their own. This discrepancy, coupled with the over collection and use of First Nations data, has led to the Canadian regime having significant power over First Nations data. This infringes upon First Nations data sovereignty, as First Nations data is being collected, accessed, used, published, shared, and stored without First Nations oversight and often without their knowledge or consent.

First Nations governments and organizations understand the value and necessity of appropriate RDM that is not only sustainable but flexible, protective, and aligned with a respective First Nation's world view. These concerns predate Canada's open data initiatives and the establishment of NDRIO. Many First Nations understand the value of open data and are keen to promote respectful engagement with First Nations data. They also understand the consequences of making all data open without due regard for First Nations data sovereignty. Not only is a lack of collaboration and co-development of data policy, systems, and tools problematic for First Nations, it is problematic for the Canadian data regime as well. Canadian data authorities have had little opportunity to engage with First Nations to learn about and understand how First Nations wish to collect, use, and define their data. This has a two-fold effect. First, we run the risk that Canadian data authorities will develop systems and policies that are not alert to and thus do not respect First Nations data sovereignty and the principles of OCAP®. Second, it strips

those systems of the opportunity to establish Nation-to-Nation relations or the ability to integrate easily with First Nations data systems. Broadly subscribing to default restriction of Indigenous data ensures that First Nations data cannot be misappropriated by non-First Nation researchers, but if done without First Nations consent it dissolves any opportunity for First Nations to connect, share, and open their own data as they see fit. Without the active involvement of First Nations throughout all processes of developing new DRI, Canada is in danger of developing a system that is not truly open.

## Bridging the Gaps

Ensuring that First Nations and NDRIO are able to co-develop and implement mutually effective policies, tools, and services within the DRI will require active engagement from both parties. Below are several suggestions to explore how to bridge the gap between where we are today and how we can achieve success and mutual benefit in the future:

- Including First Nations in active dialogue on how to appropriately protect their own data and allow for interaction of that data within the Canadian DRI. Co-developing policies, resources, and tools with First Nations will allow for the creation of systems that can restrict, limit, and share First Nations data with flexibility and to whatever degree the respective Nation chooses.
- Providing opportunities for First Nations to appoint technical advisors and political leaders to represent their interests in dialogue with Canadian experts and data leaders. The creation of a joint technical table of First Nations, as well as Indigenous and non-Indigenous experts, could address the two key issues of: (i) development and implementation of Canadian systems, tools, and protocols that respect First Nations data sovereignty, and (ii) development and implementation of First Nations systems, tools, and protocols necessary to exercise their data sovereignty.
- Education and training will play a significant role in the success of this work. Canadian data experts and leaders could benefit from OCAP® training and cultural awareness training that would support successful collaboration and engagement with First Nations. Conversely, First Nations will need opportunities and capacity support, including funding for training to support their technical capacity within the data space as needed.
- Finally, access to equitable funding for First Nations to collaborate with the Canadian data regime as well as develop their own data structures that can interface with the Canadian system and protect First Nations data on their own terms.

## Future State of DRI

First Nations governments require timely access to quality data in order to plan for the future, deliver the services their citizens need and expect, and to make informed decisions in a rapidly-growing global digital environment. The First Nations Data Governance Strategy (FNDGS) sets

out the vision for a First Nations-led, national network of regional information governance centres across the country equipped with the knowledge, skills, and infrastructure to serve the information needs of their citizens. The strategy is rooted in community-driven and Nation-based collaborative approaches and charts the path necessary to further advance First Nations' self-determination.

FNIGC envisions a future where First Nations have achieved data sovereignty in alignment with their unique worldview. This requires a DRI ecosystem that not only respects First Nations rights but is flexible and adaptable enough to meet the needs of the Canadian State and the First Nations who share these lands. The interoperability of the Canadian DRI should be able to navigate the distinctions between worldviews and accommodate any assertion of the First Nations Principles of OCAP®. This means sophisticated and well-informed systems and policies, as well as educated and enthusiastic data authorities within the Canadian data regime. FNIGC has developed education and training resources on First Nations Data Sovereignty and the principles of OCAP® with this goal in mind.

We are confident that such a system can exist. Ideas for strong and effective collaboration can be drawn from the Tui'kn Partnership in Nova Scotia, which allows five distinct Mi'kmaq communities, district health authorities, the province, and Health Canada to share the Mi'kmaq citizen's data across systems for research, analysis and project planning, under the direction of the First Nations [5]. The foundational element of this partnership is that the First Nations always retain their ability to access their information and can implement restrictions as they see fit. Research projects stemming from this partnership carry mutual benefit for the Canadian parties involved as well as the Mi'kmaq. There are similar structures in Ontario and British Columbia [6]. These examples highlight that establishing channels of communication and dialogue between the Canadian DRI and First Nations will support its overall vitality.

Participants within these conversations need to be knowledgeable not only in the technical aspects of data but in the real-life applications of data as well. It is integral that First Nations are able to select representatives who have experience in how First Nations view data differently from the Canadian state, but also the unique ways First Nations data and people are at risk within the current Canadian DRI. It is not possible for data authorities without this lived experience to recognize the implicit biases or problems their policies and systems may create for First Nations. A mutually beneficial and successful future of DRI is one where the Canadian data regime accepts this reality and prioritizes collaboration and co-development with First Nations.

### Conclusion

NDRIO is at the precipice of foundational change for not only the Canadian data regime, but also for First Nations. FNIGC urges NDRIO to remember that their work does not happen within a vacuum and, for First Nations especially, their decisions will have significant impacts on data management and data policy. As Canada consolidates its RDM regime and moves towards an Open Data and Open Government approach, it is critical that First Nations are brought to every table for collaboration and co-development. Prioritizing the inclusion of First Nations is the only way to ensure that NDRIO implements policy, funds research and provides services that benefit all parties. NDRIO has the ability to create opportunities for co-development and collaboration

as a move towards reconciliation with First Nations and not repeat the establishment of exclusionary practice by data authorities of the past.

## References

- [1] New Digital Research Infrastructure Organization. (2020). NDRIO Homepage. Retrieved November 24, 2020 from: https://www.engagedri.ca
- [2] Minister of Innovation Science and Economic Development. (2019, August 07). Digital Research Infrastructure. Retrieved November 24, 2020 from: https://www.ic.gc.ca/eic/site/136.nsf/eng/home
- [3] Treasury Board of Canada Secretariat. (2020, October 09). Canada's 2018-2020 National Action Plan on Open Government. Retrieved November 24, 2020 from: https://www.open.canada.ca/en/content/canadas-2018-2020-national-action-plan-open-government
- [4] Assembly of First Nations. (2019, June). *Recommendation 18*. Honouring our Ancestors by Trailblazing a Path to the Future: Interim Report of the Joint Advisory Committee on Fiscal Relations for Engagement Purposes. Retrieved November 27, 2020 from: https://www.afn.ca/wp-content/uploads/2019/11/Interim-Report-of-the-Joint-Advisory-Committee-on-Fiscal-Relations-Jun...4.pdf
- [5] Tui'kn Partnership. (n.d.). Tui'kn Partnership: Because Health Belongs to Us All. Retrieved November 27, 2020 from: http://www.tuikn.ca/about-tuikn/collaborative-projects/
- [6] Walker, J., Pyper, E., Chong, N., Jones, C.R., Legge, D., Khan, S., and Schull, M.J. (2018) Unlocking First Nations Health Information Through Data Linkage. *International Journal of Population Data Science*, *3*(1). Retrieved from: https://www.researchgate.net/publication/325308082\_Unlocking\_First \_\_Nations\_health\_information\_through\_data\_linkage
- [7] The First Nations Health Council. (2010, April 16). First Nations in B.C> Tripartite Data Quality and Sharing Agreement. Retrieved November 27, 2020 from: http://fnhc.ca/pdf/BC\_Tripartite\_Data\_Quality\_and\_Sharing\_Agreement\_-\_SIGNED\_COPY.pdf