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Pathways to First Nations' data and information sovereignty

First Nations Information Governance Centre (FNIGC)¹

Introduction

In 1994, the Government of Canada launched three major national longitudinal health surveys that excluded First Nations people even though, at that time, the greatest data gap existed for First Nations people living 'on reserve'. The federal government eventually moved to address this deficiency with a new supplemental survey, subsequently named the First Nations and Inuit Regional Health Survey (RHS), to collect data on reserve. To try to ensure the success of the new survey, a group of First Nations representatives came together from coast to coast, formulated the RHS Steering Committee and took over the project and resources from the Canadian Government. The RHS project created space in the Canadian research environment in which to progress rapidly towards data jurisdiction and it helped secure the environment for data and information sovereignty that fundamentally changed the way that research on and with First Nations was conducted in Canada.

¹ The original version of this chapter was presented on behalf of the FNIGC by Ceal Tournier (Chairperson of the FNIGC) at the Academy of the Social Sciences in Australia workshop 'Indigenous data sovereignty: current practice and future needs', Canberra, 9–10 July 2015.

This chapter outlines the steps taken by First Nations, and the First Nations Indigenous Governance Centre (FNIGC) on their behalf, towards giving expression and practical meaning to the concept of indigenous data sovereignty in Canada. It begins by explaining the preconditions for this development in the decades of dubious research practices in regard to indigenous peoples. It then traces the origins of the RHS, before examining the construction of ideas and principles of data ownership, control, access and possession that are now a registered trademark (OCAP®: ‘ownership, control, access and possession’) of the FNIGC (AFN 2007). Finally, the mechanisms that give practical expression to OCAP® are detailed.

A gift from the people

In the world view of First Nations, the conduct of the Regional Health Survey (RHS) in 1997 was by them and for them, and the processes and principles of OCAP® that stemmed from it came from ‘the people’. Rooted in self-determination and inherent rights, within the context of data and information management, the cultural framework of the RHS was the foundation from which many tools, documents, theories and mechanisms regarding data sovereignty emerged and matured.

The success of the work on this survey—past, present and into the future—is directly attributed to the support, investment and vigilance of First Nations people at the grassroots and leadership levels. Without this, no success would ever have been achieved and no foundational principles would have been developed to challenge the status quo in research, data collection, data holdings and stewardship. This body of thought, along with the obligation to ensure its integrity in appropriate contextual applications, was entrusted to a regionally representative steering committee, which transitioned over time to become the FNIGC. This work has had a transformational impact on the status quo, the credit for which needs to remain with *the people*.

This trust obligation requires the FNIGC to ensure that the products that come from the work of *the people* are attributed rightfully back to the people in a manner that is recognisable and attached to its initial formulation. It is for this reason that appropriate citation in the written world is credited back to *the people* through reference to the mandated custodians of this endeavour, the FNIGC. It is also

why sanction is sought from, and given by, the FNIGC to the veracity and application of these principles and processes in third-party documents and applications. It is because of the strength of the First Nations' teachings and the support and encouragement given by the people that this work was accomplished. The work, therefore, must be appropriately recognised and attributed.

Data: a renewable resource

First Nations recognise that information is a resource that has value and that First Nations' information has value to First Nations. In a practical sense, information can be used to advise policy and decision-making, it enhances understanding of a particular area of study and it can be used to leverage funding for specific purposes. For example, information about the health conditions of First Nations allows them to identify particular risks and to target programs to mitigate those risks. First Nations' information also has value to the extent that it is a representation of the knowledge, status and conditions of a community.

First Nations' information also has value to non-natives. In the context of research, information can lead to academic prestige and advancement. It can also be used by the Crown to influence its policy and decision-making vis-a-vis First Nations. First Nations' information also has financial value to entities such as pharmaceutical companies, resource development companies and others. To put it more succinctly, the problems with the use of First Nations' information stem from who is in control—and thus what gets done, how it is done and who knows about it. The question of whose interests are served is central. And, of course, there is a clear advantage for those who collect and control data and information over those who provide the data and seek to benefit from that contribution. As aptly expressed by Ceal Tournier, Chair of the FNIGC, 'he who controls the data controls the gold' (Tournier 2002).

First Nations themselves are the only ones who have the knowledge and authority to balance the potential benefits and harms associated with the collection and use of their information. There is no law or concept in Western society that recognises inherent community rights and interests in data and information. First Nations' principles of

OCAP® arose in this context. As a more general expression of OCAP®, First Nations own their information; therefore, First Nations govern their information in the same way that jurisdiction is exercised over First Nations' lands.

When First Nations' information is viewed as a resource, with value to both First Nations and non-First Nations, it is easier to see that the governance of that resource is part of a First Nation's inherent right. Inherent right, as it relates to First Nations, implies having the requisite jurisdictional authorities to enact laws and implement governing structures, institutions and processes along with institutional capacities to formulate policies, to design, deliver and evaluate programs, as well as to develop financial, technical and human resource capacities. First Nations' governance and self-governance also imply jurisdictional authorities and institutional capacities in respect of research and information (FNIGC 2003: 4–5). First Nations' citizens and leaders acknowledge and act on the premise that information needs defending and protecting; just as we protect our lands, our forests, our animals and our fish, we need to protect our data, which are an extremely valuable renewable resource.

The need for First Nations' data jurisdiction

In hindsight, it is clear that the stage was set for the developments that resulted in the FNIGC taking complete control of the first RHS and developing OCAP®. Quite simply, First Nations people and their communities recognised that they had been subjects of dubious research practices for decades. While the phrase 'we've been researched to death' has been said too many times to cite, there is more to this than just a view about the volume of research, as it also derives from recurring grievances about research and researchers over the years. The American Indian Law Center has catalogued an extensive list of such complaints and these provide the backdrop from which OCAP® emerges (AILC 1999).

To paraphrase from this source, First Nations have been the subject of too much irrelevant research, with the majority of research projects initiated by, paid for and carried out by non-indigenous people from universities, government and industry. Accordingly, researchers have tended to select subjects of personal or academic interest,

or of interest to the larger society, and have often not been interested in First Nations' priorities. In this way, they have frequently preempted meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start. For their part, governments gather administrative and other data on First Nations often without their knowledge or consent and both they and researchers analyse, interpret and report First Nations' data, often without consent, approval, review or input by First Nations representatives.

Part of the problem here is the fact that research funding is largely controlled by a few external agents and is generally not accessible to community groups and First Nations organisations, with the result that researchers have profited professionally and economically from First Nations research without employing local people or compensating research subjects; they have often treated First Nations as merely a source of data and have pressured community authorities and individuals to support or consent to a project because it is 'good for the community' rather than asking community members what kinds of projects might serve their needs. In this way, individuals have felt pressured to participate in studies or other data-gathering processes because community authorities have consented or are involved. They have been persuaded to participate in research without fully understanding risks to health and safety or the potential application or misapplication of research outcomes. First Nations have been led to believe that participation in research projects is necessary to maintain their right to services.

On the matter of informed consent, researchers have not explained their studies in a language or manner to fully ensure this and they have treated First Nations researchers as informants, rather than colleagues, and have appropriated or failed to acknowledge some of their work. Research results are often not returned to the community or, if they are, they are returned in a form or language that is inaccessible. Although community elders consider certain researchers unworthy to speak the community's truths, researchers rely primarily on peers and funding agencies to confer their speaking rights. Even where good rapport has been built, members of a research team can often be replaced with people who are not known or trusted by the community members.

Other issues of research integrity include the observation that researchers have not respected individual or community confidentiality to the same degree that they would for non-First Nations people and that they often disrespect the basic human dignity of participants or their religious, spiritual or cultural beliefs. As examples of this, they have collected First Nations' genetic material for purposes that are demeaning to the dignity of First Nations communities and individuals and have gathered information on dissident indigenous groups that has later been used against them by repressive regimes (for example, in South America). Researchers have also disregarded cultural taboos and secrecy by publicising (and sometimes profiting from) sensitive cultural information. They have also presented cultural information out of context and drawn inaccurate conclusions. Human remains and cultural property have been taken for storage, display in museums or sale, and information made available by researchers has been distorted, appropriated and treated as a commodity. For example, First Nations legends and stories have been used for movies, books and toys, while spiritual practices and ceremonies have been adapted and often marketed to practitioners of New Age spirituality. Researchers, particularly from government and industry, have collected information about traditional remedies—sometimes under false pretences—in a search for medicines to be patented and used for commercial gain and they have used leftover portions of blood samples for secondary research without consent. Finally, researchers have recklessly sensationalised problems among First Nations, without regard for the impact on communities or their social and political interests. Their research tends to focus on problems without looking at the positive and it often portrays First Nations people as solely poor, sick, dependent, violent and child-like. Not surprisingly, given this catalogue of complaint, the benefits of research to First Nations individuals and communities are frequently unclear.

Examples abound of the misuse and abuse of First Nations' information and many of those who stimulated the articulation of OCAP® are drawn from the field of community health information. An infamous example is provided by the Nuuchah-nulth First Nation 'Bad Blood' research. Between 1982 and 1985, University of British Columbia (UBC) researcher Dr Richard (Ryk) Ward took 883 vials of blood from the Nuuchah-nulth people under the guise of a \$330,000 Health Canada-funded study of arthritis among the nation. In 1986, Ward left UBC

and moved to the University of Utah and then to Oxford University, taking the blood samples with him, collecting research grants and furthering his own academic career. He subsequently published over 200 research reports based on the blood samples in areas as diverse as HIV/AIDS and population genetics. Ward even used the blood samples to support his theories about migration across the Bering Strait, entirely disrespecting and undermining the Nuuchah-nulth traditional beliefs about Creation (Wiwchar 2004).

Another example involves the misuse of community health information of the Havasupai Tribe in Arizona. In the early 1990s, the tribe approved a diabetes study including genetic analysis by Arizona State University researchers. Without consent, the data were subsequently used for published research on in-breeding, anthropological migration patterns and schizophrenia (Rubin 2004). Likewise, in the 1970s, the Barrow Alcohol Study on alcoholism in an Alaskan community released its unfavourable findings at a press conference at the researchers' university in Philadelphia. Not only did this lead to internal stigmatisation by people from Barrow and nearby Alaskan communities, it also resulted in the devaluation of the municipality's Standard & Poor's bond rating to the economic detriment of the entire community (Kaufman & Ramarao 2005).

An equally troubling example of the Canadian Government's management of First Nations' information is the Non-Insured Health Benefits (NIHB) database controlled by Health Canada. NIHB holds an enormous amount of information about First Nations beneficiaries' use of health services and goods such as prescription drugs, medical transportation, dental care and medical devices. In 2001, Health Canada began releasing comprehensive pharmacy claims data to Brogan Inc., a health consulting and analysis firm that then offered the NIHB data for sale to pharmaceutical companies for their own research use. Health Canada removed personally identifying information from the data that were given to Brogan, but community identifiers remained. First Nations were not advised that their health data were being given to private companies or being sold to pharmaceutical companies until 2007. In 2007, Health Canada, having already agreed to extend Brogan's access to NIHB data for an additional five years, advised the Assembly of First Nations and provided a copy of the agreement. The rationale provided by Health Canada for disclosing the data was that personally identifying information had been removed and there

were no longer any privacy interests attached, and that Health Canada felt that if Brogan made an 'Access to Information Act' request, the pharmaceutical use information would have to be disclosed anyway. Those involved in the Brogan disclosure had no concept whatsoever that First Nations would have an interest in such commercial use of their data. In 2010, Brogan amalgamated with IMS Health, a global company that provides information, services and technology to the health care industry. According to the IMS/Brogan website, NIHB data continue to be provided to the global company, available for sale to IMS clients (IMS Health Inc. 2014).

Government officials, researchers and corporations may or may not understand, support or even be aware of the aspirations of First Nations. They may not prioritise these and may even be at odds with community interests. Nonetheless, these other 'users' of First Nations' data are often seen as unbiased experts, endorsed by others with power, able to speak with authority about First Nations realities.

It was in this environment in 1995 that First Nations representatives from each region of Canada found themselves called to Ottawa to discuss the opportunity of helping the Medical Services Branch (MSB) of Health Canada (now First Nations & Inuit Health Branch) to implement a national health survey on First Nations reserves. At this time, the issue of First Nations jurisdiction over all matters including ownership of information was at the forefront of First Nations' political thinking. Innocuous as that invitation may have appeared, it led to a positioning by the First Nations caucus that established RHS as the new '*red standard*' approach to conducting survey work in First Nations communities (AFN & FNIGC 2007: v). The RHS thereby became the first national survey to be fully owned, controlled and stewarded by First Nations. Nothing like it had ever been successfully completed anywhere in the world. Concepts such as full ownership of data and intellectual property by First Nations, First Nations stewardship of data and government access through a limited licence to use were to become essential elements of the original RHS and they form the backbone of the OCAP® principles as they exist today.

The vehicle: the First Nations Regional Health Survey (RHS)

In 1996, the Assembly of First Nations (AFN) Chiefs Committee on Health (CCOH) mandated that a First Nations health survey be implemented every four years across Canada. This mandate came as a result of activities that began in 1994, when three major national longitudinal surveys were launched by the federal government, which specifically excluded First Nations living on reserve and in northern First Nations communities. These decisions subsequently led MSB to extend the aforementioned invitation.

The first RHS took place in 1997. The survey was implemented to address First Nations and Inuit health and wellbeing issues while acknowledging the need for First Nations to control their own health information. The survey design sought to balance First Nations content with content from comparable Canadian surveys while remaining culturally and scientifically valid. Community participation in all aspects of design, collection and analysis assisted in communicating both the need for and the relevance of the RHS to every First Nation in Canada. Space was made in the survey design to allow for region-specific inquiry or enhancement. The groundwork for future development and capacity in information governance was being laid but, most importantly, it ensured that the data were beneficial and relevant to the local community. Governance and accountability mechanisms were developed and implemented.

Although the resulting data were invaluable, helping to generate program resources in several key public and community health areas, First Nations were acutely aware of the opportunity to utilise the RHS as a vehicle to move the benchmark ahead in favour of First Nations' data jurisdiction and ensure the continued forward momentum of sovereignty over data, information, knowledge and stories. It was from the work of the RHS that the concepts inherent to data jurisdiction were articulated.

The fuel: OCAP®

OCAP® has been described as a ‘political response to colonialism and the role of knowledge production in reproducing colonial relations’ (Espey 2002: 6). Much of the impetus for OCAP® can be linked to the sorry history of research involving First Nations people in Canada described earlier. According to the report of the Royal Commission on Aboriginal Peoples:

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. (Canada Royal Commission on Aboriginal Peoples 1996: 498)

OCAP® is self-determination applied to collective data, information and knowledge. It is a response to being ‘researched to death’ and offers a way forward for First Nations research and information management. Originally known as ‘access, control and ownership’, the principles were named during a 1998 brainstorming session of the RHS National Steering Committee (now FNIGC). Cathryn George of the Association of Iroquois and Allied Indians is credited with arranging the original concepts into ‘OCA’—a more resonant acronym with its nod to the 1990 OKA Crisis between Mohawk people and the town of Oka in Quebec. The ‘P’ was soon added to create OCAP® when the FNIGC recognised the importance of considering ‘possession’ of First Nations’ data and the rights and limitations associated with it under Canadian law.

The notions inherent in OCAP® are not new. The term’s salience lies in the fact that it crystallised themes advocated by First Nations for years. Inherently internalised in the context of history, treaty rights and resourcing opportunities by First Nations, OCAP® was not understood or respected in all venues of data and knowledge generation. Those who felt threatened deliberately attempted to manipulate OCAP® understanding to ensure their continued unfettered access to First Nations’ data, information and resources.

These continued attempts to manipulate OCAP® definitions led not only to the supplemental descriptions published by the FNIGC, but also to the protection of the concepts through Canadian trademark law. OCAP® is also an expression of First Nations' jurisdiction over information about the First Nation. The descriptions below are useful to provide understanding of the context of the OCAP®; however, they are not a definition. OCAP® goes beyond the strict definition of each word in the acronym. It represents principles and values that are intertwined and reflective of First Nations' view of jurisdiction and collective rights. As Bonnie Healy² explained:

[W]e cannot pick and choose which elements of OCAP® that will be followed. They are one. We cannot ignore 'ownership' or 'possession' any more than the Four Directions can omit the East or the North.

Nonetheless, the various components can be described as follows:

- **Ownership:** The notion of ownership refers to the relationship of a First Nations community to its cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns their personal information. Ownership is distinct from stewardship. The stewardship or custodianship of data or information by an institution that is accountable to the group is a mechanism through which ownership may be maintained.
- **Control:** The aspirations and inherent rights of First Nations to maintain and regain control of all aspects of their lives and institutions extend to information and data. The principle of 'control' asserts that First Nations people, their communities and representative bodies must control how information about them is collected, used and disclosed. The element of control extends to all aspects of information management, from collection of data to the use, disclosure and ultimate destruction of data.
- **Access:** First Nations must have access to information and data about themselves and their communities, regardless of where it is held. The principle also refers to the right of First Nations

² Operations Manager, Alberta FNIGC, former FNIGC board member and officer speaking at an OCAP® information session at the invitation of Aboriginal Affairs and Northern Development. FNIGC, Ottawa, 14 January 2013.

communities and organisations to manage and make decisions regarding who can access their collective information.

- **Possession:** While ‘ownership’ identifies the relationship between a people and their data, possession reflects the state of stewardship of data. First Nations possession puts data within First Nations’ jurisdiction and, therefore, within First Nations’ control. Possession is the mechanism by which to assert and protect ownership and control. First Nations generally exercise little or no control over data that are in the possession of others, particularly other governments.

The mechanics: making it all work

To give practical expression to these principles and values, the FNIGC also developed a set of governance and structural supports to ensure that data sovereignty was achieved and protected. These include the following.

Code of research ethics

The Code of Research Ethics (FNIGC 2016) (a framework that originated as part of the RHS project) has been revised to reflect the evolving needs of the FNIGC and the information governance principles of the First Nations regions participating in the RHS and other data-collection processes. The RHS Code of Research Ethics protocol for access to data is entirely logical and has been used as a template by many First Nations information governance systems. It requires approval by the national governing body³ for access to national-level First Nations’ data, while access to regional-level First Nations’ data must be authorised by the regional First Nations organisations. Finally, community-level data cannot be accessed without the direct consent of the First Nation involved. This protocol respects and reflects the governance structure and unique processes that exist within the contemporary First Nations’ organisational structure.

3 Originally, the First Nations Information Governance Committee, and now the First Nations Information Governance Centre.

Privacy impact assessments

Mindful that the survey respondents participating in the RHS share very personal and often sensitive information, the RHS has also been very vigilant in the protection of personal privacy. Independent privacy impact assessments have been conducted and updated, and policies and procedures regarding privacy and security have been implemented. The RHS continues to meet the highest standards of personal privacy protection. OCAP® is the application of the collective privacy of the First Nation.

Cultural framework

The FNIGC's RHS *Cultural framework* (FNIGC 2004), among other things, reconciles a First Nation or indigenous world view with the need to collect data and conduct research. It presents a framework from which data on the health and wellbeing of First Nations can be collected, used and presented in a manner that is meaningful to First Nations peoples and communities.

Incorporation

The RHS was 'hosted' by several organisations in its formative years. Jokingly referred to as the 'foster child of First Nations' institutions', it bounced from home to home until getting the gentle push from then national chief Phil Fontaine while he hosted at the AFN, stating, 'it's time you move out and establish the required arm's-length distance from which the RHS and FNIGC credibility cannot be challenged'. It was a timely turning point, as the FNIGC committee had recently explored the trademarking of OCAP® and it was aware that a legal entity would be required to hold that trademark 'in trust' for the First Nations of Canada. With a flood of documents, papers and presentations purporting to assert what OCAP was and was not, it was time to protect OCAP® as the tenement of the First Nations' world view of data jurisdiction and governance. Therein, on 22 April 2010, the First Nations Information Governance Committee became the First Nations Information Governance *Centre*, absorbing the committee members as directors of the board.

The FNIGC has a clear mandate to make the most of research and information that will truly benefit the health and wellbeing of First Nations. It strives to partner with entities that seek to achieve success in working with First Nations through the use of credible information and processes that respect First Nations' jurisdiction to own, protect and control how their information is collected, disclosed and published.

OCAP® certification

The FNIGC has a special role in advocacy and education involving OCAP®. Immediately on incorporation, the board pursued the trademarking of OCAP® as a protective measure against misuse, misapplication or improper interpretation of what OCAP® actually means and how it is to be applied. This requires the development of and then adherence to a trade certification process. The OCAP® certification process will be a valuable tool that can be used to establish OCAP® credentials for research projects or information management systems. The process itself will also result in the publication of more information about OCAP® standards, adding to the knowledge base for those interested in First Nations research and information management.

Conclusion: achieving indigenous data jurisdiction

In Canada, it is from the premise that First Nations are accountable to their membership for the use and management of community information that First Nations will exercise jurisdiction in relation to information governance. This authority is based on inherent and treaty rights supported by international instruments such as the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). Internationally, indigenous political leaders, technicians and administrators must be aware of the impact that ignoring their sovereign and inherent rights over data and information will have on their citizens and territories into the future. Leaders in all sectors will need to provide direction on how information can be used to benefit the community in a manner that mitigates any harm. In addition, those

responsible for outlining a plan of action will need to be well versed in their relevant constitutional and legal frameworks. In Canada, some examples include:

- **Jurisdiction:** First Nations can exercise jurisdiction through enacting privacy, OCAP® and access to information laws in their community. These laws can govern how community information may be used and under what circumstances. It can also address personal privacy concerns.
- **Policies and procedures:** These can be developed to provide direction on the protection of personal and collective privacy. They can describe what requirements are needed for data-sharing agreements or licences to use contracts. Policies may define the relationship with outside contractors and researchers, ensuring that supplementary publication is controlled and approved.
- **Repatriation:** First Nations should investigate where their information/data are held or collected and consider how they can exert governance over those data. Federal and provincial governments, universities and other organisations hold First Nations' data. Governance can be exerted ideally through repatriation of the data back to the First Nation. Where repatriation is not possible or practical, data governance agreements or data-sharing contracts can be negotiated to effectively maintain First Nations' control over their data (see Hudson et al., Hudson, and Jansen, this volume for examples of this from Aotearoa/New Zealand).

The concepts of OCAP® can be applied by indigenous peoples worldwide, although approaches may need to be modified. Every indigenous population will face opportunities, as well as challenges, as they strive to exert jurisdiction over their data and information. The most important element is to make a start. From the FNIGC's experience, this would involve gathering or inviting a representative group of concerned indigenous citizens whose *only* focus is data jurisdiction and then ensuring there are no conflicts between that objective and individual biases or conflicts. Following an examination of the operating environment, a plan of attack should be drawn up that guarantees success. This would involve utilising every tool, law, initiative and mechanism available to capture one of the most important renewable resources of modern times: data. There will be

a need, as well, to examine the impacts of 'open government, open data' initiatives, and to weigh the benefits and the consequences to the local indigenous populations.

In Canada, as First Nations take control of their own data and participate in a society in which digital recordkeeping is the norm, the importance of OCAP® has grown from a set of principles and standards for the conduct of research to a path for First Nations' information governance. While it may appear that there are many barriers to OCAP® implementation, there are equally many tools that can be used to overcome those barriers. The examples contained in this chapter assure that success can and will be achieved but it must be based on the local reality, environment and construct of laws. OCAP® is a path to First Nations' information governance. By building information governance capacity, enacting our own laws, entering into data-sharing and licence-to-use contracts, creating regional data centres and repatriating our data, First Nations are getting closer to exercising full jurisdiction over our information.

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