



Ownership, Control, Access and Possession (OCAP™): The Path to First Nations Information Governance



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Introduction

The First Nations Information Governance Committee published its first paper on OCAP™ in 2002. Since that time OCAP™ has become ubiquitous. It is the *de facto* standard for conducting research on First Nations, and has grown beyond research to include the governance of all First Nations information. OCAP™ has been successfully applied in communities across Canada, as communities are increasingly asserting jurisdiction over their own data. Yet there are also many myths and barriers associated with OCAP™. One of the positive by-products of this has been the trademarking of OCAP™ through The First Nations Information Governance Centre.

This paper will update the 2002 paper, reviewing the origins and rationale for OCAP™, looking at some successful case studies, and considering where OCAP™ goes from here.

Background

Originally coined as “OCA” —a more resonant acronym with its nod to the 1990 “Oka Crisis”—OCAP™ continues to change the way that First Nations research and information governance is viewed. “Ownership, Control and Access” originated during a 1998 brainstorming session of the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey (RHS). The original acronym has been attributed to committee member, Cathryn George, representing the Association of Iroquois and Allied Indians. The “P” was added to create OCAP™ soon thereafter when the committee recognized the importance of considering “possession” of First Nations data and the rights and limitations associated with possession.

Since that time, the National Steering Committee transitioned to the First Nations Information Governance Committee, and in 2010 was ultimately incorporated into The First Nations Information Governance Centre, with a mandate from the National Chiefs in Assembly.

The notions inherent in OCAP™ are not new. The term’s salience lies in the fact that it crystallizes themes advocated by First Nations for years. Although there may be a good degree of consensus, the interpretation of OCAP™ is unique to each First Nation community or region. OCAP™ is not a doctrine or a prescription. It is a set of

principles that reflect First Nation commitments to use and share information in a way that brings benefit to the community while minimizing harm. It is also an expression of First Nation jurisdiction over information about the First Nation.

The descriptions below are useful to provide some understanding of the context of the term 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' world-view of jurisdiction and collective rights. Bonnie Healy¹ explained: "We 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."

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 communities and organizations 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 Nation

¹ Bonnie Healy: Operations Manager, Alberta First Nations Information Governance Centre; former Board Member and Officer, The First Nations Information Governance Centre, speaking at an OCAP™ Information Session at the invitation of Aboriginal Affairs and Northern Development, January 14, 2013.

possession puts data within First Nation jurisdiction and therefore, within First Nation control. Possession is the mechanism to assert and protect ownership and control. First Nations generally exercise little or no control over data that is in the possession of others, particularly other governments.

Why OCAP™?

OCAP™ has been described as “a political response to colonialism and the role of knowledge production in reproducing colonial relations.”² 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.³

“We’ve been researched to death.” It is a continuing refrain in First Nation communities.

To understand what it means, consider some of the recurring grievances about data collection and research on First Nations over the years. These complaints provide the backdrop out of which OCAP™ emerged:⁴

- First Nations have been subject to too much research.
- The majority of research projects are initiated, paid for and carried out by non-First Nations from universities, government and industry.

² Espey, Jennifer “Stewardship and OCAP: A Discussion Paper for the First Nations Statistical Institute” May, 2002.

³ Canada. Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples*. Volume 3: Gathering Strength. Chapter 5 pp. 4 (1997).

⁴ 5 Some items have been adapted from: American Indian Law Center Inc. Model Tribal Research Code. With Materials for Tribal Regulation for Research and Checklist for Indian Health Boards. 3rd edition (September 1999).

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- Researchers have selected subjects of personal or academic interest or of interest to the larger society, but have not been interested in First Nations priorities.
- Researchers have pre-empted meaningful community involvement by presenting completed research designs, often already funded, for community approval rather than collaborating from the start.
- Governments gather administrative and other data on First Nations without their knowledge or consent.
- Governments gather data on First Nations that is far beyond their needs for the administration of programs and services. First Nations have no influence over the use or disclosure of that data.
- First Nations data is analyzed, interpreted and reported on without consent, approval, review or input by First Nations.
- Researchers have profited professionally and economically from First Nations research without employing local people or compensating research subjects.
- Researchers have treated First Nations as merely a source of data.
- First Nations have been led to believe that disclosure of their information is necessary in order to continue receiving certain programs and services.
- Researchers have not explained their studies in a language or manner adequate to ensure fully informed consent.
- Researchers have treated First Nations researchers as “informants” rather than colleagues and have appropriated or failed to acknowledge their work.
- After building good rapport, members of a research team have been replaced with people that community members don’t know or trust.
- Research has disrespected basic human dignity of participants or their religious, spiritual or cultural beliefs.
- Researchers have collected First Nations genetic material for purposes that are demeaning to the dignity of First Nations communities and individuals.
- Human remains and cultural property have been expropriated for storage or for display in museums, or for sale.
- Researchers, particularly from governments and industry, have collected information about traditional remedies, sometimes under false pretenses, in a search for patentable medicines and commercial gain.
- Researchers have claimed ownership and used biological samples taken from First Nation participants, for secondary research, without consent.
- Researchers have recklessly sensationalized problems among First Nations, without regard for impact on communities or their social and political interests.

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- Research focuses on problems without looking at the positive, and has often portrayed First Nations as poor, sick, dependent, and violent.
- Research results are not returned to the community or they are returned in a form or language that is inaccessible.
- Benefits to First Nations individuals and communities are often unclear.
- A holistic view of potential harm to First Nations is not considered.

One example of the misuse and abuse of community health information include the Nuuchah-nulth First Nation “Bad Blood” research. Between 1982 and 1985, University of British Columbia 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 amongst the nation. In 1986 Ward left UBC and moved to the University of Utah, and then to Oxford University – taking the blood samples, collecting research grants and furthering his own academic career. He subsequently published over 200 research reports based on the blood 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.⁵

Another example involves the misuse of community health information of the Havasupai Tribe in Arizona. In the early 1990’s the tribe approved a diabetes study including genetic analysis, by Arizona State University researchers. Without consent, the data was subsequently used for published research on in-breeding, anthropological migration patterns, and schizophrenia.⁶

Likewise, in the 1970’s 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 stigmatization by people from Barrow and nearby Alaskan communities, but it resulted in the devaluation of the municipality’s Standard & Poor’s bond rating, to the economic detriment of the entire community.⁷

⁵ “Nuuchah-nulth blood returns to west coast” Ha-Shilth-Sa, Vol. 31 – No. 25 – Dec. 16, 2004.

⁶ Rubin, P. “Indian Givers” Pheonix New Times May 27, 2004.

⁷ Kaufman and Ramarao “Community confidentiality, consent, and the individual research process: Implications for demographic research” *Population Research and Policy Review*. Vol 24, No. 2, April 2005 at 149.

An equally troubling example of the Canadian government's management of First Nations information is the non-insured health benefits database (NIHB) controlled by Health Canada. NIHB holds an enormous amount of information about First Nation 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 was given to Brogan, but community-identifiers remained.

First Nations were never advised that their health data was 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 5 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 that 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 healthcare industry. According to the IMS|Brogan website, NIHB data continues to be provided to the global company, available for sale to IMS clients.⁸

Government officials, researchers and corporations may or may not understand, support or even be aware of the aspirations of First Nations. They may not prioritize 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.

To put it more succinctly, the problems with use of First Nations information stems 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

⁸ <http://imsbrogansolutions.com/main.php?i=22&t=services>

is an unambiguous relationship between control and benefit. As aptly put by Ceal Tournier, chair of The First Nations Information Governance Centre:

“He who controls the data controls the gold.”⁹

How Information Management and Research Have Tried to Adapt

Ethical guidelines, and their enforcers— Research Ethics Boards— are designed to rein in the researchers and encourage/ensure appropriate research practices. They aim to mitigate a power differential between researchers and subjects and, of interest here, between researchers and First Nation communities or groups.

In Canada, the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS), adopted by the three major funding agencies¹⁰ and the standard used by most universities, established a standard for the ethical review of research, which applies as a condition of funding by those agencies. Approximately 10 years after the TCPS was released, a new “Revised Draft Chapter 9” was released: “Research Involving Aboriginal Peoples in Canada and CIHR Guidelines for Health Research involving Aboriginal Peoples.”

The TCPS reflects a pan-Aboriginalization of concepts of “participatory research” and “community involvement”, the incorporation of “traditional knowledge”, “culturally appropriate” and “community- based” research methods. These are all consistent with OCAP™, but the TCPS does not reflect the specific priorities and values of First Nations as a distinct ethnic and political group, with established governance structures and processes for community engagement. Rather than acknowledging OCAP™ as reflecting universal First Nation values, it places OCAP™ as just one consideration for some First Nations, which may conflict with their own institutional policies. Under the title “Respect for Community Customs and Codes of Practice” at Article 9.8, the Tri-Council provides its understanding of OCAP™:

⁹ Tournier, Ceal, “Don’t be on the other side of the digital divide: An overview of Current Health Information Initiatives Impacting Aboriginal Peoples” [Live address]. February 12, 2002. Delivered as part of the Aboriginal Health Information Symposium held in Ottawa, February 11-13, 2002.

¹⁰ The Canadian Institutes of Health Research, the Social Science and Humanities Research Council and the Natural Sciences and Engineering Research Council.

Many First Nations communities across Canada have adopted an ethics code originally developed to govern practice in the First Nations Regional Longitudinal Health Survey. The code asserts ownership of, control of, access to, and possession (OCAP) of research processes affecting participant communities, and the resulting data. OCAP addresses issues of privacy, intellectual property, data custody and secondary use of data, which are also covered later in this chapter.

...

Researchers should consult their own institutions to ensure that the application of OCAP or other community-based ethics codes is consistent with institutional policies. Where divergences exist, they should be addressed and resolved prior to the commencement of the research.

From the perspective of First Nations, the TCPS guidelines are a form of government and academic *self-regulation*. Government and the academic research “community” have their own set of rules and expectations for how members should behave. The rules may or may not be in the best interests of First Nation communities. Only First Nation communities are able to determine whether something is in their best interest. Determinations by outside Boards may meet the requirements of government and other institutions, but they do not meet First Nation requirements under OCAP™.

The existing research ethics guidelines and the Research Ethics Boards (REB’s) that apply them can provide a (sometimes false) sense of security that ethics are ‘being taken care of’. Unfortunately, the guidelines and REB’s are not necessarily able to adequately address First Nations research issues or values regarding information governance. While self-regulation is entirely understandable and well intentioned, it can have the ironic effect of precluding direct First Nations’ regulation of research.

Clearly the policy and procedural framework¹¹ for government and universities do not consider First Nations information governance as a priority. Nonetheless, OCAP™ is incrementally finding its way into both types of institution, in a very practical way. As First Nations and First Nation-controlled organizations are becoming the stewards of their own data, other potential users of that data, such as government and universities, are recognizing the value in accessing that data for

¹¹ The legal landscape for government also creates significant barriers, which will be discussed below.

research or administrative purposes. Through First Nation stewardship of First Nation data, First Nations are able to ensure that service contracts, data sharing agreements, licenses to use and other forms of legal agreement whereby First Nations information is shared with other institutions, contain all of the necessary provisions to protect First Nations OCAP™ of the data. This is often met with very strong resistance from institutions that are historically resistant to change. But it has also provided excellent opportunities for education and information sharing about OCAP™, resulting in some models for partnership – some of which will be described below.

First Nations Inherent Right and Jurisdiction over Information and Research

Information is a resource and has value. 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 can be used to leverage funding for identified weaknesses. For example, information about First Nations health conditions allows First Nations to identify particular risks and 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-First Nations. 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-à-vis First Nations. First Nations information also has financial value to entities such as pharmaceutical companies, resource development companies, and others.

Yet that same information can also harm a community. It can lead to discrimination and stigmatization, and has led to the many complaints and damages discussed above. The misuse of information can also harm relationships and lead to mistrust.

First Nations themselves are the only ones that 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 recognizes community rights and interests in 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 Nation 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, institution and processes; and the institutional capacities to formulate policies, design, deliver and evaluate programs, as well as to develop financial, technical and human resource capacities. First Nations governance and self-governance also implies jurisdictional authorities and institutional capacities in respect of research and information.¹²

How can First Nations exercise jurisdiction in relation to information governance? It starts with the premise that First Nations are accountable to their membership for the use and management of community information. Leadership will then provide direction on how information can be used to benefit the community in a manner that mitigates any harm. Some examples include:

- First Nations can exercise jurisdiction through enacting privacy laws in their community and access to information laws. These laws can govern how community information can be used and under what circumstances. It can also address protection of personal privacy.
- Policies and procedures could also be developed that provide direction on the protection of personal privacy and community privacy (and security).
- First Nations should investigate where First Nations information/data is held or collected and consider how they can exert governance over that data. Federal and provincial governments, universities, and other organizations 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 agreements be reached that effectively maintain First Nation control over data.

¹² Submission of the First Nations Centre at the National Aboriginal Health Organization to the House of House of Commons Standing Committee on Aboriginal Affairs, Northern Development and Natural Resources on the Proposed First Nations Fiscal and Statistical Management Act (Bill C-19), prepared by Effie Panousos for the First Nations Centre, June 2003, p.p. 4-5

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There are many examples of First Nations in regions across Canada exercising jurisdiction over their information. What follows are just four examples of First Nation-driven initiatives that considered OCAP™ as a priority from the outset and have designed information systems that respect First Nations ownership and jurisdiction over information in innovative ways to meet the needs and capacities of the First Nations involved.

OCAP™ in Action

The First Nations Information Governance Centre (FNIGC) and The First Nations Regional Health Survey

It is fitting to start at the birthplace of the term OCAP™.

In 1996, the Assembly of First Nations Chiefs Committee on Health 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 that specifically excluded First Nations living on-reserve and in northern First Nation communities.

The first RHS took place in 1997 (RHS 1997) and involved First Nations and Inuit from across Canada. The survey was implemented to address First Nations and Inuit health and well-being issues while acknowledging the need for First Nations and Inuit to control their own health information. RHS 1997 is commonly referred to as the pilot survey.

The survey design phase sought to balance First Nations content with content from comparable Canadian surveys while remaining culturally and scientifically valid. The RHS also incorporated sensitive issues such as HIV/AIDS, suicide and mental health. The adult and youth questionnaires included these topics as well as questions on residential school, alcohol and drug use and sexual activity. In addition, the survey design allowed for a region-specific survey module.

The RHS Phase 1 was implemented in 2002-03 with the addition of two new regions, the Yukon and Northwest Territories. At the same time, the Inuit withdrew from the RHS process. Data collection for RHS Phase 1 began in the fall of 2002 and was completed in mid-2003.

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The RHS Phase 2 was initiated in 2008 and completed in the fall of 2010. The target sample for Phase 2 was 30,000 First Nations individuals in 250 First Nations communities in the 10 participating regions in Canada. For RHS Phase 2 (2008/10), the questionnaire content underwent extensive reviews and revisions. The adult survey now includes questions about migration, food security, violence, care giving, depression, the health utilities index and gambling. The youth survey includes questions on community wellness and the children's survey has added questions on immunization.

Community participation in all aspects of design collection and analysis continues to ensure that the data are relevant and the governance and accountability mechanisms are appropriate.

An independent review was completed by Harvard University's Project on American Indian Economic Development in 2006. The Harvard Review Team found that the RHS Phase 1 (2002/03) iteration of the survey was technically rigorous, included numerous improvements over the RHS 1997 pilot survey and had many advantages relative to other surveys internationally.¹³

“Compared to ... surveys of Indigenous people from around the world ... RHS was unique in First Nations ownership of the research process, its explicit incorporation of First Nations values into the research design and in the intensive collaborative engagement of First Nations people ... at each stage of the research process.”

The First Nations Information Governance Centre will continue with RHS Phase 3 in 2014.

At the time of the RHS's inception, the issue of First Nation ownership of information was also at the forefront. This combination resulted in the advent of the concept of OCAP™. The RHS thereby became the first national survey to be fully owned, controlled and stewarded by First Nations. In those early years it was recognized that Health Canada, while an important partner, did not have the capacity and trust credentials to carry out a role in the governance of RHS data. Concepts such as: full ownership of data and intellectual property by First Nations, First Nation stewardship of data, and government access through a limited license to use – were essential elements of the original RHS, and form the backbone of the

¹³http://www.fnigc.ca/sites/default/files/ENpdf/RHS_2002/rhs_harvard_independent_review.pdf

OCAP™ principles as they exist today. At the same time, the RHS Code of Research Ethics¹⁴ was developed and has been revised to reflect the evolving needs of the RHS and the information governance principles of the First Nation regions participating in the RHS.

The RHS Code of Research Ethics provides the set of principles and procedures that guide the implementation of the RHS. It codifies how the RHS will approach OCAP™, contains data access protocols, procedures for analysis and publication and much more. It also contains the following First Nations Research Policy Statement:

- It is acknowledged and respected that the right of self-determination First Nations includes the jurisdiction to make decisions about research in their communities.
- The benefits to the communities, to each region and to the national effort should be strengthened by the research.
- Research should facilitate First Nation communities in learning more about the health and well being of their peoples, taking control and management of their health information and to assist in the promotion of healthy lifestyles, practices and effective program planning.
- The First Nations Information Governance Centre promotes making the most of the funding opportunity on behalf of First Nations. We will reclaim the original foundations of our health and healing.

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 for access to national level First Nation data, by the national governing body¹⁵; access to regional level First Nation data must be authorized by the regional First Nations organizations; and finally, community-level data cannot be accessed without direct consent of the First Nation involved. This protocol respects and reflects the governance structure and unique processes that exist within the First Nations organizational structure today.

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

¹⁴ http://www.fnigc.ca/sites/default/files/ENpdf/RHS_General/rhs-code-of-research-ethics-2007.pdf

¹⁵ Originally, the First Nations Information Governance Committee, and now the First Nations Information Governance Centre.

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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 while also respecting OCAP™ principles.

In 2005 the RHS published its RHS Cultural Framework¹⁶. Among other things, this document 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 well-being of First Nations can be collected, used and presented in a manner that is meaningful to First Nations peoples and communities.

Today the RHS is recognized as the “First Nations Survey of Choice” and has gained tremendous credibility among First Nations communities, leadership, federal government and academic scholars. Scientifically and culturally validated information is seen as crucial to health planning, advocacy and emerging areas of First Nations Governance. The expertise and structure for RHS information management has been leveraged within the entire operations of the First Nations Information Governance Centre (FNIGC).

The First Nations Information Governance Centre was federally incorporated under the Canada Incorporations Act on April 22, 2010. It was mandated through the Assembly of First Nations Special Chiefs Assembly and is governed by a Board of Directors appointed by each First Nation Region. The Centre has a clear mandate to make the most of research and information that will truly benefit the health and well-being 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, used and disclosed.

FNIGC Vision:

“Founded on First Nations Principles, the First Nations Information Governance Centre is a premier Indigenous model of research and data excellence for the well-being of our Peoples and Communities.”

¹⁶ http://www.fnigc.ca/sites/default/files/ENpdf/RHS_General/developing-a-cultural-framework.pdf

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FNIGC Mission:

The First Nations Information Governance Centre, under the guidance of its member organizations; will build capacity and provide credible and relevant information on First Nations using the highest standards of data research practices, while respecting the rights of First Nations self-determination for research and information management and in true compliance with the First Nations Principles of Ownership, Control, Access and Possession (OCAP).¹⁷

The FNIGC has a special role in advocacy and education involving OCAP™. Recently, this has led to FNIGC trademarking the acronym OCAP™, and applying for trade certification for an OCAP™ process.¹⁸

The Tui'kn Partnership – A System for Health Information Management¹⁹

The Tui'kn Partnership consists of the 5 First Nations located on Cape Breton, Nova Scotia: Eskasoni First Nation, Membertou First Nation, Potlotek First Nation, Wagmatcook First Nation and Waycobah First Nation. All 5 communities are part of the Mi'kmaq Nation. Tui'kn's shared vision is to achieve *health status and outcomes that are equal to, or better than, the overall Canadian population*. The Partnership focuses on a number priority areas such as primary health care and mental health. A key focus for the Partnership has been health information." They work together with the District Health Authorities, the Nova Scotia Department of Health, First Nations and Inuit Health Branch (Health Canada) and Dalhousie University, leveraging the expertise, resources and funding to meet health information needs.

The Tui'kn Partnership has developed a health information system that enables First Nations to own, control and access data about their own health needs, services and outcomes. Through the development of the health information system, the Tui'kn Partnership has set the stage for the eventual establishment an Atlantic Aboriginal Centre of Excellence for Health Information that will make First Nations the custodians of their own data.²⁰

¹⁷ See <http://www.fnigc.ca/node/16>.

¹⁸ Discussed below.

¹⁹ Except where otherwise noted, information for this section was obtained from a presentation ("Telling Our Stories: Documenting and Articulating Our Health Needs) delivered by the Tui'kn Partnership at the OCAP™ Forum hosted by the Assembly of First Nation on March 9-10, 2010.

²⁰ http://www.tuikn.ca/pdfs/tuikn_health_information_brochure.pdf

It began with a desire by the Tui'kn First Nations to measure the impact of changes and new programs that had been introduced to their primary health care delivery model. There was anecdotal evidence of positive impacts on quality of care, access and outcomes, but there was no way to quantitatively measure. Better evidence was needed to support the model and to support health care planning in the communities. A priority of the initiative has always been to respect OCAP™ principles at every stage.

To that extent, the Tui'kn Partnership wanted to link First Nation identifiers to provincial health databases for the purpose of generating Health Indicator Reports and to support research on their own communities. The challenge was to maintain ownership and control of First Nations data, while linking it to provincial data. The solution began with the creation of the Unama'ki Client Linkage Registry (UCR). The UCR is an anonymous, electronic registry of First Nation community members. To create the registry, individuals receiving health care in the Unama'ki communities are identified using data from the communities' electronic medical record (EMR) systems.²¹ Individuals registered as members of the five Unama'ki Bands are identified using data from the federal Indian Registry System at Aboriginal Affairs and Northern Development Canada.²² These data sources are linked to create the registry. A provincially recognized identifier, the NS Health Card number from the provincial health card registry, is added to allow linkage with provincial health data sources.

Creation of the UCR was contracted out to Medavie Blue Cross and Dalhousie's Population Health Research Unit, which have the capacity and expertise to conduct the necessary data cleaning and matching. The First Nations control use, access and disclosure to the information through their Data Sharing Agreement with the Province and their Service Agreement with Medavie Blue Cross. That agreement was drafted by the First Nations to incorporate OCAP™ principles and to protect personal privacy. A key provision in the agreement is that any individual First Nation or all of them can terminate the agreement at any time and have their data removed. This mechanism ensures an easy remedy in the event of the breakdown of relationships or simply, the transition of data to another data steward.

²¹ The Electronic Patient Records are already owned and controlled by the First Nations. Electronic charts are stored on local client servers at each health centre.

²² The Indian Registry System (IRS) is a database containing membership details and other vital statistics on all status Indians. The IRS is held by the Department of Indian Affairs and Northern Development (AANDC). The Tui'kn Partnership, together with its government partners, had to make an application under the federal *Access to Information Act*, to obtain a copy of the relevant IRS files.

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The UCR can then be linked, at the direction of the Unama'ki Client Linkage Registry Data Access Committee, with provincial administrative and clinical registry data kept by provincial health programs such as the Nova Scotia Reproductive Care Program, Cancer Care Nova Scotia and Cardiovascular Health Nova Scotia.

Linkages can also be carried out with data housed at Dalhousie's Population Health Research Unit (PHRU) – such as: provincial physician billing data, hospital discharge data, and mental health outpatient information system data. In accordance with data sharing agreements amongst the partners (again drafted to meet OCAP™ principles) that linked data is extracted from the provincial system, so that it can be governed strictly in accordance with First Nation directions within the data sharing agreement, and not be exposed to general use, access or disclosure within the provincial data system. The First Nations data is quarantined and available only as authorized.

This mechanism for creating and protecting First Nations health data has allowed the development of community health indicator reports and provided the First Nation health centres with a new source of aggregate data on health status and health care utilization.

Some essential elements of the Tui'kn Partnership First Nations Health Information Management System, which are all consistent with sound information governance principles and OCAP™, include²³:

- **Data Sharing Agreement:** All 5 First Nations of the Tui'kn Partnership have entered into the data sharing agreement with the Nova Scotia Minister of Health. This agreement allows the 1) linkage of information from the First Nations with provincial information in health card number registry to create the UCR and 2) linkage of the UCR with provincial health data, protecting personal privacy as well as OCAP™ principles. From an OCAP™ perspective, it limits the collection, use and disclosure of First Nations information and creates a protocol and mechanism for the First Nations to consider requests to access their data. Ownership of the UCR remains with the Tui'kn Partnership. The DSA also contemplates the termination of the agreement and provides for the permanent and complete removal or destruction of First Nations data, upon termination.

²³ See Tui'kn Partnership: "Aboriginal Health Information Management – Our Journey Toward a Centre of Excellence", on-line at http://www.tuikn.ca/pdfs/tuikn_health_information_brochure.pdf

Very importantly, in the DSA the province of Nova Scotia also acknowledges the First Nations as “Aboriginal governments” under provincial freedom of information legislation. This allows the Tui’kn Partnership to exchange information with the Ministry of Health, in confidence, without risking disclosure in the event of a request under that legislation.²⁴

- A “Privacy Sensitive” Culture: As part of the initiative, the Tui’kn Partnership has completed a privacy impact assessment which identifies potential privacy and security risks and provides mitigation strategies. Strong legal and service agreements that protect both personal and community information have been executed with service providers, contractors and staff. As well, the Tui’kn Partnership fosters a “privacy sensitive” culture within their organizations through regular privacy reviews, privacy training and the development of a comprehensive privacy policy framework and procedures.
- Capacity Building – Epidemiological Training: The Tui’kn Partnership recognizes that in order to be custodians of their own health information, they require local staff to be skilled in all aspects of data collection and interpretation. Capacity building is central to the comprehensive strategy to improve the quality of health planning, management and evaluation.
- Data Access Process and Protocols: The Tui’kn Partnership has created the Unama’ki Client Registry Data Access Committee, which reviews all requests for access to the UCR data holdings. This process is respectful of both OCAP™ principles surrounding First Nations data and the Ministry of Health’s legal and policy requirements surrounding provincial health data.

The Tui’kn Partnership is currently leveraging the technical expertise, resources and capacity of outside organizations to steward First Nations data, as well as to clean and link First Nations data with provincial health data. However, it is the explicit intention and long-term goal of the Partnership to work with other First Nations in the Atlantic Region to establish an Atlantic Aboriginal Centre of Excellence for Health Information Management that will make First Nations the stewards of their own data. The Centre for Excellence will be a data repository that will integrate a

²⁴ The vulnerability of First Nations data under federal and provincial freedom of information (or access to information) legislation is one of the most significant barriers to the implementation of OCAP™ when working with government partners. The nature of Nova Scotia legislation and the specific provisions in the DSA protect the Tui’kn Partnership data from such vulnerability.

broad range of health information collected by First Nation, provincial and federal governments.²⁵ This was a consideration in drafting the data sharing agreement and service agreements with other partners, so that transition of data to First Nations stewardship will not be limited by any agreement.

The Tui'kn Partnership has developed its own health information management system that meets the immediate health planning and development needs of the First Nations while respecting First Nations OCAP™ principles and setting the stage for a First Nations data steward through a Centre of Excellence. It is an OCAP™ model for partnering with government and non-government entities.

Chiefs of Ontario and The Institute for Clinical Evaluative Sciences – Data Governance Agreement

In December 2009, Chiefs of Ontario (COO) Special Chiefs Assembly Resolution 09/33 was passed to direct the Health Coordination Unit (HCU) and the Ontario Chiefs Committee on Health (OCCOH) from COO to explore the development of a process for creating an ongoing First Nation cancer surveillance system. Thus, in March 2010, a Cancer Surveillance Working Group was established. The Group included representatives from COO, Cancer Care Ontario and Health Canada (First Nation Inuit Health - FNIH), to begin investigating different models and ways in which a First Nations Cancer Surveillance System could be developed, in a manner consistent with OCAP™ principles. The Working Group also recognized that access to the Indian Registry System (IRS) Database held by Aboriginal Affairs and Northern Development Canada (AANDC – formerly, INAC), would be required in order to identify First Nations individuals within the Ontario Cancer Registry through linking the two databases.

In April 2010, the Institute for Clinical Evaluative Sciences (ICES), a private non-government entity, approached COO and discussed the possibility of more extensive surveillance opportunities (i.e. beyond cancer) through linkages with other databases that are owned by ICES. Among other things, ICES hold health data from a very large number of health programs and networks, including but not limited to diabetes, Ontario Cancer Registry, hospital discharge abstracts, OHIP (provincial health insurance) claims, Home Care Database, mental health, the Ontario Trauma Registry, the Stroke Network, and Cardiac Care Network. ICES is also a “designated entity” under the provincial health privacy law, the *Personal Health Information and*

²⁵ See above note [add cross-reference].

Protection Act (PHIPA).²⁶ This subjects ICES to strict regulations and standards for the protection of personal privacy, as laid out in PHIPA.

As a non-government entity, ICES is also able to hold First Nations data and permit control and access by First Nations, while protecting the privacy of both personal and community-level data. This is something that was not possible for provincial departments and institutions such as Cancer Care Ontario, which fall under the Ontario *Freedom of Information and Protection of Privacy Act*, and exposes community-level data to public disclosure.

COO recognized the benefit of ICES being the custodian of the Indian Registry System data and the opportunity to expand surveillance beyond cancer into other chronic diseases for example, diabetes, mental health, and heart and stroke. Accordingly, COO began negotiating a Data Governance Agreement with ICES regarding stewardship of First Nations health data, and also worked with its partners to prepare and submit an application for access to the IRS.

The resulting Data Governance Agreement was a comprehensive and innovative collaboration between COO and ICES. It insures that First Nations control their own data, building upon OCAP™ principles and ultimately envisioning a First Nations Data Centre. Some key provisions include:

- In addition to the data specifically provided through the IRS, “First Nations Data” is defined to include any data set formed for the purpose of identifying First Nations, First Nation communities or Indian reserves. This therefore captures data pertaining to First Nations within provincial databases such as the Ontario Cancer Registry that can be extracted using postal code or residential code filters. First Nations Data also includes any other information or data set held or created by ICES, that is capable of identifying First Nation communities, First Nation membership, Indian status, or residence on a reserve. By defining First Nations Data in this manner, it captures all data “about” First Nations regardless of where that data resides and who technically “owns” that data.²⁷ This allows First Nations to govern all First Nations Data within ICES and insures that no such data can be created or used for any reason without going through the First Nations process established through COO.

²⁶ PHIPA 2004; s. 45[1]; and *O.Reg 329/04 Section 18 [1]*.

²⁷ The Province of Ontario retains ownership of provincial health administrative data, such as the Ontario Cancer Registry.

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- ICES agrees to protect community-identifying (and First Nation identifying) data according to the same rigorous privacy and security standards as it holds personally-identifying health information.
- Access to and use of First Nations Data will be governed by First Nations according to the processes and authorizations contained within a First Nations Data Access Protocol, developed by COO in accordance with regional processes, and consistent with OCAP™ principles.
- COO and ICES will work together to build First Nations capacity and expertise in the area of population research, which will include opportunities for mentor or fellowship programs or other continuing education opportunities for First Nation individuals.
- Mechanisms for terminating the agreement and transferring the data to another data steward have been included in the agreement. This contemplates the transfer of data to a First Nations data steward when issues of First Nation capacity and resources for such an initiative have been achieved.

This approach to a contracted Data Steward works particularly well at this time in the context of provincial health data because under PHIPA, only “designated entities” have legal authority to hold such data. Until First Nations in Ontario develop their own separate entity, with designation to receive and hold data from provincial health information banks (for the purpose of linking that data to First Nation identifiers such as the IRS), they are able to exercise all elements of governance over First Nations data at ICES, and to use that data for important surveillance and research work, particularly in priority areas such as chronic disease. With the assistance of ICES, COO has developed a health research and surveillance program that meets OCAP™ principles, and builds future capacity for First Nations.

The Alberta First Nations Information Governance Centre²⁸

In January 2010 First Nations Leadership from Treaty No. 6, Treaty No. 7 and Treaty No. 8 in Alberta, passed a resolution mandating the creation of the Alberta First Nations Information Governance Centre. An independent satellite of The First Nations Information Governance Centre, it is directly accountable to First Nations through its governance structure. Specifically, the Assembly of Treaty Chiefs is the member of the corporation, and Treaty No. 6, Treaty No. 7 and Treaty No. 8 appoint a Chiefs Senate, and delegates from First Nation communities to serve as the Board of Directors.

In March 2010 Alberta leadership passed a “the OCAP Resolution” which further directed that “The Centre will promote, protect and advance the First Nations Ownership, Control, Access and Possession (OCAP) principles, the Inherent Right to self-determination and jurisdiction in research and information management.”

This was further particularized in the AFNIGC mission statement:

Facilitate the exercise of First Nations jurisdiction and greater ownership, control, access and possession of First Nations data and information by:

- *Increasing the impact of research and information that measures the state of First Nations health and wellbeing;*
- *Providing sound governance and oversight to research initiatives and specialized surveys;*
- *Permanently hosting data; and*
- *Building the individual and systemic capacity for respectfully engaging in data collection, analysis and utilization through:*
 - *Professional development, training and tools,*
 - *Standards of excellence, and*
 - *Access to equitable funding.*

The AFNIGC coordinates and administers the First Nations Regional Health Survey (RHS) for Alberta Region, as well as the new First Nations Regional Employment and Education Survey (FNREES).

²⁸ Except where otherwise noted, information for this section was obtained from a presentation (“The Alberta First Nations Information Governance Centre: Our Data, Our Information, Our Traditional Knowledge”) delivered by Bonnie Healy for an OCAP Information Session at the invitation of Aboriginal Affairs and Northern Development, March 2012.

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- A large part of the activities of the AFNIGC involve education and capacity building. AFNIGC provides the following:
- OCAP™ Training
- Data 101 (and how to translate data into meaningful stories)
- Strengthening Communities as Data Stewards
- Assisting First Nations in Data Collection
- Development of culturally relevant survey tools
- Culturally relevant and meaningful analysis and interpretation of data
- Assisting First nations in repatriation of their own information.

The AFNIGC is able to leverage the capacity and tools of the national FNIGC to meet specific needs and requirements of Alberta First Nations. For example, the RHS Code of Research Ethics can be adapted to reflect the cultural practices and requirements of Alberta First Nations. The AFNIGC is also building partnerships with the federal government, the province and other institutions, in order to meet the information needs of First Nations

Through its many activities, the AFNIGC is well-placed to hold data on behalf of First Nations across the region – acting as First Nation data steward - in a manner that meets OCAP™ principles and personal privacy standards, within First Nations governance structure.

Myths and Barriers²⁹

There are many other examples in First Nations across Canada where OCAP™ principles have been successfully implemented and integrated within information management systems. Yet there is still resistance – from governments, from researchers and universities, and from other institutions. This section will discuss some the key barriers, both real and perceived that impede the implementation of OCAP™.

²⁹ Some of the content in this section has been adapted from First Nations Information Governance Centre, *. (2014). Barriers and Levers for the Implementation of OCAP™. *The International Indigenous Policy Journal*, 5(2). Retrieved from: <http://ir.lib.uwo.ca/iipj/vol5/iss2/3>

Legal Barriers

Because of the federal Crown's relationship with and responsibilities in relation to First Nations, Canada collects and holds more information on First Nations people than perhaps any other group in Canada. Aboriginal Affairs and Northern Development Canada (AANDC) alone holds 210 data banks of First Nations information³⁰. The collection, use and disclosure of this information is regulated by the *Privacy Act*, the *Access to Information Act*, and the *Library and Archives of Canada Act*,³¹ all of which apply exclusively to federal government institutions. While the *Privacy Act* protects personal information, the *Access to Information Act* and the *Library and Archives of Canada Act* present legislative barriers to OCAP™.

One of the most important principles within OCAP™ is that First Nations control the use and disclosure of First Nations data. In other words, information (records, reports, data) that identifies any particular First Nation, or group of First Nations should not be used or disclosed without consent of the affected First Nation – regardless of where that information or data is held. The models of OCAP™ in action presented above show two examples where a non-First Nation data steward has been chosen by First Nations. This is possible and reasonable, to meet the needs and capacities of First Nations. However, First Nations must ensure that any non-First Nation data steward does not have legal barriers that prevent it from stewarding First Nations data in accordance with OCAP™ principles. For the great majority of First Nations in Canada, this means that neither the Canadian government nor any institution thereof should be considered as a steward of First Nations data. This is because *Access to Information Act* and the policies and procedures that support it (ATIP) prevent First Nations from exercising control over the use and disclosure of First Nation-identifying data or information.

Access to information legislation rightly supports democratic concepts of accountability and transparency in government. It gives citizens the general right to access all records³² within the control of government. Canada InfoSource, mentioned above, is intended to list all of the categories and classifications of data holdings for that purpose – to permit citizens to request access.

³⁰ Canada InfoSource.

³¹ *Privacy Act*, R.S.C. 1985, c. P-21, as amended; *Access to Information Act*, R.S.C. 1985, c. A-1, as amended; *Library and Archives of Canada Act*, S.C. 2004, c.11.

³² The right to access covers records in any format: written, video, digital, etc.

The Act presumes that all records in government control are accessible. Records containing personal information are protected from disclosure³³. Sections 13 to 24 contain all of the categories for exemption where the government institution either must maintain the confidentiality of the documents, or in some situations, has the discretion to withhold disclosure under the Act. Some of these categories include:

- information obtained in confidence from another government (s.13);
- information injurious to the conduct of Canada in federal-provincial affairs (s.14);
- information which is part of ongoing law enforcement investigations (s.16);
- information that could be injurious to economic interests of Canada (s.18);
- third party information, if it contains trade secrets, confidential financial or commercial information (s.20);
- records containing advice or recommendations developed by or for a government institution or a Minister of the Crown (s.21 (a));
- information that is subject to solicitor-client privilege (s.23);

The Act goes on to define “government” for the purposes of the first bulleted exception to include any level of government from municipality to the United Nations and all of their organizations. “Aboriginal governments” are specifically included in that section. However, the term is later defined to exclude the overwhelming majority of First Nations in Canada. In fact, the only First Nations that are recognized as “aboriginal governments” under the Act are six that have entered into self-government agreements or “modern treaties” with Canada, plus “participating First Nations” under the *First Nations Jurisdiction over Education in British Columbia Act*. No other First Nation in Canada can share confidential information with the government of Canada and expect that information to be treated confidentially.³⁴

While the exemption categories under the Act may protect the personal privacy of First Nation members, it would not protect aggregate reports or demographic or

³³ *Access to Information Act*, s.19. It should be noted that government institutions are required to redact or sever personal information or other exempted information from records and to release the remainder of the ‘unprotected’ information upon request (s.25).

³⁴ The exception to this statement is if the information falls within one of the other exemption categories under the *Access to Information Act*. For example, if a First Nation shares trade secrets or information to assist an ongoing law enforcement investigation, that information might be considered exempt.

survey data, nor would it protect any traditional knowledge, or reporting under contribution agreements. In fact, except for those few First Nations that the Act recognizes as “governments”, almost any information or data that First Nations provide to Canada, or that Canada collects from its members and other sources (as long as names and personal identifiers are removed) can be released to the public under the *Access to Information Act*.

This means that federal databases such as Non-Insured Health Benefits (NIHB) data, nominal rolls (education) data, financial reporting, and social services data are available upon request by Canadian residents provided personally-identifying information is stripped. As a result of the *Access to Information Act*, AANDC and other federal government institutions cannot withhold disclosure of a significant amount of First Nations information within their control. This is particularly true with the digitization of data, allowing records to be easily stripped of personally-identifying information and then released to the requesting public.

This vulnerability was markedly demonstrated through Health Canada’s release of NIHB data to Brogan Inc., described above. Health Canada’s position was that de-identified NIHB data was available under ATIP if Brogan made the request. Therefore, Health Canada entered into an agreement with Brogan to release the data, in exchange for some data analysis services from Brogan.

As long as personally-identifying information is capable of being digitally “stripped”, it appears to be the federal government’s position that the remainder of the data is subject to disclosure under the *Access to Information Act*.

Canada’s Infosource regarding AANDC data holdings lists the categories of records that are held by the department. Just a sampling of the categories include:

- Band Governance Management System – containing information on First Nation by-laws, elections, estates, appeals, custom codes
- Elementary/Secondary Data – nominal roll
- First Nations and Inuit Youth Employment Strategy – participant information
- Post-secondary Education Data
- Income Assistance
- Pre-Employment and Income Support
- First Nation Child and Family Services
- The Indian Registry System (IRS) – containing detailed personal and biographic information about all First Nation members.

All of these databases can be stripped of personal identifiers and mined for any purpose through an ATIP request. Any analysis, research or reporting can be conducted on the data, without oversight or limitation. Although in some cases where requesters seek access to records provided to the government by individual First Nations (such as Band Council Resolutions or leases for designated lands) First Nations are not even given notice when their data is released. This is entirely inconsistent with OCAP™ principles and the only way to resolve this conflict is through amendments to the *Access to Information Act*. One necessary amendment would be to recognize all First Nation governments as “governments”. However, that still would not protect information collected by government from entities other than the First Nation. For example, client details about drug benefits under NIHB are typically collected from pharmacists and not from a First Nation. The communication between pharmacist and Health Canada would not be considered government-to-government communication and therefore even with the proper recognition of First Nation governments, the NIHB data would still be vulnerable to release. As such, even further amendments are required.

The legislative conflict with OCAP™ is further exacerbated through the *Library and Archives of Canada Act* (LACA), which mandates that all records (including electronic) in the control of federal departments/institutions be transferred to the Archives when they are no longer used by the department/institution. Once transferred to the Archives, even personal information becomes vulnerable to an ATIP request, because the *Privacy Act* does not protect the privacy of personal information if the person has been dead for more than 20 years.³⁵ This means that through ATIP and the LACA, even personally-identifying information about First Nations people can be released (20 years after death). Since the federal government collects so much information about First Nations, this exposes First Nations and First Nation families to significantly greater potential harm and continuing problems with OCAP™.

The combination of the *Access to Information Act* and the LACA is the greatest barrier to the practical application of OCAP™ principles for data within the control of any federal government institution. All First Nations information collected through the multitude of federal programs and through reporting requirements with various departments is vulnerable to public release. No agreement or understanding amongst First Nations and any federal department can avoid the application of this legislation. The statute will supersede any agreement.

³⁵ *Privacy Act*, s. 3 “personal information” (m).

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These legal barriers also apply to information acquired by the federal government through data sharing agreements and licenses to use wherein First Nations and First Nation organizations agree to share data tabulations and summaries with the federal government. Entities such as The First Nations Information Governance Centre make significant efforts through the agreements to preserve ownership and other intellectual property rights, to limit use and access and to obtain reporting and accountability for use and access – all are important applications of OCAP™. However, in recognition that the tabulations and summaries are subject to release pursuant to an ATIP request as soon as they are within the control of the federal government, FNIGC strives to restrict their agreements with governments so that they disclose only information that FNIGC deems acceptable if it were to be publicly disclosed.

Unfortunately, First Nations do not have the ability to restrict the amount or type of information that AANDC collects via its normal operations and the databases described above. Data sharing agreements, service agreements and licenses to use can be effective only if it is a First Nation sharing with AANDC. When AANDC already holds the data, First Nations have no ability to restrict access, use or disclosure.

How can First Nations work with the federal government to address these legal barriers? First, there must be changes to legislation. Unfortunately, such changes are not on the Government's legislative agenda and they are unlikely to be added. This leaves us with the strategies that have already been adopted by First Nations.

First Nations (including First Nation-controlled organization) should only give information to the federal government that would be acceptable for public release, if an ATIP request was made. This is what FNIGC does, as explained above. Of course, this has limited application because most often First Nations do not have a choice on what information they must give to departments such as AANDC and Health Canada; it is generally a condition of funding for programs and services.

An even better solution is for First Nations to repatriate their own data, to be placed within First Nations stewardship, or by contract with another entity that does not have the legal restrictions of ATIP. This type of data stewardship has been described above in the section on OCAP™ in Action. There is no reason that First Nations and Canada cannot use this model, in partnership. Changing stewardship of the data could take First Nations data out of the control of a federal institution. This would enable First Nations and government to enter into agreements on the governance of the information that may permit Canada to access certain types and

levels of data for its legitimate purposes, but without the level of control over the totality of the data that would make it vulnerable to ATIP. It would allow First Nations to control access, use and disclosure of First Nations data; all of which is impossible where the federal government is data steward.

Provincial and territorial governments are also large “stewards” of First Nations data, particularly through provincial health records and education records. These jurisdictions also have access to information legislation, which they typically call “Freedom of Information”. Freedom of information legislation extends to all provincial departments and institutions, as well as to municipalities and in some cases universities and colleges. These statutes have provisions similar to the federal *Access to Information Act* to exempt from mandatory disclosure certain government-to-government communications and other categories such as trade secrets and investigation files. However, some jurisdiction actually recognize ALL First Nations in Canada as governments, providing varying levels of protection for documents shared by First Nations and, in some cases, First Nation institutions. Two such jurisdictions are Nova Scotia and Alberta. This recognition of First Nations as governments facilitates information sharing between First Nations and their provincial counterparts, since First Nations data is not vulnerable in the same way as it is under federal legislation.

Myths: Knowledge as a Barrier

Lack of knowledge or incorrectly assumptions are often a preliminary barrier to understanding OCAP™ and then, logically to implementing OCAP™.

OCAP™ is not a 4-criteria shopping list that can be “checked-off” according to the interpretation and interests of someone seeking to use or access First Nations data. OCAP™ must be understood in the context of a particular First Nation or First Nations. It involves consideration of First Nations governance structures, values, history and expectations. What may work for one community may not be appropriate for another. The requirements and protocols for national level data would not be the same at a regional or community level. Yet there are some very common standards and consistent themes in the application of OCAP™, which will be discussed in the section below.

Awareness of OCAP™ as the standard for First Nations information governance and for research is also expanding. First Nations’ regional organizations and The First Nations Information Governance Centre continue working to build knowledge and relationships with government partners and universities. It is incumbent upon First

Nations and First Nation organizations to continue to educate themselves and all other potential users of First Nation data about this, *not so new*, First Nation standard for information governance and research.

Unfortunately, in many corners of government and academia myths about OCAP™ are outpacing the truth; myths such as:

“OCAP™ stifles research.”

“First Nation control will bias research.”

These are unfortunate beliefs held by some researchers. This statement fails to recognize that in all societies, both First Nation and non-First Nation, ethics require a balancing between considerations of social benefit and the potential for harm. OCAP™ arose partly in response to the inability of researchers to properly balance these considerations. According to Castellano, if researchers and those researched have vastly different notions of what constitutes social benefit and how it is achieved, the research is unlikely to satisfy the needs and expectations of participants on both side of the divide³⁶. Again from Castellano:

Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable. Just as colonial policies have denied Aboriginal Peoples access to their traditional lands, so also colonial definitions of truth and value have denied Aboriginal Peoples the tools to assert and implement their knowledge. Research under the control of outsiders to the Aboriginal community has been instrumental in rationalizing colonialist perceptions of Aboriginal incapacity and the need for paternalistic control.³⁷

In fact, accusing First Nations of bias in this context reflects a Eurocentric notion that the “West” has some quality of mind, race, culture, environment, or historical advantage, which confers a permanent superiority over all other communities.³⁸ Eurocentrism persists in government and in universities, despite the efforts of many to provide a larger and more respectful worldview. Henderson posits that

³⁶ Castellano, Marlene Brant “Ethics of Aboriginal Research” JAH, January 2004, at 103.

³⁷ Castellano at 102-103.

³⁸ Blaut, J.M. (1993). *The Colonizer’s Model of the World*. (New York: The Guilford Press).

Eurocentrism is a “dominant intellectual and educational movement that postulates the superiority of Europeans over non-Europeans ... it has been the dominant artificial context for the last 5 centuries and is an integral part of scholarship, opinion and law”.³⁹

“OCAP™ is inconsistent with personal privacy.”

“First Nations can’t protect personal privacy.”

Misrepresentations about personal privacy persist when discussing OCAP™. Unfortunately, these myths are promulgated by the Tri-Council Policy on Research Ethics that states at Article 9.16:

In First Nations communities, privacy and confidentiality of identifiable personal and community information may be affected by the application of the principles of ownership, control, access and possession (OCAP – see definition in Application of Article 9.8).

Concepts of personal privacy are not typically addressed in existing OCAP™ literature, or expressed as OCAP™ principles. However, personal privacy is a fundamental element in First Nations information governance and is consistently present in OCAP™ models.

A probable explanation for this gap is that through OCAP™ First Nations express their values and principles, that were not respected or even recognized by other governments and western-based researchers. OCAP™ is a way for First Nations to express principles of information governance and community privacy in an aggregate sense – a notion that seems quite foreign to many non-First Nations. Personal privacy, on the other hand, is a universal value that is reflected in western society, through laws, policies and ethics. It is not something that First Nations must fight for, or to vigilantly defend. Canadian laws protect personal privacy.

Accordingly, we see First Nations building a privacy infrastructure that includes both OCAP™ and personal privacy. Personal privacy is examined and considered using the same principles as western society. First Nations conduct privacy impact assessments, implement privacy and security policies and procedures, and participate in privacy training. The federal *Personal Information Protection and*

³⁹ Henderson, J. Y. (2000). “Postcolonial ghost dancing: Diagnosing European colonialism” in M. Battiste (ed.) *Reclaiming Indigenous voice and vision* at 58.

*Electronic Documents Act*⁴⁰ applies in relation to some First Nation records, and in some provinces/territories provincial health privacy legislation may apply to First Nation health clinics. Moreover, many First Nations are considering and enacting their own privacy laws.

Suggestions that following OCAP™ principles will result in a breach of personal privacy are simply incorrect. All of the models presented above, under OCAP™ in Action, have examined and protected personal privacy to the same or better standards as found in applicable laws. In fact, respecting OCAP™ principles and concepts of community privacy add an additional layer of privacy protection for individuals; not only is an individual's personal identity protected from disclosure and any resulting harm, but their group identity and status as a member of a community is also protected.

If an Aboriginal person is conducting the research (holding the data, sitting on the research ethics board, participating in the writing, the member of a team, on the faculty, on the ethics committee ...) then the project is OCAP™ compliant.

Having individuals that are representative of First Nations can be helpful in the translation of worldview or in aiding communication amongst researcher and First Nation. They can add perspective that is lacking in any group with decision-making power. This type of participation is an important part of inclusion and balance. But it has nothing to do with OCAP™.

That person does not represent First Nations in a manner that is accountable to First Nations through their governance structures and through First Nation processes. That person has no authority or jurisdiction to speak on behalf of any or all First Nations or to consent to research on their behalf. First Nations do not delegate their authority to make decisions regarding the governance of their information to someone who is not politically or legally accountable to First Nations leadership. OCAP™ principles call for ownership and control – not just by any individual with First Nation ancestry, but by the First Nation community that the information or data describes.

“OCAP™ applies to Métis and Inuit too.”

Values associated with community consent and governance over research are not unique to First Nations in Canada.

⁴⁰ PIPEDA, S.C. 2000, c.5 (as amended).

In analyzing 16 documents written by or for Indigenous Peoples in Canada, Australia and the United States, Weijer identified five common research principles that arose:

1. Communities must be consulted when developing research protocols and be kept informed during implementation.
2. Community leaders must provide informed consent prior to approaching individuals.
3. The community must be involved in conducting the research, with the additional purpose of building capacity within the community.
4. Community consent to additional/secondary use of sample beyond the original project is required, together with agreement on storage and ultimate destruction of samples.
5. Advance drafts of research reports should be distributed to the community to identify community views.⁴¹

Likewise the Tri-Council Policy Statement (TCPS) presents its ethical standards regarding community interests that it applies to all Aboriginal groups in Canada: First Nation, Métis and Inuit.

However, OCAP™ as a term was specifically coined to reflect First Nations values and jurisdiction regarding First Nations information. It reflects the worldview of First Nations which have a unique history within Canada, a unique relationship with the Crown and unique jurisdiction and legal structure. The principles expressed in OCAP™ may be shared by other Indigenous groups in Canada and across the world. But there has never been any intention or expectation that the term OCAP™ and the bundle of values and history that encapsulates First Nations relationship with information and knowledge would or could be adopted as a common pan-Aboriginal standard. OCAP™ describes First Nations values and relationship with data. While studies and writing on OCAP™ have certainly been and continue to be used as a model by other Aboriginal groups to describe their principles, it should be adapted to reflect their unique position, and a descriptive word that has meaning to them should be adopted.

⁴¹ Charles Weijer, Gary Goldsand and Esekiel J. Emanuel, "Protecting communities in Research: Current Guidelines and Limits of Extrapolation," *Nature Genetics*, Vol. 23 (November 1999) p. 275-280 as also cited by Marlene Brant Castellano in "Ethics of Aboriginal Research", *JAH*: January 2004, at 108.

While it may be easier for users of Indigenous Peoples data (such as government and universities) to have one common standard for all Indigenous subjects, that approach fails to recognize the unique aspects of each group and the fact that they should each be able to express their values in a way that is meaningful to them.

The principles upon which OCAP™ were founded may be shared by other Indigenous Peoples, including Métis and Inuit. OCAP™ does not apply to non-First Nations information or research.

Institutional Barriers

In addition to legal and knowledge barriers, the implementation of OCAP™ can be impeded by institutional barriers that exist within the culture of an organization.

Academic Culture: In universities, for example, there is an academic culture where researchers assume that they ‘own’ the data that they collect, and that they hold all intellectual property rights to the data. The competitive culture of academic research often prevents collaborative thinking and attribution of research ‘credit’ to the subjects of that research. Assertions of First Nation control or ownership over research and data can be met with hostility and a breakdown of relationships. This reaction is a reflection of a researcher’s lack of knowledge or understanding about OCAP™, but it also represents an academic culture that views research as a commodity and a source of prestige and academic advancement.

This academic culture may be founded, in part, upon the concept of “Academic Freedom” which according to the Tri-Council Policy is an important research ethic, and is defined as:

The collective freedom of faculty and students to conduct research, and to disseminate ideas or facts without religious, political, or institutional restrictions. It includes freedom of inquiry, freedom to challenge conventional thought, freedom to express one’s opinion about the institution, its administration, or the system in which one works, and freedom from institutional censorship.⁴²

This self-proclaimed right of scholars has been used:

⁴² TCP – Glossary at 189.

- Challenge the posting of a job description for a visiting Aboriginal-scholar position in an Indigenous Studies Program because it was only open to Aboriginal applicants.⁴³
- Criticize a university's vision statement that included the word: "We foster an environment where Indigenous knowledge is respected and recognized as a valid means by which to understand the world."⁴⁴
- Generally to defend the release of research that is clearly harmful to a First Nation.

However, claims to academic freedom, individual initiative, and unfettered intellectual leadership have been described as no more than elitist aspirations of researchers to keep themselves distinct and distant from the communities they study and as a way of maintaining their positions of "earned" advantage and conferred dominance (McIntosh, 1998).⁴⁵

Thus the Tri-Council Policy qualifies the limits of academic freedom within a framework of ethical conduct, prefaced by the following:

With academic freedom comes responsibility, including the responsibility to ensure that research involving humans meets high scientific and ethical standards that respect and protect the participants. Thus, researchers' commitment to the advancement of knowledge also implies duties of honest and thoughtful inquiry, rigorous analysis, commitment to the dissemination of research results, and adherence to the use of professional standards.⁴⁶

Yet who defines "ethics" and how First Nation "participants" should be respected and protected? OCAP™ provides its own framework that says First Nations are the only ones who have authority to make those decisions on behalf of First Nations.⁴⁷

⁴³ Society for Academic Freedom and Scholarship:

<http://www.safs.ca/issuescases/safslettertorunte.htm>

⁴⁴ Society for Academic Freedom and Scholarship:

<http://www.safs.ca/issuescases/trentfranklin.htm>

⁴⁵ As cited by Ermine, W, et al. "The Ethics of Research Involving Indigenous Peoples: Report to the Indigenous Peoples' Health Research Centre to the Interagency Advisory Panel on Research Ethics" Indigenous Peoples' Health Research Centre, July 2004 at 25.

⁴⁶ Tri-Council Policy (2) at page 5.

⁴⁷ For further discussion on conflicting ethics, see Ermine, W, et al. "The Ethics of Research Involving Indigenous Peoples: Report to the Indigenous Peoples' Health

This academic culture and the cultural bias associated with it transfer from universities to government, when those same researchers become employed in the public service.

Bureaucratic Culture: There are other practical and administrative barriers to the application of OCAP™ principles in the collection, management and sharing of information. A shift in perception and flexibility is required for those wishing to engage in partnerships with First Nations that would allow universities, governments and others to use and perhaps even steward First Nations data. For example, template service agreements or data sharing agreements probably will not meet the needs of First Nations. Many such agreements contain unreasonable demands for ownership of intellectual property and data, and the abandonment of moral rights – all inconsistent with OCAP™ and simply not necessary in the context. Some contracts have no mechanism for the removal or destruction of data in the event of a breakdown of relationships. These are all things that are usually easily negotiated, but because it requires referral to legal staff and additional drafting work, it can become a significant barrier.

Capacity as a Barrier

“Aboriginal governments would need at their disposal the human resource skills, technologies and equipment necessary to meet the challenges of managing information in an Aboriginal government with confidence.”⁴⁸

The best way for First Nations to implement OCAP™ is for First Nations and First Nation-controlled organizations to be the steward of their own data. This facilitates ownership, control and access based upon physical possession. However, capacity is a fundamental barrier that limits the implementation of possession. Unfortunately, many First Nations lack the funding, expertise, hardware and software, and privacy and security infrastructure to securely hold their own data. It can require a great commitment of funding and long-term development for a First Nation to have the capacity to be steward of its own data; particularly where that data is sensitive – such as health information that contains personal as well as community-identifying information. This is why capacity-building is part of OCAP™,

Research Centre to the Interagency Advisory Panel on Research Ethics” *Indigenous Peoples’ Health Research Centre*, July 2004, especially at 22-23.

⁴⁸ Canada. Royal Commission on Aboriginal Peoples. *Report of the Royal Commission on Aboriginal Peoples. Vol. 2 Restructuring the Relationship*, at 335. [Ottawa] Royal Commission on Aboriginal Peoples, 1997.

together with a recognition that as First Nations build capacity within their communities and create their own organizations with the jurisdiction and capacity to hold information, that data will be transferred to First Nation stewardship. As we have seen above, First Nations in Alberta have already created such an entity in the Alberta First Nations Information Governance Centre. Ontario and Nova Scotia have also planned for the transition to First Nations data stewardship at a regional level.

At the same time, First Nations already hold a significant amount of community information and personal information within their files and computer; information regarding education, social services, housing, administration, employees, membership lists, emergency services, and health care. Most communities have privacy policies and procedures; some have already enacted their own Privacy Laws. These are all steps towards building the capacity and infrastructure for First Nations to repatriate all sources of data.

Tools for Implementing OCAP™

In the preceding sections, several tools for implementing OCAP™ have been discussed in relation to specific models of OCAP™ and as strategies to address identified barriers to OCAP™. This section provides more context and background for how those tools and strategies can be used.

Education is such a large piece and a factor in most barriers that it should be mentioned first. As OCAP™ awareness grows, so do myths and misunderstandings. First Nations and First Nation organizations must reach out to their own communities, to government partners, to universities and to anyone else that may wish to collaborate with First Nations in research or to assist with information governance. Information should be made available on-line and through other media. Part of this education component will be The First Nations Information Governance Centre's OCAP™ certification process, which will be discussed below.

Some specific activities could include:

- Share knowledge about OCAP™ (background and application) with academics and government, helping to build a new culture for First Nations information.
- Educate government and university legal/contract staff regarding OCAP™ requirements and how contracts may be changed (proactively) to meet the needs and values of First Nations and government.

The First Nations Information Governance Centre

- Create partnerships with Universities.
- Make OCAP™ -ready tools available for use by communities:
 - OCAP™ “standards”, how to preserve ownership and other intellectual property rights, etc.
 - Template data sharing agreements
 - First Nation privacy laws
 - Privacy and security policies and procedures for First Nations.
- Share OCAP™ knowledge with communities and leadership.
- Promote the development of First Nation entities as First Nations data stewards.

Legislation: First Nation laws are a tool that can help address some of the barriers associated with jurisdiction and capacity. A privacy law, with accompanying policies and procedures, would support a First Nation in holding its own data.

A First Nation’s exercise of jurisdiction in the area of privacy protection also builds capacity within a community for privacy protection. Such a law can deal with both personal privacy and community privacy, incorporating universal standards of personal privacy together with OCAP™ principles. A First Nation privacy and security infrastructure can then be built in a manner that supports the law and codifies community’s own values and principles regarding privacy.

Another tool that could be part of a privacy statute or be included as a separate piece is a freedom of information/access to information law. This could be used by a First Nation to regulate how information about the First Nation and its members can be collected, used and disclosed - again, incorporating the community’s own values and principles regarding OCAP™. Obviously a First Nation access to information law would not follow the federal government’s lead, which makes First Nations information vulnerable to access without First Nation consent.

As we have seen above, the single largest barrier to OCAP™ implementation with federal government partners is the *Access to Information Act*. The most obvious solution is an amendment to that statute. However, there is no indication from government that it is prepared to recognize all First Nations as governments, or to respect First Nations collective privacy interests. Therefore, other practical options must be considered.

Change the Data Steward: The best and only reliable method of preventing application of the federal *Access to Information Act* or other similar

provincial/territorial law that does not recognize all First Nations as government, or that fails to protect First Nation collective information, is to prevent First Nations data from being within the control of a federal institution. This can be done through:

- Transferring data to the stewardship of a First Nations or First Nation-controlled organization;
- Retaining a third-party data steward that is not subject to access to information/freedom of information legislation.

The third party could be a university, or a private entity, and in some cases provincial partners may be appropriate. A legislative review would have to be conducted to ensure that there are no other barriers in relation to the alternative data steward. For example, if a province were considered as a data steward, the province's freedom of information legislation would have to be reviewed for similar barriers. In some provinces, colleges and universities also fall under provincial freedom of information legislation.

Data Sharing Agreements: ⁴⁹ Agreements are a very important part of OCAP™. Because OCAP™ principles, particularly First Nation values of collective privacy, are not recognized in Canadian law, the only way that First Nations can regulate the use of their information is through agreement.

In all cases where First Nations information is being held by an entity other than the First Nation, there should be a legally binding agreement that governs the collection, use and disclosure of the data. First Nations can exert effective governance over their information through appropriately-drafted agreements.

The following lists just some important questions to ask or elements that should be considered as part of every agreement⁵⁰:

⁴⁹ As stated above, it is important to note that data sharing agreements where the federal government or certain provincial/territorial governments are the data stewards will expose First Nations data to disclosure through the Access to Information Act. Data sharing agreements cannot override federal, provincial or territorial laws. Therefore, while data sharing agreements may help regulate some aspects of the use of First Nations information within the control of (some) governments, it will not be able to regulate access to or disclosure of data.

⁵⁰ This list is neither exhaustive nor mandatory. The relationship, circumstances and jurisdiction of the parties are unique and different/additional questions and priorities will arise in each case. The questions to ask and provisions to include will also differ significantly depending upon whether the agreement is a service

- Are the proper parties represented in the agreements? For example, the agreement should not be between the data steward and a First Nation staff member or Department, it should be the First Nation itself, acting through Chief and Council, that is party.⁵¹
- Is First Nation ownership of data acknowledged?
- How are intellectual property rights in research results addressed?
- How can First Nations access their own data?
- Controlling all possible use, access and disclosure – listing uses that are acceptable to First Nation and requiring First Nation consent prior to any use not listed. No secondary use without consent.
- How will decisions be made about the use of data for linked data that includes First Nations data and, for example, provincial data?
- Regular reporting requirements by the data steward regarding all access
- Personal privacy protection and community privacy.
- Legislative review to determine vulnerability under access laws, and to determine applicable privacy legislation.
- Can the First Nation terminate the agreement for any reason?
- What happens to the data upon termination or expiry of the agreement?
- Is there a breach protocol that requires First Nation notification?
- Are there specifications for publishing to ensure that First Nations are properly attributed for their contributions, given an opportunity to comment upon works prior to publishing?
- Are there requirements to present research results to the community before publication?
- Can the partnership/project be used to build First Nation capacity in the area of information management, analysis, etc.?
- Are there requirements for continued consultation and communication between the data steward and the First Nation?
- Does the agreement contemplate or accommodate the future transfer of data to a First Nation data steward?

agreement for stewardship or technical services (where there is no contemplated 'use' of data by the steward), or whether the agreement is aimed towards research or another use or disclosure of First Nations data.

⁵¹ Although, depending upon the delegation of authority it may be a staff member that actually signs the agreement on behalf of the First Nation.

What's Next for OCAP™?

This paper has reviewed where OCAP™ began and how it is being implemented by First Nations today. It is only fitting to conclude with a look at where First Nations may take OCAP™ from here.

OCAP™ Certification Process

As a result of growing misuse and misrepresentations about OCAP™ The First Nations Information Governance Centre chose to protect OCAP™ in a way that would be recognized by government, academia and society in general. In 2012 the FNIGC registered the acronym OCAP™ as a trademark. A trademark is used in intellectual property law to distinguish the products or services of one person or organization from those of others in the marketplace.⁵² A trademark distinguishes the source of the product or service. While not entirely fitting within First Nation concepts of governance and property, trademarking will attribute the source of OCAP™ as being First Nations through a First Nations-controlled organization. It is hoped that this may limit some of the misuse of the term.

As a complementary initiative to publicly recognize projects and initiatives that truly represent OCAP™ in action, FNIGC will be granting an OCAP™ certification mark.⁵³ The *Trade-marks Act* provides the following definition:

“certification mark” means a mark that is used for the purpose of distinguishing or so as to distinguish wares or services that are of a defined standard with respect to

- (a) the character or quality of the wares or services,*
- (b) the working conditions under which the wares have been produced or the services performed,*
- (c) the class of persons by whom the wares have been produced or the services performed, or*
- (d) the area within which the wares have been produced or the services performed,*

⁵² See “A Guide to Trade-marks”, Canadian Intellectual Property Office: http://www.cipo.ic.gc.ca/eic/site/cipointernet-internetopic.nsf/eng/h_wr02360.html

⁵³ The FNIGC is awaiting approval for this process from the Canadian Intellectual Property Office.

*from wares or services which are not of such a defined standard.*⁵⁴

The certification mark will require the FNIGC to establish two crucial features: (1) What is the “defined standard” that will earn certification? And (2) what process will be put in place to respect regional and First Nation differences in the interpretation and application of OCAP™? Both of these questions were the subject of presentations and discussion at a National Workshop “First Nations Information Governance – OCAP™ in Action” hosted by the FNIGC in March 2013. Much of what follows is drawn from that event.

In establishing a “defined standard” for OCAP™ certification, the FNIGC must be flexible enough to recognize regional and community differences. A simple way to manage the apparent conflict is through the process and the standard. One option for a process would be for the FNIGC to delegate the determination of OCAP™ “compliance” to the regional First Nations organizations that form the membership of the FNIGC and which are accountable, in turn, to the First Nation communities within their respective regions. Regional organizations would be able to evaluate OCAP™ certification applications for projects that take place at a regional level, and the FNIGC would be able to evaluate applications for national-level projects.

Community-level or community-drive projects could also obtain OCAP™ certification. However, one of the primary benefits of OCAP™ certification would be to establish the credentials of a project within First Nations communities, government or academia. If a community-level project were looking for external validation in that way, the certification process would be appropriate; but if the project is First Nation-driven and represents concerns internal to the community, a First Nation may find the certification process unnecessary.

Again, this is just one possible approach to national and regional processes that FNIGC and the member regions will consider as the certification process is developed.

Likewise, a defined but flexible-standard must be finalized. The following considerations or criteria were presented at the National Workshop in March 2013

⁵⁴ R.S.C. 1985, c.T-13, s.12.

as a starting point for more extensive considerations and questions that would be asked of applicants.⁵⁵

Ownership

- How are First Nations identified in data?
- Who owns the data? Is there any licensing of data?
- How is ownership established?
- How is consent managed?
- Are First Nation(s) attributed as author/contributor?

Control

- How will First Nations exercise control over data?
- Are any agreements proposed or in place?
- What is the decision-making process for use of data?
- What is the data flow?
- What happens to data and results upon completion?

Access

- How can First Nations access their data?
- If personal information is being collected/held, how can First Nation individuals access their data?
- Who will be accessing data?
- Will everyone that has access to data receive training/education?
- What security/privacy policies and procedures are in place?

Possession

- Will data be held by a First Nation or a First Nation-controlled entity? If not, why?

General

- How does the project benefit First Nations?
- Is there any potential harm to First Nations or First Nations people? If so, how will that be mitigated?
- Is there a communication strategy for ongoing communication

⁵⁵ In no way are these questions intended to be exhaustive of the criteria or considerations for OCAP™ compliance. They present a starting point only. Considerations for certification will go far beyond the question listed here.

- Does the project include any opportunities for First Nation capacity building?
- If the project includes the collection of personal information, has a Privacy Impact Assessment been conducted?
- Will the data and/or results of research be returned to the community?
- Has the project been reviewed by an Ethics Review Board?

There would be no “correct” or “incorrect” answers to the questions. They would just provide information that could be weighted according to the priorities and values of the project and of the regions or communities involved.⁵⁶

As proudly expressed by Gail McDonald⁵⁷: “The OCAP™ Certification Mark presents an exciting move for the FNIGC towards its mandate “to promote, protect and advance the First Nations principles of Ownership, Control, Access and Possession (OCAP).” How the OCAP™ standard will be presented and the final process for granting the certification mark will be decided by the FNIGC Board of Directors⁵⁸ in the months to come.”

Repatriation of First Nations Data

Legal agreements have been discussed above as very effective tools that can enable First Nations to exercise control over their information. Agreements can be used to regulate the collection, use, disclosure and destruction of First Nations data when a First Nation does not have actual possession of that data.

We know that “possession” is a component of OCAP™ and that possession is the best way for First Nations to exercise jurisdiction over their data; to control access, use and disclosure. Yet we have seen above that in some OCAP™ models First Nations have chosen to partner with non-First Nation data stewards. This is because there remain some situations where a contracted data steward is necessary. These situations arise when the First Nations do not have the capacity. For example, First

⁵⁶ Interestingly, the Trade-marks Act does not permit the owner of the Certification Mark to certify its own “product or service.” Therefore, the FNIGC would not be able to certify the First Nations Regional Health Survey or other surveys that it conducts as “OCAP™ Compliant”.

⁵⁷ Gail McDonald: Operations Manager, The First Nations Information Governance Centre, speaking at “A National Workshop – First Nations Information Governance – OCAP™ in Action”, hosted by the FNIGC, March 6, 2013.

⁵⁸ The FNIGC Board of Directors consists of a member appointed by each First Nations region, plus a member appointed by the Assembly of First Nations. There are currently 11 members on the Board.

Nations involved in a particular project may not have the security and privacy infrastructure, or they may not have qualified personnel or equipment to perform data cleaning or matching or other technical work on the data. Another example is the case of personal health information - where that information may be subject to provincial health privacy legislation that may limit who can hold the data.⁵⁹ As First Nations' capacity in the area of information governance grows, this need for outside data stewards will decrease. In the OCAP™ models described above, the transition to First Nation stewardship is a clear vision within the information management systems.

The path to First Nations data stewardship is for First Nations to build the capacity within communities and to build regional First Nation data centres or centres of excellence, so that First Nations can repatriate their own information and knowledge. First Nations should investigate all potential sources of their information; institutions such as federal government, provincial government, universities, archives and museums.

Where First Nations are not able to repatriate their data, for reasons such as capacity, legal limitations, or otherwise, they should engage in partnerships with the stewards of their data for the purpose of entering into agreements to control over the use and disclosure of their own data.

CONCLUSION

Any collection, use and disclosure of our data, our information and our traditional knowledge must adhere to a First Nations of Alberta Information Governance model, clearly stating the Chiefs are stewards of their own data, that would require free, prior and informed consent and that leadership must be involved in every stage of research involving Alberta First Nations communities which reflect First Nation research ethics, values and accountability to Alberta First Nations Leadership in Treaty No. 6, Treaty No. 7 and Treaty No. 8 (Alberta).

⁵⁹ Other situations may also warrant a non-First Nation data steward, such as shared data repositories where First Nations participate in a larger data-sharing platform in which First Nations data is intermingled with all other residents of a province. As well, the *Indian Act* directs the Minister of Indian Affairs to maintain band membership lists and land registry data for reserves. Amendments to the legislation would have to take place to repatriate that data to First Nations.

Excerpt Assembly of Treaty Chiefs (Alberta) Resolution 30-03-2010#03 R
[March 2010]

The Atlantic Policy Congress of First Nations Chiefs Secretariat hereby immediately adopt a research mandate to implement the Atlantic First Nations' leaderships' right to self-determination, control and jurisdiction in reliable research and accurate statistics, based on First Nations principles of Ownership, Control, Access and Possession (OCAP) of First Nations data, information and traditional knowledge in the Atlantic First Nations communities.

Excerpt Atlantic Policy Congress All Chiefs Resolution #2011-16 [Feb. 2011]

As First Nations take control of their own data and participate in a society where digital record keeping is the norm, the importance of OCAP™ has grown from a standard for the conduct research, to a path for First Nations Information Governance.

While it seems that there are many barriers to OCAP™ implementation, there are equally many tools that can be used to overcome those barriers. In fact, through education and capacity building almost all barriers will fall. Models such as The First Nations Information Governance Centre, the Tui'kn Partnership, the Chiefs of Ontario Data Governance Agreement, and the Alberta First Information Governance Centre all demonstrate how OCAP™ is effectively working in practice.

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.

OCAP™ is the path to First Nations Information Governance. By building information governance capacity, enacting their own laws, entering into data sharing agreements, creating regional data centres and repatriating their own data, First Nations are exercising jurisdiction over their information.