



**OCAP**

**OWNERSHIP, CONTROL, ACCESS AND POSSESSION**

**FIRST NATIONS INHERENT RIGHT TO GOVERN FIRST NATIONS  
DATA**

Produced by the:

**ASSEMBLY OF FIRST NATIONS**

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## Background:

As First Nations we have always maintained an understanding and relationship to our information and recognized and respected certain protocols pertaining to the collection, use and passing on of information. Information governance is multi-layered. Communities ‘owned’ the stories that were shared amongst all the families while families ‘owned’ their songs and stories as well as governed how, when and who these could be shared with and passed on to. Finally, individuals within the communities had certain rights and responsibilities as dictated by their position within the community. For example, Shaman would generally protect traditional healing practices with strict protocols to ensure appropriate and responsible use of the practices and medicines.

The First Nation principles of OCAP (Ownership, Control, Access and Possession) were initially coined as ‘OCA’ in 1998 as a framework for asserting self-governance over information related to research by Cathryn Mandoka (George) of the Association of Iroquois and Allied Indians at a First Nations Regional Longitudinal Health Survey (RHS) Committee meeting<sup>1</sup> in an attempt to translate the First Nations inherent ways of knowing about information into something that could be easily described and interpreted to the research community. The ‘P’ was later added as a mechanism to support the previous three principles. Possession of data was identified to be of vital importance as it has proved nearly impossible to exert ownership, control and access over data when it is in the possession of governments and academia. The current legislative and policy environments generally do not respect First Nations as self-governing jurisdictions with collective rights over community information.

The original research focus of OCAP was to provide a framework related to data ownership, collection, analysis and dissemination for the RHS, as well as to provide a political response to counteract the harm done to First Nations by research that failed to respect the importance of understanding the First Nations way of knowing while treating First Nations as specimens rather than people with specific human rights. The First Nations principles of OCAP, with respect to research, provided a foundation for taking control over these activities.<sup>2</sup>

Since its initial research focused inception, OCAP has come to represent a far broader spectrum of self-governance over information than originally envisioned and now directs First Nation processes over all First Nations data.

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<sup>1</sup> Mandated by the Chiefs’ Committee on Health

<sup>2</sup> Ownership, Control, Access and Possession, First Nation Centre @ NAHO



## The ‘Principles’:

As much work has already been done to define the principles this section is intended to provide an overview for those unfamiliar with the principles. The key to understanding these principles is that compliance with OCAP is determined by the First Nation and no one else.

- **Ownership** describes the relationship of the First Nation to its cultural knowledge, data and information in all forms. This information is owned collectively by the Nation as an individual owns their personal information. Ownership is distinct from possession as one can own something with the ability to exercise all the rights inherent with that ownership despite not holding possession.
- **Control** reflects the aspirations and inherent rights to regain control of all aspects of our lives including control of information. This control extends to all aspects of information management including resources, policy development and implementation, review processes, formulation of conceptual frameworks, data management, etc.
- **Access** is the right to have access to information, data about yourselves and your Nation, wherever it is held. First Nations’ communities and organizations have a right to manage and make decisions regarding access to their collective information.
- **Possession** is a mechanism to assert and protect ownership. When First Nations data is in the possession of others (e.g. government, academia, etc.), there is often little to no control over management of data as a result of conflicting policy and legislation (Privacy Act, Statistics Act, Archives Act, Access to Information Act, etc.)

As previously stated, given the distinctiveness of each First Nation and respecting each other’s autonomy it is the sole right of each individual First Nation to determine how these principles are to be interpreted and enforced at the Nation level. All who consider their work as OCAP compliant must take care to ensure that First Nation rights to manage their information have been respected. Failure to incorporate the principles of OCAP is both unethical due to potential harm to the nation and unlawful as entrenched in First Nations legal right to self-governance.

Fundamentally, it is the community that decides what OCAP means. The community will decide how information about them is collected, managed, analyzed and disseminated. Some communities may not use the term OCAP specifically but prefer their own terminology that best express their rights to self-governance of information. What this means to outside organizations is



that there is a requirement to fully engage First Nations throughout each data initiative regardless of terminology used to express self-governance over information.

## **Objective:**

The First Nations principles of OCAP have been driving progress in the area of First Nations ownership and control of data with respect to research. However, much confusion remains as to what these principles mean in the broader context of information management. To address these concerns, it is the objective of this paper to provide clarity and direction around specific issues of confusion such as:

- Who decides what the First Nation Principles of OCAP really mean?
- What do these principles mean to non-First Nation entities?
- What is needed to truly implement these principles?

### **Who decides what the First Nation Principles of OCAP really mean?**

Quite simply it is the First Nation community whose data or information is at stake that decides what these principles really mean. Given the cultural diversity of First Nations across Canada it would be irresponsible to assume that any specific set of criteria would successfully satisfy each nation's requirements. Ultimately, OCAP is about the assertion of self-governance and wherever the First Nation is not provided the opportunity to assert governance over information about itself the principles of OCAP have not been respected.

Some communities may choose not to use the specific principles of OCAP however, from the perspective of the Assembly of First Nations, the First Nation should be free to exert governance over their information in whichever way works best for them. Fundamentally, OCAP is about self-governance however a First Nation chooses to express it.

The ideal situation for most First Nations would be to develop the capacity to fully manage their information from collection and analysis to dissemination. The First Nations Regional Longitudinal Health Survey<sup>3</sup> (RHS) is an example of an OCAP compliant research initiative, fully controlled by First Nations for First Nations. A non-research example of an OCAP compliant project would be the First Nation communities who have, of their own initiative, purchased health information systems to manage the administrative and personal health data of their community members.<sup>4</sup> They are exerting full control over how they manage the health information of their community. The

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<sup>3</sup> [www.rhs-ers.ca](http://www.rhs-ers.ca)

<sup>4</sup> [www.intrahealth.com/SingleNews.aspx?id=20&view=](http://www.intrahealth.com/SingleNews.aspx?id=20&view=)



control over data enables the community to better manage the services that they deliver.

### **What do these Principles mean to non-First Nation entities?**

In general the First Nation Principles of OCAP have been a challenge for non-First Nation entities to address, in particular for Federal, Provincial and Territorial (F/P/T) governments and agencies responsible for maintaining accountability of public funds and with maintaining the privacy and security of the personal information in their care.

Non-First Nation entities must recognize and respect that the principles of OCAP are not only applies to research initiatives but extend to all data and information activities related to First Nation communities. Respecting the principles of OCAP for governments is to be considered a fiduciary responsibility, in keeping with *Section 35 of the Constitution Act, 1982* that recognizes and affirms existing inherent rights of self-government and Aboriginal title. This includes the right to make decisions respecting land and the right to political structures for making those decisions. The right to political structures necessarily includes First Nations data and the required capacity necessary to manage data as a foundation for decision-making.

OCAP should also not be seen by non-First Nations as a barrier to fulfilling organizational responsibilities. Implementations of information systems that occur at the community level under community control would be better suited to provide quality data for program reporting. Data accuracy and precision would increase both as a result of the community having a vested interest in the data they collect through ownership as well as by the implementation of systems that address their specific community needs rather than needs as perceived by an outside entity with no real connection to the community. This means that there is a need for investments by non-First Nation entities in capacity building at the community level to enable effective information management. All entities that make use of First Nations data should be making investments into community capacity building for information management.

### **What is needed to truly realize these principles?**

For the First Nation principles of OCAP to be fully respected we need to have recognition of our rights over our information. Much as F/P/T governments have a level of control over their jurisdictional information, First Nations must have control over their jurisdictional information. For example Provinces are able to decide how to approach Provincial Privacy legislation, within certain parameters, to ensure that the legislation best serves their



unique needs and interests and the federal government respects these rights and differences by providing the flexibility to do so. There have been some rumours that Privacy Legislation will be reviewed in the near future to assess how it can be reworked and harmonized specifically to address issues of cross-jurisdictional data sharing particularly in relation to personal health information. First Nations require the same recognition and flexibility to look at all options necessary to address the current issues preventing F/P/T's from supporting OCAP.

Secondly, there must be investments for building First Nations capacity to manage our own information. Currently there are minimal funds provided to First Nations for building capacity to manage information with increasing demands by governments for accountability and efficiency of service delivery along with ongoing requests for increased data for various research projects and policy decisions.

Finally, there absolutely must be a willingness to support and promote First Nations rights to self-governance. OCAP is only a barrier to collaboration where there is no willingness to respect First Nations rights to self-governance including over our information.

## **OCAP and its meaning to First Nations:**

OCAP articulates the First Nations ways of knowing about information, recognizing that everything is inter-related. A wholistic, community centred, view must be taken for everything from policy and planning to relationship building.

### **First Nations Approach to Policy Development**

OCAP supports the proposed **First Nations Wholistic Policy and Planning Model**,<sup>5</sup> initially presented by the AFN to the Council of the Federation in August 2005, to maximize the positive impact of potential new investments and partnerships flowing from the 2005 First Ministers Meeting (FMM). While to-date there has been no commitments by the current government to provide any follow up to the FMM, the approach and objectives as put forward by First Nations continue to be valid.

For example, many of the factors influencing health lie in the complex social, economic and ecological environments in which people live. Sustainable development, as well, is only possible through the creation and maintenance of

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<sup>5</sup> It is necessary to recognize that many First Nations have developed their own wholistic health models. The model proposed by AFN is not intended to usurp this work, but only to complement and guide national initiatives towards a more comprehensive, planning approach.



these environments in a prosperous state. Over the last ten years, a series of case studies have demonstrated the tight connection between resilience (capacity and adaptation to change), diversity and sustainability of socio-ecological systems.<sup>6</sup> Negative human action, including the lack of understanding of ecosystems that incorporates traditional and local knowledge, can, of course, result in a loss of resilience.

The First Nations Wholistic Policy and Planning model is unique in that it emphasizes the significance of self-government to First Nations' well being. This is consistent with research undertaken by Chandler and Lalonde (1998), and the Harvard Project on American Indian Economic Development in which Cornell and Kalt (2002-03) asserted that:

*A decade of Harvard Project research has been unable to uncover a single case of sustained development that did not involve the recognition and effective exercise of tribal sovereignty: the practical assertion by tribes of their right and capacity to govern themselves. There is a major policy lesson here. (...) The reinforcement of tribal sovereignty should be the central thrust of public policy. (210)*

This model places “community” at its core. In a study of various healing models used by First Nations, a common thread was pinpointed as the positioning of the individual in the context of the community, with all models evolving from this premise (McCormick, 1995).

The relationship of OCAP to this policy development and planning context can be seen in the following diagram where the community is at the centre and foundation of the First Nations' ways of knowing. This model illustrates how we view the inter-relation of information about our communities with OCAP embedded in the part of the circle representing First Nations self-governance.

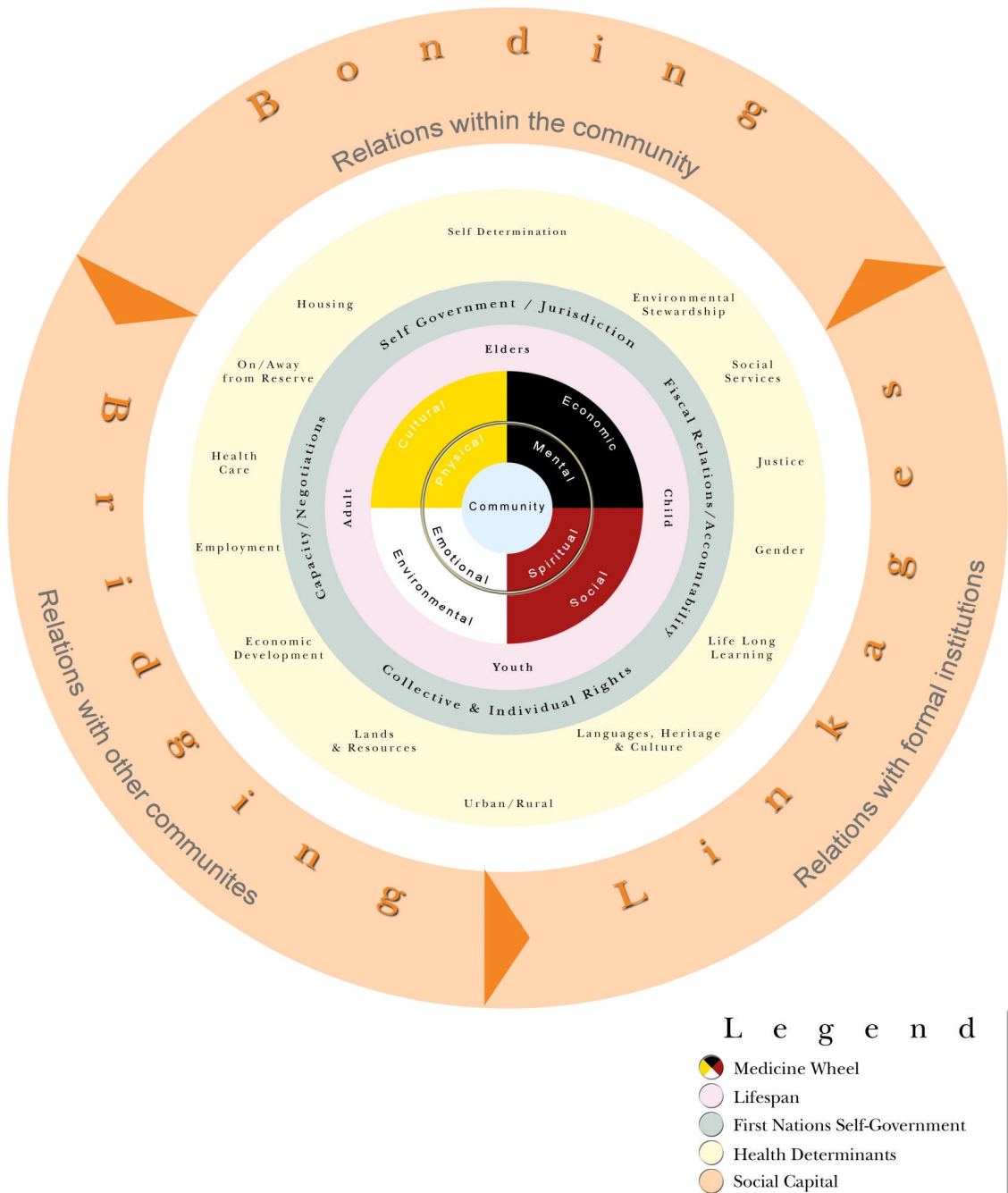
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<sup>6</sup> Folke et al, 2002 Resilience and Sustainable Development: Building Adaptive Capacity in a World of Transformations.





Figure 1: Proposed First Nations Wholistic Planning and Policy Model



## **The First Nations-Federal Crown Political Accord:<sup>7</sup>**

The First Nations-Federal Crown Political Accord commits First Nations and the Government of Canada to the establishment of a Joint Steering Committee to undertake and oversee cooperative action on policy change; the development of frameworks for the recognition and reconciliation of Constitutional, treaty and inherent rights; capacity-building opportunities for First Nations governance, and processes and legislation that will enable the development of First Nation governments. It was signed May 31, 2005 as part of the Cabinet Retreat, which brought together the Prime Minister and key Cabinet Ministers with the National Chief, AFN Regional Chiefs and representatives from the AFN's Women Council, Youth Council and Elders Council.

The First Nations-Federal Crown Political Accord provides a framework to work collaboratively toward realization of First Nations self-governance. OCAP fits within this framework by providing the principles to guide implementation of self-governance over information.

### **Success Stories:**

The best known and perhaps most successful example of the application of OCAP is the RHS. The RHS is a completely First Nation controlled survey that has garnered the support of all ten regions as the 'survey of choice' through both National and Regional resolutions. With the best example of OCAP in action being the RHS License to use agreements with Health Canada and Indian and Northern Affairs Canada that specify the terms and conditions with which these federal departments may have access to First Nations data. The RHS has also undergone rigorous academic validation by Harvard University<sup>8</sup> proving that First Nations are in fact capable of managing our data initiatives.

Lesser known initiatives include the British Columbia Tri-Partite data sharing agreement. While not fully OCAP compliant, due to the data continuing to reside outside of First Nations possession, this agreement respects First Nations as owners of their data held in Federal and Provincial databases and allowed linkages between the databases for specific health research purposes with the involvement and endorsement of the British Columbia regional First Nations governments.

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<sup>7</sup> [www.afn.ca/article.asp?id=1218](http://www.afn.ca/article.asp?id=1218)

<sup>8</sup> Harvard Review



## OCAP & Canada's Interpretation of 'Fair Information Practices':

For those who work with OCAP and are familiar with Privacy legislation, you may have noticed some striking similarities between the Canadian Standard Associations *Model Code for the Protection of Personal Information*, also known as "Canada's 10 Commandments of Privacy". The first edition of CSA Standard CAN/CSA-Q830 was prepared by the CSA Technical Committee on Privacy, under the jurisdiction of the CSA Steering Committee on Business Management Systems, and was formally approved by these Committees. The Standards Council of Canada approved it as a National Standard of Canada in March 1996.<sup>9</sup>

These 10 Commandments form the foundation of Canadian Privacy legislation and it is ironically these same legislative Acts that create the biggest barriers to First Nations attempting to assert control over their information. For those who are not familiar with the CSA Model Code for the Protection of Personal Information the principles as summarized on the CSA website are provided below.<sup>10</sup>

### Canadian Standard Associations (CSA) Principles in Summary

Ten interrelated principles form the basis of the CSA Model Code for the Protection of Personal Information. Each principle must be read in conjunction with the accompanying commentary.

1. **Accountability:** An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.
2. **Identifying Purposes:** The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.
3. **Consent:** The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate.
4. **Limiting Collection:** The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.

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<sup>9</sup> Available at [www.csa.ca/standards/privacy/publications/Default.asp?language=English](http://www.csa.ca/standards/privacy/publications/Default.asp?language=English)

<sup>10</sup> [www.csa.ca/standards/privacy/code/Default.asp?articleID=5286&language=English](http://www.csa.ca/standards/privacy/code/Default.asp?articleID=5286&language=English)



5. **Limiting Use, Disclosure, and Retention:** Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfilment of those purposes.
6. **Accuracy:** Personal information shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used.
7. **Safeguards:** Security safeguards appropriate to the sensitivity of the information shall protect personal information.
8. **Openness:** An organization shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.
9. **Individual Access:** Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.
10. **Challenging Compliance:** An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.

### Similarities & Differences

The protection of individual privacy versus the protection of a population is the main challenge when trying to reconcile Privacy Legislation with the First Nations principles of OCAP. First Nations do not necessarily challenge the CSA principles directly but rather, in the traditional wholistic fashion, see these principles embedded in our traditional way of knowing and doing by respecting individuals within our Nations. The specific notion of Individual Privacy however in First Nations communities often does not fit with the Western European perspective due to the Western emphasis on individual privacy where First Nations put the emphasis on the well-being of their population. Several First Nations languages don't even recognize the notion of Individual Privacy by way of having no words to describe it. As a result, it is often a difficult concept to explain to the many First Nations whose understandings do not include a focus on the individual.

For the non-First Nation the idea of collective rights are not entirely foreign if not as explicit. For example, current Privacy Legislation allows for



exceptions to the protection of Individual Privacy to be made where the benefit to the public good outweighs the potential damage to the individual, specifically in relation to communicable diseases and other public health issues.

The First Nation principle of Ownership along with the privilege of providing the rights to the benefits of managing community information includes the responsibility that comes with ownership. The CSA principles express this responsibility as the Commandments of Accountability, Consent, Openness and Challenging Compliance. For First Nation data held outside of First Nation control it is the responsibility of the data steward to fulfill their responsibilities to be accountable to First Nations whose data they hold by ensuring they have consent for use, are open about their use of the data while providing mechanisms for First Nations to challenge compliance.

The First Nation principle of Control also highlights the responsibilities of the Nation to the information they manage that are similar to the commandments of Accuracy, Limiting Use, Disclosure and Retention, Identifying Purposes. These principles equally emphasize the responsibilities of non-First Nations entities with respect to the collective information of First Nations held in their trust.

The First Nation principle of Access is strikingly similar to the Commandment of Individual Access with the obvious exception of different focuses between a Nation and the individual. First Nations should have access to data, in keeping with the CSA Individual Access principle, held on their people where it is not possible for the data to be held by the First Nation itself recognizing that the data is being held in trust for the community.

The final First Nation principle of Possession is the equivalent of the commandment for safeguards. To First Nations, being provided with the capacity to manage our own information is similar to the Commandment to ensure the proper safeguards are in place. Often it has been very difficult to ensure the proper safeguards for the protection of First Nations information when the information is not in the possession of First Nations due to conflicting organizational policies and legislation that does not address issues of First Nations right to self-governance.

An interesting experience that has become more and more common with the increasing profile of Privacy and Confidentiality issues as a result of changes to Privacy legislation as well as the progressive use of technology to share personal information has been where institutions who have failed to respect the principles of OCAP have, on occasion, been found to be breaking their own laws with respect to privacy. Non First Nation institutions that are responsible for First Nations information must be very cautious that they carefully consider how they are ensuring OCAP compliance by working with the



Nations whose information they are responsible for. If they are not, they might find that they are also contravening their own Privacy Legislation and policies, particularly around Consent, Identifying Purposes, Limiting Use and Accountability.

The AFN has begun work to develop a model for a First Nations Privacy Code as an enabling mechanism for data sharing with jurisdictions in order to address issues surrounding Individual Privacy within the context of OCAP. This code will use existing and proposed models of multi-jurisdictional data sharing agreements and legislative renewal such as those that will be used to facilitate the development of the Pan-Canadian Electronic Health record.

### **Reconciling Individual versus Collective Rights?**

The protection of Individual Privacy versus the protection of a population is the main challenge when trying to reconcile Privacy Legislation with the First Nations view of OCAP. Similar tensions arise around the use of personal health information in Canada with relation to Public Health Surveillance. Canada uses various information systems to track, manage and contain communicable diseases. This information becomes vital during a viral outbreak such as SARS. This view of personal health information being important to understanding and protecting health of the broader population mirrors the First Nations view of putting the community before the individual. As Canadian legislation recognizes situations where community needs trump the rights of individuals, they should be open to respecting and supporting this same worldview in First Nations.

Making exceptions to the rights of Individual Privacy also occur when doctors access all of the patient's health records to ensure that an accurate diagnosis and appropriate care plan can be implemented. Situations like this where more contextual information is used for decision-making is in keeping with the First Nations wholistic view of health. Addressing health concerns requires more than just one piece of information but rather a view of all the potential contributing factors that affect health in keeping with the term population health. Given the multi-dimensions of health, a silo approach to information management will not create the depth or breadth of information required. These views are in keeping with the Population Health Approach taken by Health Canada where *"[We] need to address the entire range of conditions and factors that determine health [and] the complex interactions among them..."*<sup>11</sup>

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<sup>11</sup> [www.phac-aspc.gc.ca/ph-sp/phdd/](http://www.phac-aspc.gc.ca/ph-sp/phdd/)



## OCAP & Ethnocultural Ethics:

Ethnocultural researchers Gerald V. Mohatt and Lisa R. Thomas bring their experiences in cross and multi-cultural settings and the importance of researcher/author perspectives forward in their publication *I Wonder, Why Would You Do It That Way?: Ethical Dilemmas in Doing Participatory Research with Alaska Native Communities*<sup>12</sup>. Mohatt is a European American of rural European descent who spent fifteen years living on the Rosebud Sioux, Sicangu Lakota reservation in South Dakota where he learned to speak Lakota. He then moved to Alaska where he continues to live and work with the Alaska Native communities as an educator, researcher and clinician. Thomas is Tlingit who was brought up with both ancestral and western values and has been working with Native communities as a consultant, researcher, and clinician since 1987. A key lesson they have jointly learned can best be described by the following quotation:

*“Ultimately, we learned that it is essential to include members of the participating communities in the decision making regarding research methodologies (including limits of confidentiality), the meaning ascribed to research questions and participant responses, and the analysis and interpretation of the resulting data. Without community involvement in each of these steps, it is clear that any results are questionable at best and harmful to the communities at worst.”*

-Gerald V. Mohatt and Lisa R. Thomas

The driving force behind the defining and enforcement of the First Nations principles of OCAP is the extensive amount of harm done to FN in the name of research. To this day First Nations and other Indigenous populations have been de-humanized, treated as research ‘specimens’ rather than respected as equal human beings. In response there has been substantial research and literature devoted to cataloguing the harmful practices, and also potential new models of engagement that can be used to regain control and ‘decolonize’ research.<sup>13</sup> Linda Tuhiwai Smith discusses the negative consequences of indigenous women losing their status in the community as a result of the ways in which indigenous women were ‘classified’ according to Western European tradition. *“At a very simple level the ‘problem’ is a problem of translation. Rangatiratanga has generally been interpreted in English as meaning chieftanship and sovereignty, which in colonialism was a ‘male thing’.”* Because roles of influence were translated and asserted as masculine roles, females were blocked from assuming leadership positions that had previously been open to them.

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<sup>12</sup> Trimble, Joseph E., Fisher, Celia B

<sup>13</sup> Smith, Linda Tuhiwai



Examples abound in our communities of harm that continues to occur due to poor understanding of collected data by non-First Nations in particular when data is collected for reporting purposes without consideration for capacity and workloads of First Nations staff and without understanding of the context from which the data was collected. For example, Western based science is coming around to what First Nations have known for millennia, that our health is related to a wide number of seemingly unrelated factors.

Mohatt and Thomas also bring forward an interesting point “...*the belief that research is not fully ethical if it violates the fundamental values of a cultural group. This implies that most research is more or less ethical rather than ethical or not ethical.*” This same reasoning applies to OCAP in that data initiatives by non-First Nations involving First Nations will be either more or less OCAP compliant, therefore falling across a spectrum rather than fitting a specific set of established criteria.

While there appears to be significant recognition of the harm done by colonial perspectives towards research especially with the recognition of research methods in keeping with First Nations values such as Participatory Action Research, narrative inquiry as data<sup>14</sup> there is still little recognition of the harm done to First Nations through non research related information management initiatives that follow colonial approaches to the study of populations.

In some cases the use of non-research methods such as ‘Evaluation’ and ‘Reporting and Accountability’ to gather data on First Nations people have been used to circumvent the principles of OCAP by attempting to distract from the primary focus of OCAP; the regaining of control over all methods of data collection, analysis and dissemination. Not only is failing to comply with the principles of OCAP likely harmful to First Nations which would qualify as unethical treatment it also fails to respect Human Rights under the Canadian Charter. In addition, the quality of data gathered without full involvement by the community is likely to be low-quality data.

## **OCAP beyond Research:**

Much work has been done in the development and understanding of the principles of OCAP from the perspective of research; however, many challenges continue to exist in non-research related information management activities. As previously mentioned some non-research activities are in fact research thinly veiled as ‘Evaluations’ specifically to avoid addressing OCAP or even Ethical reviews. The OCAP principles continue to be relevant and applicable for

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<sup>14</sup> Riley, T. & Hawe, P.





non-research related activities where the activity involves First Nations' information.

One specific example of where the principles of OCAP are relevant and where little progress has been made to date is the development of a Pan-Canadian Electronic Health Record (EHR), which is currently being driven by Canada Health Infoway (CHI). The pursuit of a National EHR is the result of many promised benefits, such as: improved access to health information, improved quality of information and increased productivity<sup>15</sup>. Many First Nations see the value in participating in this development and have endorsed the First Nations Health Infrastructure Recommendations<sup>16</sup> through regional resolutions however, the lack of recognition of the importance of OCAP to First Nations greatly contributed to the failure of the full uptake and use of the First Nations Health Information System (FNIHIS). The lack of success in this initiative has created a level of distrust in any plans brought forward by the federal government regarding the implementation of substitute health information systems. Despite this failure many First Nations continue to see the value of an electronic Health Information System that meets their specific information management needs and continue to use the FNIHIS in a limited capacity or have made personal investments in developing and/or purchasing their own systems.

The challenges facing Canada Health Infoway for facilitation of implementing a Pan-Canadian Electronic Health Record are not so different from those facing organizations looking to develop information management initiatives with First Nations. All initiatives must: respect the unique needs and environments of each jurisdiction; communicate information across jurisdictions while respecting individual privacy. They learned quickly that a National solution would not be feasible and have adopted a Standards and Integration approach, respecting each jurisdiction's autonomy to adopt systems that best meet their individual needs. First Nations through OCAP require the same autonomy.

### **Complying with OCAP**

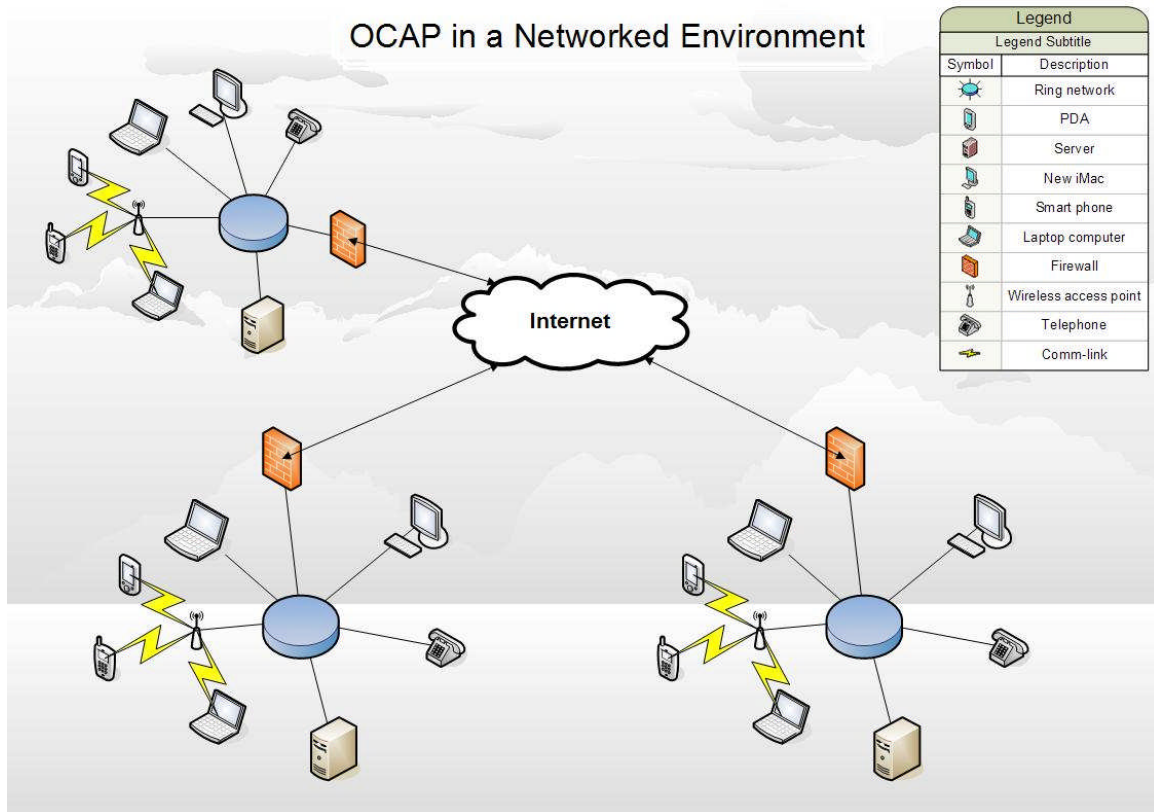
Given the example of the similarities between the challenges faced by Canada Health Infoway regarding the respect of the individual needs of jurisdiction in the development of a National EHR and the challenges faced by First Nations to ensure that our views of information management are respected, we can adopt a similar models to those employed by Canada Health Infoway. The following diagram is provided as a generalization of how information systems can be developed that respect OCAP.

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<sup>15</sup> [www.infoway-inforoute.ca/en/ValueToCanadians/Benefits.aspx](http://www.infoway-inforoute.ca/en/ValueToCanadians/Benefits.aspx)

<sup>16</sup> First Nations Center @ NAHO, *First Nations Health Infrastructure Recommendations, Briefing # FNC04-043*





The blue circle that portrays ‘the ring network’ with attached devices represents First Nations and/or non-First Nation entities with which communities might share information. All information would be under control of the First Nation and would be shared at the discretion of the First Nation through secure channels such as through a firewall to the internet to other networks which could include academic and government institutions. The key to this model is that everyone uses the same standards for communication which for example in health care the standard for messaging is often the HL7 messaging standard.

### **OCAP as an Enabler:**

There have been reoccurring issues with obtaining quality data regarding First Nations, particularly in the area of health. These current data challenges are primarily as a result of a failure to respect the importance of OCAP, both as the political stance of First Nations but more importantly as a best practice in the implementation of information systems.



For example, hospitals that attempt to implement information systems that do not meet the requirements of all the users, (doctor's, nurse's and even sometimes patients) often fail to meet the intended objectives. Even if there is limited use of such a system, the information gathered will have a high likelihood of being limited value. The principles of OCAP are in keeping with the importance of stakeholder engagements in the development and implementation of information systems best practices.

## **Conclusions:**

At the heart of the OCAP principles is the First Nation itself. OCAP is not 'owned' by the AFN but by each individual community. While the principles have been developed by the First Nations Information Governance Committee and mandated by the Chiefs' Committee of Health, these are very much First Nations principles and Nations are free to express them in the ways that are most appropriate to them.

OCAP is about building First Nation capacity to self-govern. And self-governance is about more than just control over resources but encompasses control over self-identity, ultimately leading to a higher state of well being of First Nations as a people.

OCAP is about due diligence to ensure accurate results of data analysis and beneficial dissemination for decision-making. Responsible researchers and policy makers will want the best data, which can only be had when the communities in question are fully involved from start to end in the data collection, analysis and dissemination.

Federal, Provincial and Territorial governments are currently working towards Pan-Canadian solutions for multi-jurisdictional sharing of data and as such have a fiduciary responsibility to be inclusive of First Nation governments in such activities. In addition, fully involving First Nations from the start will ensure that the best solutions are put forward providing huge potential savings in both the short and especially the long term.

Aligning OCAP with Privacy legislation and providing resources to First Nations to enact their own privacy legislation would assist in enabling First Nations to take control over their own information and enable the flow of information across jurisdictions for maximum benefit.



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