

QUEBEC FIRST NATIONS INFORMATION GOVERNANCE FRAMEWORK



FIRST NATIONS OF QUEBEC
AND LABRADOR HEALTH
AND SOCIAL SERVICES
COMMISSION

AUTHOR

EMILIE GRANTHAM, First Nations of Quebec and Labrador Health and Social Services Commission

QUEBEC FIRST NATIONS INFORMATION GOVERNANCE WORK COMMITTEE

RICHARD BASQUE, Mohawk Council of Kahnawake

PATSY BORDEAU, Onkwata'karitahtshera, Kahnawake

EMILIE GRANTHAM, First Nations of Quebec and Labrador Health and Social Services Commission

NANCY GROS-LOUIS MCHUGH, First Nations of Quebec and Labrador Health and Social Services Commission

PATRICE K. LACASSE, First Nations of Quebec and Labrador Health and Social Services Commission

CARL SIMARD, First Nations of Quebec and Labrador Health and Social Services Commission

TIM WHITEDUCK, First Nations Education Council

COLLABORATION

MICHEL DESCHÊNES, First Nations of Quebec and Labrador Health and Social Services Commission

MARJOLAINE SIOUÏ, First Nations of Quebec and Labrador Health and Social Services Commission

TRANSLATION

VERA ROY

GRAPHIC DESIGN

KARINEPOTVIN.COM

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FIRST NATIONS OF QUEBEC AND LABRADOR HEALTH AND SOCIAL SERVICES COMMISSION

250 Place Chef-Michel-Laveau, Suite 102

Wendake, Quebec G0A 4V0

info@cssspnql.com

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ABOUT THE COVER PAGE

The turtle is a symbol of truth. Grandmother Turtle was present when the Creator made man and gave him the seven sacred laws. She ensures that these laws are not lost or forgotten.

SOURCE: trauma-informed.ca/trauma-and-first-nations-people/cultural-practices

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FOREWORD

In recent years, the First Nations in Quebec have adopted various mechanisms to better organize and structure their information. These include, among others, the *First Nations in Quebec and Labrador's Research Protocol*, the *Framework for the Protection of Information Held by a Quebec First Nation Community or Organization*, as well as various agreements and tools provide a structure for the development and implementation of the information management systems used in First Nations communities and organizations.

The publication of the *Quebec First Nations Information Governance Framework* arises from the need expressed by the First Nations for principles to guide these many efforts to put into practice ways of regaining control over our information. This document is one step in the collective process of asserting our autonomy, our inherent rights and our treaty rights.

Information is an undisputed source of power. It is crucial for information about us to be used in the interests of our nations and our organizations. We have the right and the responsibility to control the way our information is to be accessed, collected, shared, preserved, protected and used. This framework sets out principles to guide these facets of information governance, while ensuring respect for the autonomy and specific characteristics of each of our nations.

We must insist that governments and our partners respect our principles and any local or regional actions that arise under this framework. Commitment from the governments is essential to confirming a common intent to establish a true government-to-government relationship.

Ghislain Picard
Regional Chief

INTRODUCTION

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

Article 31.1 of the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2008)

From time immemorial, the First Nations have possessed knowledge they wish to protect, organize and pass on in accordance with their values and customs. Interwoven with their traditions, culture and land, this knowledge helps them sustain future generations, promotes their flourishing and provides them with a foundation for decision-making. In recent decades, new kinds of knowledge and wisdom have come into being. Authorities established by the federal government have repeatedly recognized the First Nations' inherent right to govern information about themselves. The work of the Royal Commission on Aboriginal Peoples (RCAP) found that a complete review of the relationship between Aboriginal people and non-Aboriginal people was necessary, and that Aboriginal peoples' cultures, values and right to self-determination should be recognized (RCAP, 1996). The recommendations of the Truth and Reconciliation Commission (TRC) call on the federal government to address health inequities, establish measurable objectives, and identify and respond to disparities (TRC, 2012). Internationally, the United Nations Declaration on the Rights of Indigenous Peoples also sets out the right of Indigenous peoples to self-determination (United Nations, 2008).

New information derived from research, population surveys, and various information management systems is now included among the information assets of communities and organizations of the First Nations in Quebec. To advance the goals of self-determination and the democratization of information, mechanisms will have to be established to ensure that all the information collected will be governed by the First Nations for their individual and collective benefit. Decision-makers in First Nations communities and organizations need expertise and resources to use this information in their planning, management, evaluation and decision-making processes. For too long, data has been collected for the purposes of accountability, solely for the benefit of governments; the paradigm must now shift to one that aligns with the aims of First Nations. Today, that information must meet the needs and expectations of the First Nations, both individually and collectively.¹

¹ Many resolutions supporting greater information governance by First Nations have been adopted by the Chiefs of the Assembly of First Nations. Resolutions 57/2016 and 42/2018 reiterate the desire for First Nations to be at the heart of decisions regarding their information.

www.cssspnql.com/docs/default-source/centre-de-documentation/resolution-57-2016-aga-apn-eng.pdf?sfvrsn=8
www.cssspnql.com/docs/default-source/centre-de-documentation/resolution-42-2018-aga-apn-eng.pdf?sfvrsn=8

Impediments and inequities currently preventing First Nations from exercising full authority over their information must be countered with local and regional mechanisms created by First Nations to regulate their information assets. Reclaiming control asserts cultural specificities, thus promoting cultural safety, which is an important agent of power, equality and respect, and a first step towards true reconciliation among nations (Brascoupé and Waters, 2009).

INFORMATION: A WORLD IN CONSTANT EVOLUTION

We are currently witnessing an extraordinary evolution in technology and information, which has resulted in the development of new information management systems, the matching of data from various sources, new ways of storing information (the “cloud”), and the emergence of open data portals, to name but a few examples. Although these developments bring new opportunities, they also raise ethical questions about confidentiality and information security.

In this changing environment, First Nations must remain vigilant and take a position to ensure respect for the principles that must underpin the governance of their information, such as the principles of OCAP®.

FIRST NATIONS INFORMATION GOVERNANCE IN QUEBEC

VISION

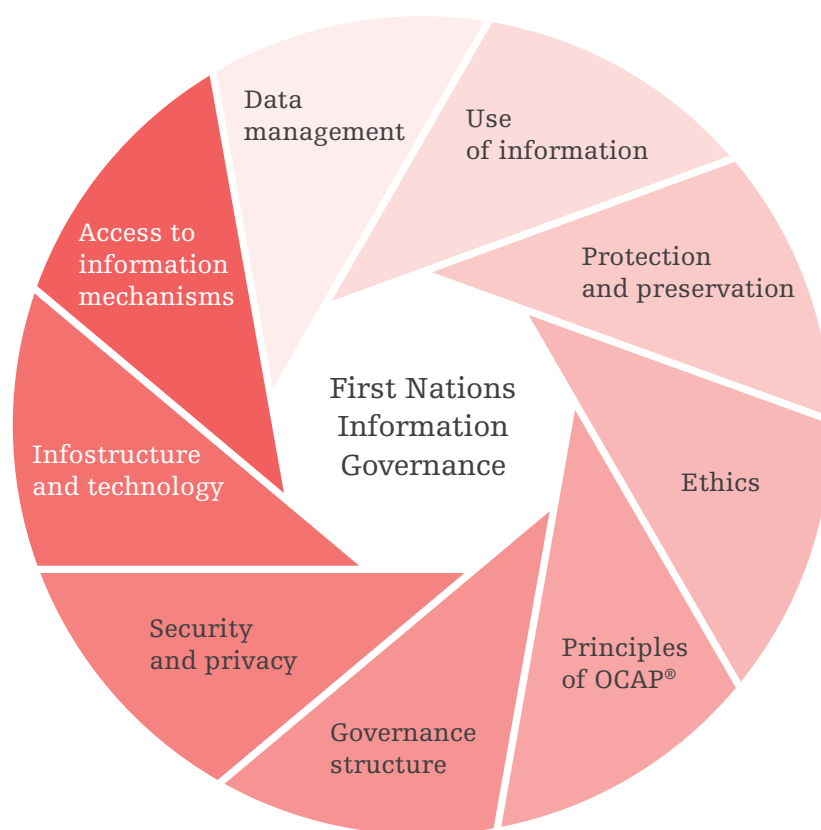
In keeping with their right to self-determination and sovereignty of information, the First Nations in Quebec organize, structure, control and manage their information assets in ways that accord with their values, worldview and practices, so that they may make informed decisions and orient their actions to serve their populations effectively.

DEFINITION

Information governance refers to the structure, processes and protocols by which First Nations become integral actors in decisions regarding the collection, use, sharing, management and protection of their data.

COMPONENTS OF INFORMATION GOVERNANCE

First Nations information governance comprises several components. Communities and organizations must define the relevant roles and responsibilities, along with the structures that will enable them.



PURPOSE AND OBJECTIVES OF THE INFORMATION GOVERNANCE FRAMEWORK

Information governance is a fundamental component of First Nations governance. The repatriation of powers and taking control of information are important attributes of self-governance.

The purpose of the *Quebec First Nations Information Governance Framework* is to promote the autonomy of First Nations to establish local information governance processes or mechanisms.

This framework is designed to support the First Nations of Quebec as they take control of their information and give them tools to strengthen and organize it. By identifying the guiding principles, the framework provides a key to defining the strategies to be adopted on how First Nations information should be gathered, preserved, protected, used, managed, accessed and shared.

The objectives sought are the following:

- To raise awareness among First Nations about the issues related to information governance and changes in the environment that may hamper such governance.
- To have common First Nations standards to protect information assets collectively and to act as a counterbalance to values imposed unilaterally by the State and public institutions.
- To identify the roles and responsibilities of each of the stakeholders in information governance by and for First Nations.
- To support First Nations in the development of mechanisms or in the adaptation of existing mechanisms to structure their information assets.
- To raise awareness among the partners of the First Nations about the principles of information governance by and for First Nations.

WHY AN INFORMATION GOVERNANCE FRAMEWORK?

The application of the guiding principles set out in this framework fosters self-determination and the sovereignty of information, empowering First Nations to carry out their own practices that align with their values and culture. This framework applies and promotes the principles of OCAP®, helps define common standards and encourages the use of information in response to the needs, priorities and opportunities of First Nations.

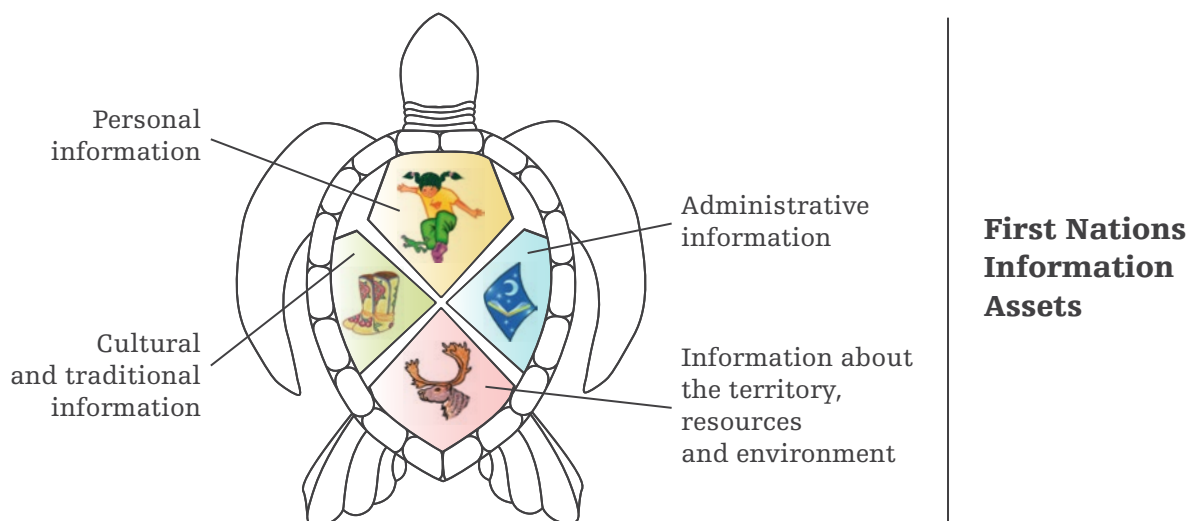


SCOPE OF THE FRAMEWORK

The *Quebec First Nations Information Governance Framework* applies to all data, knowledge and wisdom, and to any other information that belongs to the information assets of First Nations.

Information assets include four types of information:

1. **Personal** information, such as medical or school records.
2. **Administrative** information, such as band lists, financial reports and minutes.
3. **Cultural and traditional** information, including language, ceremonies, stories and legends, songs, and traditional know-how including medicine and traditional healing, etc.
4. Information about the **territory, resources and environment**, such as knowledge about plants and animals, cartography, and hunting, fishing, gathering and trapping.



Any information about a group of individuals, an organization or a community, whether it is held by the First Nations or by a third party (government or organization), and whether material or immaterial, is part of these information assets.²

The *Quebec First Nations Information Governance Framework* recommends that any person or organization collecting, preserving, using, managing or sharing information that is part of the information assets of the First Nations in Quebec should respect this framework and any other tools developed by the First Nations with the same scope, according to the will of First Nations.

² Special attention should also be given to aggregate data, which is a collection of data gathered from several measurements, sources and information types. The method of data aggregation can be a source of vast knowledge that could greatly benefit First Nations.

LIMITATIONS TO THE FRAMEWORK

This framework in no way amends any existing community, provincial, territorial or federal laws or regulations. The guiding principles in the framework are proposed, not imposed. Each First Nations community and organization is thus responsible for establishing its own rules and procedures. First Nations also bear responsibility for promoting the framework, raising awareness in their partners, and ensuring respect for the principles adopted by their community or organization.

This framework is not an action plan. Strategic directions are proposed, but concrete action is the responsibility of First Nations communities and organizations.

GUIDING PRINCIPLES OF QUEBEC FIRST NATIONS INFORMATION GOVERNANCE

Current practices in First Nations information governance must be improved because they do not always meet the needs of communities and organizations or the challenges they are facing.³ A number of issues can be identified: a recurrent lack of funding that makes it difficult if not altogether impossible to establish large-scale projects to properly organize and use information both locally and regionally, the need for durable infrastructure to support better information governance, and the small efforts made by governments to promote information governance by and for the First Nations. Changes must be made to ensure that the First Nations' vision of information governance can be realized by enhancing capacities, providing assistance and gaining access to the necessary resources.

The principles that guide Quebec First Nations information governance are founded on the notion that each First Nations community or organization is best placed to govern its own information because it is autonomous.

The guiding principles were developed to support First Nations in the creation of mechanisms to manage and protect their information assets. They promote an approach focused on self-determination and the sovereignty of First Nations information. These principles are guides. Flexibility is required to reflect the needs and realities of the different First Nations communities and organizations.

³ At the 2016 pre-annual general meeting of the FNQLHSSC, a half-day was devoted to governance and information management. The workshops documented the mechanisms put in place at the local level, both for the application of the OCAP® principles and for the management of information assets. A majority of participants stated that a regional information governance framework providing guidelines that could be adapted to the reality and needs of each community would help them better manage their information assets. Community representatives also stated at the meeting that they did not have human resources available to dedicate to managing and governing their information (FNQLHSSC, 2016). The 2017 pre-annual general assembly of the FNQLHSSC, which focused on information governance, also revealed more about the current situation. It confirmed that there is no uniformity between the communities and organizations in terms of either the mechanisms in place to control information assets or each community and organization's capacity to use information for decision-making purposes (FNQLHSSC, 2017).

1

THE RESPONSIBILITY FOR PROTECTING THE INFORMATION ASSETS OF QUEBEC FIRST NATIONS BELONGS FIRST AND FOREMOST TO FIRST NATIONS INSTITUTIONS.

This first principle establishes the legitimacy of an approach based on the autonomy of First Nations communities and organizations in the governance of their information. The sovereignty of information will be achieved through, above all, the repatriation of First Nations information. Therefore, First Nations must know and decide where and how their information is collected, preserved and shared. They must take part in decisions about repatriating their information or creating sharing agreements to guarantee that they have access to and control over it. This principle also establishes that each community and organization determines who can make decisions about collecting, storing, preserving, transmitting, using and sharing their information assets. Each community and organization has the right to develop its own structure to collect, preserve and share information.

2

THE RIGHT OF FIRST NATIONS TO SELF-DETERMINATION GUIDES THE USE OF INFORMATION ASSETS.

The information assets of First Nations must serve the needs of First Nations. First and foremost, information must support First Nations in their informed decision-making, whether in the context of management activities or in planning or evaluation processes. First Nations must also identify the information that they consider to be relevant and appropriate.

3

FIRST NATIONS INFORMATION GOVERNANCE IS A LOCAL AND COLLECTIVE RESPONSIBILITY.

The pooling of expertise, the sharing of experiences, and the mobilization of communities in defence of their interests improves knowledge, practices and the communication thereof. This collective takeover of information governance makes it possible to build on the strengths of individuals and to rely on an economy of scale that allows each community and organization to access the best practices and expertise.

4

FIRST NATIONS INFORMATION GOVERNANCE IS SUPPORTED BY A GOVERNMENT-TO-GOVERNMENT RELATIONSHIP.

First Nations information governance must be based on a government-to-government relationship of equals in which the data sovereignty right of First Nations is acknowledged. Within this relationship, First Nations make their own decisions, and the federal and provincial governments must undertake to respect and support them in this process. Moreover, a government-to-government relationship presupposes that First Nations will be involved in any issue having to do with their information.

5

TRADITIONAL AND CULTURAL FIRST NATIONS KNOWLEDGE IS RECOGNIZED, VALUED AND PROTECTED.

Traditional First Nations knowledge is recognized on the same footing as empirical or scientific knowledge. Its distinctive characteristic is the fact that it belongs to a community or a nation, not to a person or limited group.⁴ Traditional wisdom is unique and culturally valuable knowledge. It must be valued and protected. Decisions concerning the preservation of this wisdom are the responsibility of the First Nations, who must all ensure that this knowledge will be passed on to the next seven generations.

6

FIRST NATIONS PRINCIPLES OF OCAP® APPLY TO ALL FIRST NATIONS INFORMATION ASSETS.

Each community and organization has its own interpretation of the OCAP® principles and can therefore determine how it will require their application. Regardless of the type of information or the context in which it is collected, the First Nations principles of OCAP® must be applied.

7

INFORMATION GOVERNANCE IS SUPPORTED BY AN EFFICIENT AND UP-TO-DATE INFOSTRUCTURE.

The First Nations need to control the technical architecture⁵ and operational processes that support the optimal use of their information. This infostructure must employ best practices and the highest security standards. Sufficient human, financial and material resources must be available and accessible locally, regionally and nationally to set up and administer this infostructure.

⁴ This principle may vary depending on the culture and the diversity of the communities and nations.

⁵ The notion of technical architecture refers to all the rules governing the arrangement, interaction and interdependence of the different components of the infostructure.

8

LOCAL CAPACITY BUILDING IN INFORMATION GOVERNANCE IS ADEQUATELY SUPPORTED.

To assist the First Nations in their information management and governance, support for capacity building and enhancement must be available. This aid must include technical support, training, coaching, networking, help with funding research and assistance with developing tools.

9

ALL STAKEHOLDERS ENSURE THE OPTIMAL USE OF FIRST NATIONS INFORMATION ASSETS.

Information about First Nations must be gathered using a rigorous approach and with respect for privacy. To the extent possible, information should be gathered only once, and mechanisms and agreements must be put in place to maximize its use. The purpose of the entire process, from the collection of information to its analysis and interpretation, must be to make useful and high-quality information available to decision-makers. All secondary use of the information must respect the ethical principles in force.

STRATEGIC DIRECTIONS FOR THE IMPLEMENTATION OF THE VISION AND THE GUIDING PRINCIPLES

Strategies must be implemented to ensure that the vision and principles that must guide the governance of information by and for First Nations become reality. Five strategic directions are proposed:

STRATEGY 1 ● COMMITMENT OF FIRST NATIONS

The first strategy requires First Nations to commit to developing and establishing mechanisms to raise awareness in and mobilize First Nations communities and organizations. First Nations political leadership must be mobilized, and it must support the implementation of these mechanisms.

STRATEGY 2 ● PROTECTION OF INFORMATION ASSETS

Locally and regionally, the protection of information assets must be based on shared individual responsibility. It may be appropriate to appoint an information guardian to oversee the information assets, develop standards and provide support. Mechanisms to protect traditional and cultural knowledge must be developed.

STRATEGY 3 ● ADDITION OF RESOURCES

Enhanced oversight of information assets requires communities and organizations to be better equipped, which means that financial, material and human resources must be added.

STRATEGY 4 ● CAPACITY BUILDING

To ensure that each First Nations community and organization takes responsibility for implementing its own information-protection mechanisms, capacity building through mentoring, coaching and personalized training must be provided.

STRATEGY 5 ● RAISING THE AWARENESS OF GOVERNMENTS AND PARTNERS AND RECEIVING THEIR SUPPORT

The government and the First Nations' institutional partners must be familiar with the *Quebec First Nations Information Governance Framework*. Communities and organizations are responsible for raising awareness in their partners and are entitled to insist that they comply. Governments and other partners of the First Nations must commit to a partnership based on collaboration, respect and fairness.

TOOLS AND REFERENCE DOCUMENTS

In recent years, various tools, reference documents and training programs have been developed to support the implementation of mechanisms to ensure better First Nations information management and governance.

Coloured dots indicate the information governance components addressed by each tool, reference document or training program.



TOOLS AND REFERENCE DOCUMENTS⁶



- **Consultations Protocol of First Nations of Quebec and Labrador (Assembly of First Nations Quebec-Labrador, 2005)⁷**

The aim of this protocol is to establish a permanent framework to ensure that the federal and provincial governments consult with the First Nations in Quebec and Labrador and make accommodations for them before any decisions that have the potential to infringe the rights of First Nations are made. The protocol is designed for situations where Aboriginal claims or rights are not yet fully recognized.



- **Data Protection and Stewardship Protocol (First Nations Information Governance Centre, 2013) (not available)**

In population surveys coordinated nationally by the Information Governance Centre, each participating region must complete a document detailing the practices it has implemented to ensure privacy and data security.



- **First Nations' Data Governance: Measuring the Nation-to-Nation Relationship (British Columbia First Nations' Data Governance Initiative, 2017)**

This discussion paper presents an analysis of what a true nation-to-nation relationship between the federal government and First Nations might look like and how to measure this renewed relationship. The document also provides the background to and a portrait of information governance initiatives in every region of Canada.



- **First Nations in Quebec and Labrador's Research Protocol (Assembly of First Nations Quebec-Labrador, 2014)**

This research protocol is a guide for First Nations and the scientific community in research activities on First Nations territories. It sets out three fundamental values: respect, fairness and reciprocity. The research protocol contains adaptable tools such as model research agreements and consent forms.

⁶ Most of these tools and reference documents are available on the FNQLHSSC Documentation Centre at centredoc.cssspnql.com.

⁷ A new version of this document is currently being drafted and should be available in 2019.



- **Framework for the protection of information held by a Quebec First Nation community or organization (First Nations of Quebec and Labrador Health and Social Services Commission, 2014)**

- This framework, which was adopted by way of resolution by the Assembly of First Nations Quebec-Labrador (AFNQL), is adaptable to every community.
- Written for First Nations communities and organizations, it provides a framework to enact rules to govern how personal information is collected, protected and accessed.



- **Guidelines for Research with Aboriginal Women (Quebec Native Women, 2012)**

- This document was developed for Aboriginal women, members and employees of Quebec Native Women, community decision-makers and managers, and researchers. Its aim is to support Aboriginal women when they make decisions about their involvement in research projects. It also proposes a series of steps to ensure that research is ethical and respectful.



- **Regional Information Governance Centre: Self-Assessment Toolkit (First Nations Information Governance Centre, 2016) (not available)**

- In 2016, the First Nations Information Governance Centre designed a new self-assessment tool for the First Nations of each region to identify the areas where capacity building is needed to set up regional information governance centres.⁸



- **Regulations for Research in Kahnawake (Onkwata'karitáhtshera Health and Social Services Research Council, 2006)**

- The Kahnawake community has adopted a framework defining its control over health and social services research. It contains principles and criteria that guide the decisions of the community's research council about any research taking place in Kahnawake. This document also outlines the obligations of each of the parties during a research project.

⁸ The purpose of creating a regional information governance centres is to support local and regional information governance by providing services including training, support, data collection and analysis and technical support.



- **Research Guidelines (First Peoples Working Group, Institut nordique du Québec, 2017)**

These guidelines for researchers and students associated with the Institut nordique du Québec are also guides to good practice for researchers interested in working in the North. The document sets out ethical research principles and processes for research in a Northern environment.



- **The Matrix: Computerizing Health and Social Services in my Community – The Infostructure and The Matrix: Computerizing Health and Social Services in my Community – The Measures (First Nations of Quebec and Labrador Health and Social Services Commission, 2011)**



These two documents outline a vision of a First Nations health infostructure. They present a readiness assessment model designed for First Nations communities that wish to equip themselves with a health infostructure. Every step in the implementation of an infostructure is explained.



- **The Tri-Council Policy Statement – Ethical Conduct for Research Involving Humans (Social Sciences and Humanities Research Council of Canada, Natural Sciences and Engineering Research Council of Canada and Canadian Institutes of Health Research, 2022)**

This is a joint policy statement by the three federal research organizations to guide how Canadian researchers may conduct research involving human beings. One chapter concerns research on the First Nations, Inuit or Métis in Canada, and highlights the importance of relationships based on respect, dialogue and collaboration.



- **Toolbox of research principles in an Aboriginal Context (First Nations of Quebec and Labrador Health and Social Services Commission, Centre de recherche en droit public, Université du Québec en Abitibi-Témiscamingue and Réseau DIALOG, 2018)**

The goal of this toolbox is to assemble existing tools that support a renewed approach to practices in research and collaboration with First Nations and to make them available to all. These concrete tools will open dialogue and foster collaboration between research partners.

TRAINING PROGRAMS



- **Online training program on the First Nations principles of OCAP® (First Nations Information Governance Centre)**

The First Nations Information Governance Centre (FNIGC) offers an online training program on the First Nations principles of OCAP®. This training program was developed in partnership with Algonquin College and leads to a certificate.



- **Training on protecting personal information in First Nations communities and organizations (First Nations of Quebec and Labrador Health and Social Services Commission)**

This training course offered by the FNQLHSSC educates interveners about protecting personal information and sets out a reference framework for First Nations communities and organizations. The training includes three modules: (1) raising awareness about protecting privacy; (2) understanding the federal and provincial legal framework applicable in communities to protect personal information; and (3) discussing how the proposed framework could be put to use in participants' communities or organizations.

- **Training on the First Nations of Quebec and Labrador Research Protocol and the principles of OCAP® (First Nations of Quebec and Labrador Health and Social Services Commission)**

This workshop offered by the FNQLHSSC presents managers and interveners with background to the research taking place on the territory of the First Nations or with the First Nations populations, and to the principles of OCAP®.



- **Using your data (First Nations of Quebec and Labrador Health and Social Services Commission)**

The aim of this training workshop given by the FNQLHSSC is to introduce participants to the information tools available to community managers and workers and First Nations organizations to support planning and decision-making processes based on probative data.

WEBSITES

Alberta First Nations Information Governance Centre: www.afnigc.ca

First Nations Information Governance Centre: fnigc.ca/fr

British Columbia First Nations' Data Governance Initiative: www.bcfndgi.com

First Nations Health Authority: www.fnha.ca

Mi'kmaw Eskinuapimk (Mi'kmaw Ethics Watch):
www.cbu.ca/indigenous-affairs/unamaki-college/mikmaq-ethics-watch

Tui'kn Partnership: www.tuikn.ca

CONCLUSION

This information governance framework proposes improved information governance, by and for First Nations. Not only does it further the aim of regaining power, it is also a way to fulfill the desire, which is shared by the governments of Canada and Quebec, to redefine our government-to-government relationships. The mechanisms proposed, which focus on the needs of First Nations and their ways of doing things, should help ensure that the information assets of communities and organizations are better protected and developed.

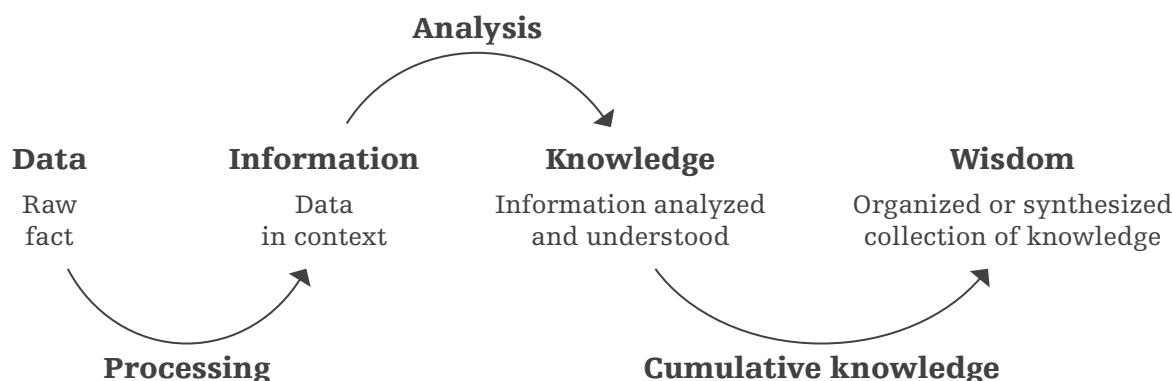
Rethinking information governance in this way will ultimately give First Nations in Quebec access to a more exhaustive set of relevant information, principles and strategic orientations that can guide them as they develop an efficient approach to managing and processing information. This will in turn allow them to more accurately identify needs, potentially leading to decisions and actions that are more purposefully directed at achieving results that the First Nations have determined themselves.

The approach put forward in this framework will in many ways help improve living conditions and secure a better future for the First Nations in Quebec.

DEFINITIONS OF THE TERMS USED

Data, information, knowledge and wisdom

The terms *data*, *information*, *knowledge* and *wisdom* have more than one meaning each and are used in a variety of ways. One approach is to conceive of them as a progression of elements, with data as the smallest unit.



It has been decided to keep the term *information* and to define it as an organized set of details, about someone or something, that is likely to be processed, preserved or sent. These details are found in different formats and media, such as data from an information management system or database, or in an image, text or audio recording.

First Nations Information Assets

First Nations information assets represent all information about groups of First Nation individuals, communities, or organizations, whether or not the information is held by First Nations, and whether it is tangible or intangible.

First Nations Principles of OCAP®

In 1998, the National Steering Committee of the *First Nations and Inuit Regional Longitudinal Health Survey* created the First Nations principles of OCAP®. At first, the principles were identified as “OCA” and the “P” was added later to recognize the importance of the First Nations possessing their own information. The First Nations principles of OCAP® are an assertion of the will to self-determination applied to information governance by and for First Nations.

Ownership | Ownership refers to the relationship of First Nations communities to their cultural knowledge, data and information. A community or group owns information collectively, just as an individual owns his or her personal information. The principle of ownership includes intellectual property rights.

Control | The First Nations, their communities and their representative bodies should control how the information about them is collected, used and disclosed. This principle extends to all aspects of information *management* (collection, use, sharing, and destruction of information).

Access | Wherever the information is held, First Nations must have access to it. First Nations are also entitled to manage and make decisions about access to their collective information. When First Nations are not the stewards of their information, agreements may be made to manage their access to it.

Possession | Possession is a mechanism ensuring that First Nations control their information. First Nations are more capable of taking ownership and control of their information and ensuring their access to it when it is in their possession. Possession refers to the physical location of the information.

Currently, the principles of OCAP® are better known in the world of research, and in particular in the area of health and social services.

Information management and governance

Information governance refers to strategic considerations such as the establishment of policies, standards and procedures that dictate how information assets are to be organized, structured, accessed and used, while also defining the roles and responsibilities of the entities concerned. Information management, on the other hand, refers to operational aspects including input, archiving and the application of protocols. Considered in light of the First Nations principles of OCAP®, information governance can be understood to refer more to the principles of ownership and control, whereas information management concerns more particularly the principles of access and possession. However, compliance with the four principles of OCAP® is based on the implementation of proper governance and effective rules of management.

Infostructure

Infostructure is described in the *2012-2015 Quebec First Nations Regional Infostructure Action Plan* as “The development and adoption of modern systems of information and communications technologies (ICTs) for the purpose of defining, collecting, communicating, managing, disseminating and using data to enable better access, collaboration, quality and productivity for First Nations” (p. 17). This term is a portmanteau of “infrastructure” and “information”.

Open data and the democratization of information

The open data approach plays an increasingly important role in the right of access to information movement. According to the *International Open Data Charter*, “Open data is digital data that is made available with the technological and legal characteristics necessary for it to be freely used, reused and redistributed by anyone, anytime, anywhere” (*Open Data Charter*, 2015). This philosophy endorses access to usable data for all, to ensure informed decision-making.

The democratization of information means not only that information must be accessible, but also that its potential users must be able to use it. They must therefore be empowered and supported in their use of the information.

Traditional Knowledge

According to the World Intellectual Property Organization, “Traditional knowledge is knowledge, know-how, skills and practices that are developed, sustained and passed on from generation to generation within a community, often forming part of its cultural or spiritual identity.” Thus, traditional knowledge is wisdom that has been accumulated since time immemorial and that has been passed on, and it reflects a deep comprehension of the complex interrelationships between the different elements of the environment (AFNOL, 2014).

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VISION

First Nations individuals, families and communities are healthy, have equitable access to quality care and services, and are self-determining and culturally empowered.

MISSION

To accompany Quebec First Nations in achieving their health, wellness, culture and self-determination goals.