



Participant Notes

Table of Contents

- Learning Objectives*..... 2
- What is the FNIGC?*..... 2
- What is OCAP®?*..... 2
- Principles of OCAP®* 4
- Why is OCAP® Important?*..... 5
- Privacy and OCAP®*..... 9

Participant Notes***Learning Objectives***

The purpose of Module 1 is to introduce OCAP® and explain the First Nations Information Governance Centre's role in supporting it.

As a result of completing this module, you will understand:

- FNIGC's purpose,
- OCAP®'s purpose and foundation principles ,
- Why OCAP® is important, and
- How OCAP® contributes to personal privacy rights.

What is the FNIGC?

What is the First Nation's Information Governance Centre?

Put simply, the FNIGC provides data collection, analysis and dissemination services, and is the premiere source of information on First Nations.

The Centre also plays an important capacity building role by helping First Nations at the community, regional, and national level establish data governance practices and procedures.

With a national office located centrally located in Ottawa, the FNIGC supports the development of regional centres that will serve First Nations information and research needs as determined by each of the participating regions.

What is OCAP®?

OCAP® is an acronym that describes First Nations' principles regarding the collection, use and disclosure of data or information regarding First Nations.

The letters in OCAP® stand for four key principles:

- Ownership
- Control
- Access
- Possession.

Each of these is an important pillar of information governance. We will explore them in more detail later in this module.

OCAP® principles originated with the First Nations Information Governance Centre's *First Nations Regional Health Survey*, which began its development in the mid 1990's. At the time, the RHS was the only nationally mandated research project under complete First Nations control.

Rooted in self-determination, nationhood, self-governance, and nation re-building, the RHS is based on the values of trust and respect for First Nations peoples, communities and nations.

Participant Notes

The RHS established a number of fundamental principles.

It is governed by First Nations for First Nations.

It implements unique protocols, agreements, and procedures based on OCAP® principles.

It is guided by a rigorous Code of Research Ethics, Cultural Framework, and ethical review process.

And, RHS ensures participating First Nations communities are fully involved and invested in the survey process from the onset.

RHS principles also require that no RHS activity takes place in a community without the explicit consent of the First Nations Chief and Council.

Community-level data cannot be used or released without the consent of the community.

Community-level RHS data is owned by the First Nation while under the data stewardship of the First Nations region.

Community-level statistical reports are returned to the community pursuant to the Protocol for the Return of RHS Results to Participating First Nations communities.

OCAP® was originally coined in 1998 by the RHS National Steering Committee as “OCA”. OCA crystallized themes advocated by First Nations for years.

The “P” in OCAP® was added later as a mechanism to support the three previous principles. Possession of data means responsibility. Possession of data was fundamentally necessary as it proved nearly impossible to exert ownership, control and access over data without it.

Since the 1990s, OCAP® principles have become an ever brighter guiding light for First Nations data and information control.

It is now widely understood that First Nations have an interest in information that describes them. It does not matter whether information is collected or held by First Nations or held by another entity such as government or a university. First Nations assert the right to govern how the information will be used and disclosed, and what limitations or conditions must be placed on its use.

The right of First Nations communities to own, control, access, and possess information about their peoples is fundamentally tied to self-determination and to the preservation and development of their culture.

As the OCAP® acronym and logo became more widely recognized, the FNIGC Board of Directors determined that measures were required to protect the term OCAP® from misuse or misinterpretation of the principles by others. An application to the Canadian Intellectual Property Office to trademark and copyright the OCAP® logo resulted in its registration in August 2014.

Participant Notes***Principles of OCAP®***

Although there may be a good degree of consensus, the interpretation of OCAP® is unique to each First Nations community or region.

OCAP® is not a doctrine or a prescription.

It is a set of principles that reflect First Nations commitments to use and share information in a way that brings benefit to the community while minimizing harm.

It is also an expression of each First Nation's jurisdiction over information about the First Nation.

Descriptions 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.

As Bonnie Healy of the Alberta First Nations Information Governance Centre explains:

“We cannot pick and choose which elements of OCAP® 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.”

Take a moment to explore the principles of OCAP® one by one.

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. This can be done with data sharing agreements and other legal instruments.

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 their 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.

Participant Notes**Possession**

Possession of data is fundamentally necessary. It is nearly impossible to exert ownership, control and access without it.

While 'ownership' identifies the relationship between a people and their data, possession reflects the state of stewardship of data. First Nations possession puts data within First Nations jurisdiction and therefore, within First Nations control. Possession is the mechanism 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 is OCAP® Important?

Why is it important for First Nations people and communities to be involved in research that is conducted in their communities?

Consider this quotation:

"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."

Royal Commission Report on Aboriginal Peoples (1996)

Concerns to be addressed

First Nations have learned, through many experiences, that outside agencies can't be expected to fully understand or be aware of First Nations interests and concerns without guidance.

There have been concerns about how external agencies gather data, analyze it, then interpret and report on it without the input, review or consent of First Nations.

In the past, information made available by First Nations has often been appropriated - with distortion - and treated like a commodity.

These actions have created barriers to the conduct of good, credible research that is of benefit to First Nations and addresses First Nations priorities.

To understand why the application of OCAP® principles is so important, consider this example.

Hungry Aboriginal People Used in Bureaucrats' Experiments

The Canadian government says it's appalled to hear hungry aboriginal children and adults may have been used as unwitting subjects in nutritional experiments by federal bureaucrats.

Recently published research by food historian Ian Mosby has revealed details about one of the least-known but perhaps most disturbing aspects of government policy toward aboriginal people immediately after the Second World War.

Participant Notes

"It was experiments being conducted on malnourished aboriginal people," Mosby, a post-doctoral fellow in history at the University of Guelph, told CBC's **As It Happens** program.

"It started with research trips in northern Manitoba where they found, you know, widespread hunger, if not starvation, among certain members of the community. And one of their immediate responses was to design a controlled experiment on the effectiveness of vitamin supplementation on this population."

Mosby also found that plans were developed for research on aboriginal children in residential schools in British Columbia, Ontario, Nova Scotia and Alberta.

"If this story is true, this is abhorrent and completely unacceptable," a spokesperson for Aboriginal Affairs Minister Bernard Valcourt stated in an email late Tuesday.

"When Prime Minister [Stephen] Harper made a historic apology to former students of Indian Residential Schools in 2008 on behalf of all Canadians, he recognized that this period had caused great harm and had no place in Canada."

The spokesperson added that the federal government "remains committed to a fair and lasting resolution to the legacy of the Indian Residential Schools."

Mosby — whose work at the University of Guelph focuses on the history of food in Canada — was researching the development of health policy when he ran across something strange.

"I started to find vague references to studies conducted on 'Indians' that piqued my interest and seemed potentially problematic, to say the least," he told The Canadian Press. "I went on a search to find out what was going on."

Government documents eventually revealed a long-standing, government-run experiment that came to span the entire country and involved at least 1,300 aboriginals, most of them children.

It began with a 1942 visit by government researchers to a number of remote reserve communities in northern Manitoba, including places such as The Pas and Norway House.

They found people who were hungry, beggared by a combination of the collapsing fur trade and declining government support. They also found a demoralized population marked by, in the words of the researchers, "shiftlessness, indolence, improvidence and inertia."

The researchers suggested those problems — "so long regarded as inherent or hereditary traits in the Indian race" — were in fact the results of malnutrition.

Instead of recommending an increase in support, the researchers decided that isolated, dependent, hungry people would be ideal subjects for tests on the effects of different diets.

"This is a period of scientific uncertainty around nutrition," said Mosby. "Vitamins and minerals had really only been discovered during the interwar period."

Participant Notes

"In the 1940s, there were a lot of questions about what are human requirements for vitamins. Malnourished aboriginal people became viewed as possible means of testing these theories."

The first experiment began in 1942 on 300 Norway House Cree. Of that group, 125 were selected to receive vitamin supplements which were withheld from the rest.

At the time, researchers calculated the local people were living on less than 1,500 calories a day. Normal, healthy adults generally require at least 2,000.

"The research team was well aware that these vitamin supplements only addressed a small part of the problem," Mosby writes. "The experiment seems to have been driven, at least in part, by the nutrition experts' desire to test their theories on a ready-made 'laboratory' populated with already malnourished human experimental subjects."

The research spread. In 1947, plans were developed for research on about 1,000 hungry aboriginal children in six residential schools in Port Alberni, B.C., Kenora, Ont., Schubencadie, N.S., and Lethbridge, Alta.

One school deliberately held milk rations for two years to less than half the recommended amount to get a 'baseline' reading for when the allowance was increased. At another, children were divided into one group that received vitamin, iron and iodine supplements and one that didn't.

One school depressed levels of vitamin B1 to create another baseline before levels were boosted. A special enriched flour that couldn't legally be sold elsewhere in Canada under food adulteration laws was used on children at another school.

And, so that all the results could be properly measured, one school was allowed none of those supplements.

Many dental services were withdrawn from participating schools during that time. Gum health was an important measuring tool for scientists and they didn't want treatments on children's teeth distorting results.

The experiments, repugnant today, would probably have been considered ethically dubious even at the time, said Mosby.

"I think they really did think they were helping people. Whether they thought they were helping the people that were actually involved in the studies, that's a different question."

He noted that rules for research on humans were just being formulated and adopted by the scientific community.

Little has been written about the nutritional experiments. A May 2000 article in the Anglican Journal about some of them was the only reference Mosby could find.

"I assumed that somebody would have written about an experiment conducted on aboriginal people during this period, and kept being surprised when I found more details and the scale of it. I was really, really surprised.

"It's an emotionally difficult topic to study."

Participant Notes

Not much was learned from those hungry little bodies. A few papers were published — "they were not very helpful," Mosby said — and he couldn't find evidence that the Norway House research program was completed.

"They knew from the beginning that the real problem and the cause of malnutrition was underfunding. That was established before the studies even started and when the studies were completed that was still the problem."

Researched to Death

"We have been researched to death" is a continuing refrain in First Nations communities.

Why do First Nations express that they have been researched to death?

First, many Nations have been subjected to far too much research and often it has been research of interest to the researcher or to the larger society, but has not reflected First Nations priorities.

In too many cases, the research has pre-empted meaningful community involvement or governments have gathered and used administrative and other data without First Nations knowledge or consent.

Governments routinely gather far more data on First Nations than is needed for the administration of programs and services and analyze, interpret, and report on what they find without consent, approval, review, or input by First Nations.

It is not uncommon for researchers to treat First Nations merely as a source of data and First Nations are frequently led to believe that, without disclosure of their information, they won't continue to receive certain programs and services.

Researchers may not explain their studies in a way that ensures fully informed consent.

Some have treated First Nations researchers as informants rather than colleagues and have appropriated or failed to acknowledge their work.

Even if good rapport has been developed, members of the research team may be replaced with people the community doesn't know or trust.

There have also been cases when research has disrespected basic human dignity and religious, spiritual, or cultural beliefs.

First Nations genetic material has been collected for purposes that are demeaning and human remain and cultural property have been appropriated without consent for storage, display, or sale.

Researchers have collected information about traditional remedies, sometimes under false pretenses, in a search for patentable medicines and commercial gain.

Researchers have claimed ownership and use biological samples from First Nations participants for secondary research without consent.

In many cases, research results are not returned to the community – or may be returned in an inaccessible form.

Participant Notes

Benefits to First Nations individuals and communities are often unclear and a wholistic view of potential harm to First Nations is not considered.

In short, OCAP® is important because it reflects First Nations commitments to use and share information in a way that brings benefits to the community while minimizing harm.

Privacy and OCAP®

OCAP® is about protecting individual privacy rights as well as the collective rights of the community.

First Nations principles of OCAP® go beyond privacy legislation that protects only individual privacy rights.

Government Information Management and Protection Values

Let's examine Government and privacy issues.

Information management and data protection from the government perspective are based on two values: personal right to privacy; and the rights of citizens to access information held by the government.

The Government of Canada reflects those values and codifies those rights in two pieces of legislation – the Privacy Act and the Access to Information Act.

Legislation also recognizes other aspects that may justify non-disclosure of documents, such as trade and commercial secrets, national security, police investigation, and so on. But community privacy interests are not recognized.

The Provincial and Territorial Approach

All of the provinces and territories have chosen to combine the two areas into one statute, usually referred to as the Freedom of Information and Protection of Privacy Act.

No federal, provincial or territorial law explicitly references OCAP® principles.

However, freedom of information and protection of privacy legislation in some provinces recognizes the potential privacy and confidentiality interests of First Nations' information, particularly where disclosure without First Nations consent could harm the relationship between the province and affected First Nations.

Federal legislation has no equivalent provision. So, First Nations information may have more protection in the stewardship of some provinces than it does by the federal government.

Take a moment to review key features of these four Canadian laws.

Privacy Act

- Protection of personal information held by the federal government
- Applies only to records in federal government control

Participant Notes**Access to Information Act**

- Requires the government to release records/information upon request (except trade secrets, personal information, police investigations, etc.)
- Applies only to records and federal government control
- This prevents the federal government from protecting the privacy of First Nations community information unless it falls within an exemption category, such as “trade secrets”

Library and Archives of Canada Act

- Requires government institutions to send all documents, data, and information to the National Archives unless an exemption is granted
- Eventually the information can be released to the public – including personal information (20 years after their date of death)
- Applies only to information in the control of a federal government institution.

Personal Information Protection and Electronic Documents Act

- For the protection of personal information outside of government
- Applies to personal information:
 - collected or used for commercial purposes, and
 - to the employment records of employees of federal undertakings (such as First Nations)

First Nations Information Management and Privacy

What are the elements of a First Nations Information Management and Privacy tool or law?

It would require three essential elements:

- Personal Privacy Protection,
- Community Privacy Protection, and
- Governance/Accountability.

OCAP® principles arise from the latter two elements.

OCAP® Can Be Incorporated into First Nations Laws

OCAP® principles are already being incorporated into First Nations laws.

Several First Nations communities have passed their own privacy laws.

For instance, the *Mohawks of Akwesasne* have enacted an Access to Information law that incorporates OCAP® principles.

The *Alberta First Nations Information Governance Centre* offers a template law for the consideration of interested First Nations.

The template can be used by First Nations across the country to draft their own laws for the protection of personal privacy.