



Introduction to the First Nations Information Governance Centre

May 29, 2018

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The First Nations Information Governance Centre (FNIGC)

- A First Nations non-profit, incorporated in August 2010 following a mandate from the Assembly of First Nations Chiefs in Assembly (#48–2009)
- Mandated to support information management, research and training needs of First Nations at the community, regional and national levels.



FNIGC | CGIPN

First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

The First Nations Information Governance Centre (FNIGC)

- FNIGC envisions that every First Nation will achieve data sovereignty in alignment with its distinct worldview.
- We partner to strengthen First Nations' data sovereignty and the development of governance and information management systems at the community level. We adhere to free, prior and informed consent, respect nation-to-nation relationships, and recognize the distinct customs of nations to achieve transformative change.

First Nations Principles of OCAP®



- Ownership, Control, Access and Possession;
- Collection, protection, use, and sharing of First Nations data;
- Benefits community while minimizing harm;
- Self-determination and preservation and development of culture



FNIGC Training



Fundamentals of OCAP®

Welcome to Fundamentals of OCAP®, FNIGC's first online training program

The First Nations Information Governance Centre (FNIGC) is pleased to introduce the *"Fundamentals of OCAP®"*, a new online training course developed in partnership with Algonquin College.

This comprehensive overview of the First Nations principles of OCAP® (Ownership, Control, Access and Possession) is a result of the requests we have received in recent years from First Nations, students, researchers, academics, federal officials and other interested individuals - nationally and internationally who are looking to gain a better understanding of OCAP® and how it pertains to principled research, data sovereignty, and information governance that respects First Nations.

On behalf of FNIGC, I hope you enjoy this online course and apply the valuable lessons and learning outcomes in your work with First Nations. We value your feedback and recommendations for this course and future training programs to be developed by the FNIGC, so please let us know if there is any way we might improve this course.

Gali Mc Donald,
Executive Director, FNIGC

ALGONQUIN
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In cooperation with Algonquin College, the FNIGC is pleased to bring you an online learning experience.

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Privacy – Legal Barriers

- First Nations data must be governed in a manner that respects personal privacy as well as community privacy and First Nations information governance principles of OCAP®.
- Often times, there are gaps in legislation and policy which present risks to both personal and community privacy for FNs. In fact, the concept of “community privacy” is not recognized in federal legislation – as a result, other tools and strategies must be utilized to apply OCAP®.
- Canada collects and holds a significant amount of information on First Nations peoples – for instance, INAC holds over 200 FN databases. The collection, use and disclosure of this information is regulated by the Privacy Act, the Access to Information Act and the Library and Archives of Canada Act.
- Information (records, reports, data) that identifies any particular First Nation or group of First Nations should not be used or disclosed without consent of the affected First Nation – regardless of where that information or data is held. This is consistent with OCAP®. This becomes problematic, however, when considering Canada’s Access to Information Act which permits public access to government information via ATIP.



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Exercising Jurisdiction

- First Nations can exercise jurisdiction through enacting privacy laws in their community and access to information laws. These laws can govern how community information can be used and under what circumstances. It can also address protection of personal privacy.
- Policies and procedures can provide direction on the protection of personal privacy and community privacy (and security).
- First Nations should investigate where First Nations information/data is held or collected and consider how they can exert governance over that data.
- Federal and provincial governments, universities, and other organizations hold First Nations data. Governance can be exerted ideally through repatriation of the data back to the First Nation. Where repatriation is not possible or practical, data governance agreements or data sharing agreements be reached that effectively maintain First Nation control over data.



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OCAP ® + Health Institutions

- The best way for First Nations to implement OCAP® is for First Nations and FN-controlled organizations to be steward(s) of their own data. This facilitates ownership, control and access based upon physical possession.
- As information governance capacity increases at a local level, FNs will seek (and, in many cases, have and are seeking) to repatriate their health information. Capacity, however, still remains a fundamental barrier that limits the implementation of possession.
- In the case of personal health information, First Nations data stewardship is complicated by the fact that the information may be subject to provincial health privacy legislation that may limit who can hold the data. However, as FN capacity in the area of information governance grows, this will likely change.
- Where First Nations are not able to repatriate their data (as may be the case with personal health information) for reasons such as capacity, legal limitations, or otherwise, they should engage in partnerships with the stewards of their data for the purpose of entering into legally binding agreements to enforce governance over that data. While this approach can help regulate some aspects of data use of FN information, it may not be able to regulate access to or disclosure of data (i.e. ATIP).

Introduction to OCAP

The Importance of Information
Governance to Nation Rebuilding



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Virtual Mentor. [February 2011](#), Volume 13, Number 2: 113-117.

HEALTH LAW



Genetic Research among the Havasupai—A Cautionary Tale

Robyn L. Sterling, JD, MPH

Imagine that you donated a bit of blood to a researcher whom you believed intended to identify a genetic link to a disease ravaging your community, only to discover years later not only that you had been misled, but that other researchers were mining your DNA for reasons that were never disclosed to you. What would you do? This was the case for the Havasupai Tribe in Arizona, who learned that researchers at Arizona State University (ASU) had gathered blood samples from them to search for a link to diabetes but used the samples to look for other diseases and genetic markers, thereby violating the basic tenets of human subject research. To

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What Is OCAP?

- Ownership
 - Control
 - Access
- Possession

Types Of Harm

- Legal Harm
- Relational Harm
- Economic Harm
- Physical Harm
- Social Harm
- Economic Harm



Ha-Shilth-Sa

Canada's Oldest First Nations Newspaper - Serving Nuu-chah-nulth-aht since 1974

Vol. 31 - No. 25 - December 16, 2004 haašit'sa "Interesting News"

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Nuu-chah-nulth blood returns to west coast

By David Wiwchar
Ha-Shilth-Sa Reporter

Ahousaht - After a 20-year journey halfway around the world, hundreds of vials of Nuu-chah-nulth blood have returned home to the west coast. And although people welcome its return, many remain critical of the system that allowed its misuse in the first place.

After a 20-year journey halfway around the world, hundreds of vials of Nuu-chah-nulth blood have returned home to the west coast. And although many people welcome its return, many remain critical of the system that allowed its misuse in the first place.

Dr. Richard (Ryk) Ward took 883 vials of blood between 1982 and 1985 under the guise of a \$330,000 Health Canada funded study of arthritis amongst Nuu-chah-nulth; then the largest-ever genetic study of a First Nations population in Canada.

Since there are multiple forms of rheumatic disease in a high proportion of Nuu-chah-nulth, particularly

out the study, I would like to survey every person in Ahousaht so that we can be sure exactly who has a problem with rheumatic disease and who needs help."

According to Ward's final report, published in 1987, his team of researchers interviewed 1,878 (82%) of all 2,300 adult Nuu-chah-nulth, in 13 different reserve communities and members living away from home in Port Alberni, Tofino, Nanaimo, and Victoria. Of those surveyed, 883 people (44.3%) were selected to give 30 ml of blood so research could begin on whether there was a genetically inherited aspect to rheumatic diseases.

"In Caucasian populations the overall prevalence is of the order of 1%," Ward described in his project overview. "The prevalence rates for rheumatoid arthritis in adult Native Indians are between 3% and 8%," he wrote.

But after he failed to find any genetic markers in the DNA, he shelved the study, and that's where things started to go wrong.

In 1986, Ward left his position as Associate Professor of Medical Genetics at the University of British Columbia. He accepted a position as Associate Professor of Human Genetics at the University of Utah, where the U.S. Department of Health offered a further



"Our family has been hit pretty hard by arthritis," said Ahousaht Elder Cosmos Frank. "It's really, really hard to watch someone you love suffer like that when you can't do anything to help. It's hell".

academic papers were produced on topics as diverse as HIV/AIDS and population genetics.

"He profited at our expense," said Larry Baird, who offered his blood, and the blood of his children, for what he saw as

close to tears. "It's hell."

In 1999, their eldest son died of pneumonia at 47 years of age. Frank believes his son succumbed to the respiratory condition because he was weakened from a ten-year battle with a

Barriers vs Levers

Barriers to Implementing OCAP

Levers to Aid Implementation