"OCAP"
The Key to Unlocking the Value of First Nations Data

Presented by:
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OVERVIEW

• Who is the Chiefs of Ontario?
• Historical background
• Power of Data
• Basic understanding of First Nations principles of ownership, control, access and possession (OCAP)
• First Nations Data Governance
TERMINOLOGY

• Indigenous
• Aboriginal
• First Nations

In this presentation I am referring to:
• First Nations – referred to as bands under the Indian Act
The Chiefs of Ontario

- is a coordinating body and secretariat for collective decision-making, action, and advocacy for the 133 First Nations communities located within the boundaries of the province of Ontario.
- Guided by the Chiefs in Assembly
- Chiefs of Ontario upholds the self-determination efforts of the 133 First Nations in Ontario.
HISTORY AND BACKGROUND

• Pre-contact – sophisticated governance systems
  – Treaties and agreements between First Nations on Turtle Island

• After contact Treaties were signed:
  – First Nations considered governments
  – Sharing of the land
  – Medicine chest (Treaty 6)

• Transition to policies of assimilation

• Indian Act (1876)
  – Creation of the Indian Registry System (IRS)
  – registration controlled by Indian Agent (Fed Gov)
Why the need for Data Sovereignty?

• Colonization $\rightarrow$ lack of trust for government and researchers

• First Nations health data and statistics could be accessed by researchers, organizations and government without the knowledge and consent of First Nations

• Data was interpreted negatively and did not benefit First Nations

• Data interpretation did not take into consideration First Nation cultures and the history
Past Practice an Example

• Concerns on how FN data is collected, analyzed, interpreted and reported without FN input, review or CONSENT.
  – https://www.youtube.com/watch?v=nydOsKI8C8kIt

• *It caused:*
  – Personal harm – community harm – collective harm – etc.
  – Relational harm – example residential school
  – FN info/data treated like a commodity
The Power of Data

• Quality information - information that is collected by First Nations people for First Nations people - has the power to change lives by influencing knowledge based decision-making and inspiring effective policy and programs for all First Nation communities.
• Ownership
• Control
• Access
• Possession
OCAP® are First Nations Principles:

• a set of standards that establish how First Nations data should be collected, protected, used, or shared.

• OCAP® is fundamentally tied to self determination and the preservation of First Nation cultures.

• They are *in effect* standards on how to conduct research with First Nations.
 OWNERSHIP

• Is the relationship of First Nations to their cultural knowledge, data, and information

• The community or group of First Nations owns information collectively in the same way that an individual owns his or her personal information
CONTROL

• First Nations, their communities, and representative bodies are within their rights in seeking to control over all aspects of research and information management processes that impact them
• includes all stages of a particular research project-from start to finish
• extends to the control of resources and review of processes, the planning process, and management of the information
ACCESS

• First Nations must have access to information and data about themselves and their communities regardless of where it is held.

• right of First Nations communities and organizations to manage and make decisions regarding access to their collective information.

• may be achieved, in practice, through standardized, formal protocols.
POSSESSION

• While ownership identifies the relationship between a people and their information in principle, possession or stewardship is more concrete: it refers to the physical control of data.

• mechanism by which ownership can be asserted and protected.
First Nations
Data Governance Agreement

• A governance agreement signed with the Institute for Clinical Evaluative Sciences (ICES) – April 2012.
• As a health information custodian, ICES is responsible for ensuring that personal health information is collected, used, stored and shared in a manner that protects the confidentiality of the information and the privacy of individuals.
• ICES uses de-sensitized, encoded data and is able to protect community privacy, thereby respecting First Nations information and governance principles.
First Nations Principles

Ethical Relationships
- Indigenous research ethics
- Community engagement
- Mutual capacity building

Data Governance
- Formalized data governance and data sharing agreements
  - Privacy legislation

Evidence to Build Policies & Programs
- Collaborative research projects
- Service-model, data requests from communities

Methodology & Approaches
- Indigenous perspectives and models of wellbeing
  - Data gaps/quality
  - Context
  - Linkage and analytics
Indigenous Data Sovereignty is an International Movement
Strong data sovereignty means...

• First Nations people control registries and ways of identifying Indigenous population in the registry
  – In Canada, the federal government still controls the Indian Registry System through Indian Act
• For existing government datasets that identify First Nations populations, First Nations governance relationships must be in place
• Advantage: tell the story of First Nations peoples’ health from First Nations perspectives
• Leads to better advocacy, services, program development and planning within the population
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