

First Nation Health Information

And the Principles of OCAP



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On-Reserve Health Care Services

Multiple programs with multiple funders and multiple jurisdictions

- Nursing Stations/Health Centres
- Health Professionals and Health Workers
- Health Canada Health programs such as Home and Community Care and Mental Health
- Other programs can be delivered by provincial services (Healthy Babies, Healthy Children)
- Other programs by First Nations (transferred communities and Tribal Councils)

Overview

- Describe the First Nations environment
- Overview of OCAP™
- Application of OCAP™ within an eHealth environment
- Considerations for implementation
- Risk Management

First Nation Governance

- First Nations have the right to self-determination and governance
 - *United Nations declaration on the rights of Indigenous People (2007)*
- This right extends to the control of their data and the analysis of that data
- Specifically, this right extends to First Nations Community-level Information about a First Nations Community
- This refers to information that may be used or manipulated to describe the health or wellness of the community, the health care utilization of the community or any other data analysis related to health or health system use of that community

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Ownership, Control, Access and Possession (OCAP™)

“The right of First Nations communities to own, control, access and possess information about their people is fundamentally tied to self-determination and to the preservation and development of their culture. OCAP™ allows a community to make decisions regarding why, how and by whom information is collected, used or shared.”

First Nations Information Governance Centre, 2012

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Ownership

- Generally ownership refers to Trustee or Stewardship of data.
- Once information is shared outside of the First Nation, the concept of ownership becomes more difficult to exert. It becomes under the stewardship of that organization/entity with which it was shared.
- Some control of that data can be managed through the development of Information Sharing Agreements*

*Information Sharing Agreements are documents that set out, in writing, how information will be shared

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OCAP™

- While originally developed to protect First Nations data from research, thinking has now evolved around how the concepts may be applied to First Nations data contained within the health care system.
- **There are many laws covering the protection of Personal Information (PI) and Personal Health Information (PHI). No laws to protect Community-level information**
- Offers an added layer of protection for the individual
- Each First Nation has the authority to choose if and how they want to apply the principles

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Control

- The principle of Control refers to the governance of First Nations over their information
- Information Sharing Agreements (ISAs) are primary way of protecting data and controlling data use, collection, disclosure, and publication.
- Signatories define the terms under which community level data will be used through ISAs. (Note that ISAs can offer only limited protection as the prevailing provincial legislation may allow analysis of data for health system use with or without ISAs).

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Access

- Accessing Community-level Health Information is a major benefit for First Nations to link with P/T databases/registries
- May be opportunity to link community data currently held in provincial registries and access that date to the benefit of the community.

Risk

- Not always able to “take information back” in eHealth environment
- Others may be able to access information through Freedom of Information requests

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Risk Management

- Focus on two areas
1. Community management and accountability of PI and PHI and Community-level Health Information
 2. Community Data once it leaves the community

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Possession

- First Nation data bases allow for First Nations possession of their own data
- Once information is shared with P/T data bases, it is no longer in possession of the First Nation
- Regardless of who houses the data, First Nation can retain a certain level of control through partnerships and ISAs.

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Community Management

- Sound Privacy and Security Infrastructure
 - Provincial legislation not applicable within First Nations jurisdiction
 - Designated Privacy Officer
 - Designated information governance structure/committee
 - Policies and Procedures in place for management of PHI, PI and CHI
 - Develop consent process for information collection
 - Orientation and training of staff involved in the use and collection of PHI, PI or Community-Level Health Information
 - Processes developed on the management, processing, disclosure, retention, use and collection of Community-Level Health Information

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Provincial Legislation

- Not developed with the concept of OCAP™
 - Some issues with using information for management of the health care system that may be non compliant with OCAP™
 - Access to Information Acts can also be non compliant with OCAP™
 - ISAs can mitigate issues . This is, however, a “band aid” solution to legislative gaps.
 - In long-term, need legislation specific OCAP™ and the protection of Community Health Information
- “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”*
Assembly of First Nations

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Questions?

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Guidelines for Implementing OCAP™

- Understand benefits of interoperable EHRs/Registries /databases
- Build partnership approach
- Nation-to-nation negotiation
- ISAs formalize each partner's contribution and responsibilities
- May need to start small and build up and out
 ie. Community ➤ Group of Communities ➤ Treaty Area ➤ Region
- Good examples of ISAs are the Kenora Chiefs Advisory in Northern Ontario and the Tui'kn initiative in Nova Scotia
- Excellent governance models developed in B.C.

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