



FIRST NATIONS HEALTH COUNCIL

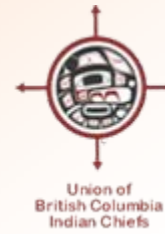
OCAP and Governance

October 25, 2007

**Population and Public Health
Evidence and Data Expert Group**

Fairmont Vancouver Airport

Richmond, BC

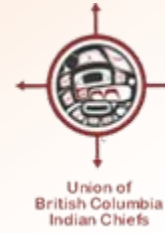


The basic principle of Ethical Research is:

“First, Do No Harm”

Harm can be caused by research through:

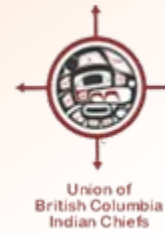
- Issues around obtaining informed consent;
- Failure to protect community and individual privacy and confidentiality;
- Ownership of data
- Mistranslation and “Ethnic Gloss”



OCAP

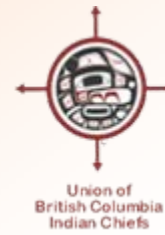
- Ownership,
- Control,
- Access, and
- Possession

Self-Governance of First Nations
Information



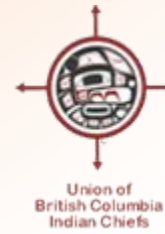
Origins of OCAP

- First Nations have always had rules about how information is owned, used and shared.
- Songs and stories can be “owned” by an individual, a family and sometimes the whole community.
- The rules for sharing information grow out of traditions that were designed to protect communities and individual citizens.



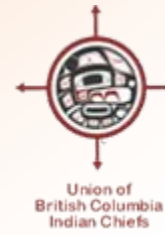
Origins of OCAP (cont'd)

The First Nation principles of OCAP (Ownership, Control, Access and Possession) were initially coined as ‘OCA’ in 1998. When First Nations Health Directors were working together at a First Nations Regional Longitudinal Health Survey (RHS) Committee meeting to develop a framework for asserting self-governance over information related to research, Cathryn Mandoka (George) of the Association of Iroquois and Allied Indians suggested “OCA” and it was immediately adopted.



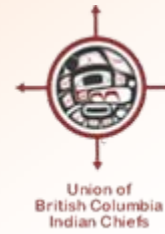
Ownership

- The relationship of a First Nation to its cultural knowledge/data/information.
- The Nation owns their information collectively, as individuals own their personal information.
- This is distinct from possession (stewardship).



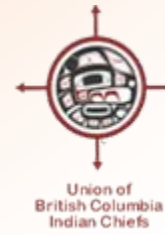
Control

- Reflects aspirations & inherent rights to regain control of all aspects of our lives including control of information.
- Control includes all stages of a project.
- Control extends to resources, policy, review processes, formulation of conceptual frameworks, data management etc.



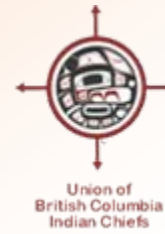
Access

- You must have access to information, data about yourselves and your communities, wherever it is held.
- First Nations', their communities and organizations have a right to manage and make decisions regarding access to their collective information.



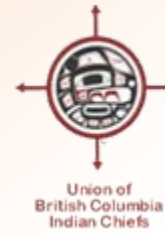
Possession

- Possession (stewardship) the mechanism to assert and protect ownership.
- When First Nations data is in the possession of others (e.g. government, academia), there is often little to no control over management of data as a result of conflicting policy and legislation (Access to Information Act, Archives Act, etc.)



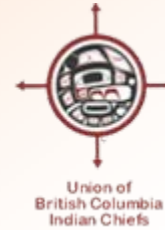
OCAP as an enabler

- First, OCAP is not a barrier to data collection and management. It is simply a duty that many choose to ignore,
- OCAP is about building First Nation capacity,
- OCAP is about Quality Assurance of data,
- OCAP is about Due Diligence to ensure accurate results of data analysis and beneficial dissemination for decision making.



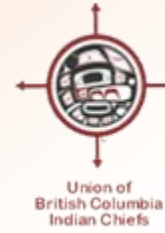
Benefits

- First Nation control and data protection rebuilds (and may be a prerequisite for) community trust
- Allows research to happen where it might otherwise be impossible
- Encourages a broader, more holistic (First Nation) approach to health
- Promotes coherent First Nation analyses and perspectives. Discourages biased non-First Nation analysis.
- Encourages more democratic (participatory) research methods.
- Produces more relevant & useful results



Benefits cont'd

- Provides meaningful capacity development.
- By regaining control of processes that impact them, communities build hope for a healthy future.



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Thank you

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