

OCAP® and Agreement Management

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OCAP®

- "Ownership, Control, Access, Possession"
- Community Privacy
- First Nation governance over First Nation information

OCAP® tells us that First Nations make the rules on how their information will be collected, used and disclosed. When a First Nation puts forward these rules and expresses them through things like data sharing agreements and First Nation policies and laws – *that* is how a community exercises sovereignty over their own information. And that is what we define as 'First Nations Information Governance'





OCAP® Sources

Beware the source!!!

Federal/provincial/territorial governments and universities do not define OCAP®.

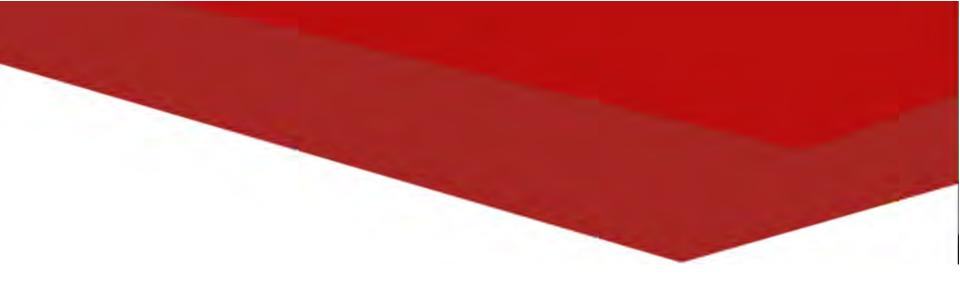
The Tri-Council Policy does not define OCAP®.

Research Ethics Boards do not define OCAP®.

Reliable sources for further learning:

- First Nations Information Governance Centre and Algonquin College (Ottawa) have an on-line program.
- AFNIGC





FIRST NATION DATA

Information that is capable of identifying First Nation status or community, regardless of who collected it or where it is located.



The Question

Can this information be used or aggregated in a way that is descriptive of First Nations people or communities?





Agreements

- Data Sharing Agreements
- Service Agreements
- Memoranda of Understanding



Data Sharing Agreements

Govern the collection, use and disclosure of First Nation Data.

Set out the terms and conditions by which a First Nation community (or group of communities) will permit their information to be collected, used and disclosed.

Give First Nations legal remedies to deal with the unauthorized collection, use and disclosure of First Nation Data.





When do we need a Data Sharing Agreement?

- When anyone wants to collect, use or access First Nation Data!
- It does not matter WHERE the data originated. A DSA may be required:
 - If data is capable of being aggregated in a way that speaks about a First Nation, group of First Nations, or all First Nations or Indigenous people
 - If data about First Nations can be extracted from a larger data set (about the general population)
 - If data is collected directly from members of the First Nation community or from FN administration
 - For use of existing First Nation Data



Examples:

- University and research organizations: research.
- Governments: research, surveillance, program administration.
- Collaborations (for research or surveillance purposes) between First Nations (and orgs) and Universities, governments, etc.
- Other First Nation organizations, such as Tribal Councils and PTO's.
- Data linkages amongst different sources of First Nation Data.



Collect facts:

WHY? Identify the purpose of the project?

WHO are the parties?

- Who is collecting the information?
- Who is data steward?
- Who will have access to the information?
- Which First Nation or org needs to be party?

WHAT information (First Nation Data) will be collected/used?

- What is the source of the data?
- Exactly what data will be collected/used at a 'field' level

WHAT is the expected output/product from the project?

WHERE will the information be held?

AND - define the data flow.

Content for all DSA's (1 of 3)

- 1. Definitions: Define any terms used consistently in the agreement, including "First Nation Data".
- 2. Purpose: Identify the purpose for data sharing.
- 3. Identities and authorities: Identify the parties and the authority for each party to collect, use and disclose First Nation Data.
- 4. Prohibition on any use or disclosure of First Nation Data except as set out in the agreement.



Content for all Agreements (2 of 3)

- 5. Data: Describe the data and the source, with specificity.
- 6. Duration/Term
- 7. Authorized Use and Disclosure: Specifically identify what the First Nation Data will be used for, setting out the proposed outputs.
- 8. Presentation of results/output to the community.
- 9. Secondary Use: Identify process for requesting use for secondary purposes; or prohibit secondary use.



Content for all Agreements (3 of 3)

- 10. Security and Confidentiality: Set out policy and HR requirements, such as NDA's. Identify physical and technological security requirements to protect the data.
- 11. Set out rights (ownership) in data.
- 12. Breach and Termination provisions.
- 13. Return or destruction of data (or transfer to a trusted third party).



Additional Considerations for Federal, Provincial and Municipal Governments

Access to Information/Freedom of Information legislation (FIPPA)

- FIPPA legislation may require the public release of First Nation Data that First Nations would otherwise protect in DSA's. Dealing with the province (Alberta), we want to trigger the "harm" clause with additional provisions in the DSA.
- FIPPA applies to municipalities, universities, colleges, technical institutes, school boards, regional health authorities, provincial health boards and hospitals.
- Federal legislation contains no equivalent to the "harm" clause for First Nations.

Additional Considerations for Researchers/Universities/Govt:

Publication Conditions: Include additional terms that deal with publication (which may also be applicable if it is a government body conducting research):

- Preview of proposed publications and right to dissent if the researcher doesn't agree to suggested changes.
- Presentation to community before public release
- Authorship and acknowledgement of data

Note that universities and most educational institutions are included under FIPPA (see previous) but that "research information of an employee of a post-secondary educational body" is exempt from mandatory disclosure requirements of FIPPA.



Service Agreements

Where the recipient of FN data is only acting as agent for the First Nation and is not using data for its own purposes in any way, a **service agreement** would be appropriate.

OCAP principles to include in service agreements:

- First Nation (or FN org) as owner of data.
- The service provider cannot use aggregate data for its own purposes. We see this too frequently in EHR vendor contracts/licenses.
- NDA requirements.
- Provisions for the return/destruction of First Nation Data on termination.





Agreements for Shared Services

There are situations where a First Nation may use a shared service/database to improve service delivery or for surveillance purposes e.g. EHR's, Panorama (immunization), social service administration, etc.

We have to be aware of how the service provider (vendor) is able to use First Nation Data.

But we ALSO must be aware of how other users of a shared service may be able to create and/or use First Nation Data. Typically the greatest OCAP® concern is through reporting functionality of shared-use databases. We ask whether other users of the service are able to generate *ad hoc* or standard reports that identify First Nations only, or First Nation communities. If so, we try to prevent or limit it through agreements or technologically through software.



Memoranda of Understanding

MOU's are typically non-binding documents where the parties agree on processes and relationship. Where FN Data is being created or used, this is not the appropriate tool. But it may be appropriate at a higher level to establish the process or protocols that will be engaged to achieve a DSA at a later stage.

OCAP® principles can be included in the MOU to manage expectations of the non-First Nation parties and to set the stage for a binding DSA in the future. For example, parties may wish to include principles that support First Nation information governance, such as agreeing that First Nation Data should be available for use of First Nations and that First Nation Data should not be used without First Nation consent.

Equally important is to ensure that there isn't language in the MOU that is inconsistent with OCAP®.



Other Notes:

- We don't need to see the term OCAP® in agreements. We do need to see the principles in place.
- The *requirements* for a good agreement (particularly DSA's) are constantly evolving. We learn from experience good and bad. Legislation changes. Relationships change. Governments change. Technology changes.
- This OCAP® process (agreement making) is separate from any other process that the government/researcher/collaborator needs to complete: PIA's, REB approval, personal consents, funding agreements, etc.



Clarification

Tri-Council Policy 'compliance' + OCAP® _{compliance}

REB approval \neq OCAP® compliance Individual Consent + OCAP® compliance

BCR's + Data Sharing Agreement



"For all intensive purposes"

A strong caution on the use of templates.





Conclusions

- DSA's should be negotiated whenever there is a collection of data that is capable of describing or identifying First Nation people or communities.
- OCAP® principles are incorporated into the DSA through provisions such as:
 - Presentation of research results back to the community.
 - Prohibition on use except as approved in the agreement.
 - Destruction or return of data upon termination/completion.
 - Security and confidentiality requirements.
- DSA's allow First Nations to govern the use, collection and disclosure of their data when not in their possession.
- Other agreements, such as service agreements and MOU's may be appropriate in some circumstances, but OCAP® principles must still be considered and appropriate provisions included.



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