



The Alberta First Nations  
Information Governance Centre

# Framework for a Data Sharing Agreement

Prepared for  
The Alberta First Nations  
Information Governance Centre

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**ISBN:** 978-0-9937112-4-4



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# Introduction

The Alberta First Nations Information Governance Centre, in partnership with our legal counsel Krista Yao of Nadjiwan Law, is pleased to provide this community template for development of a First Nation data sharing agreement. Since our inception as an Alberta Chiefs' mandated organization in 2010, The Alberta First Nations Information Governance Centre has worked to promote ownership, control, access, and possession (OCAP®) of First Nations information for First Nation people. The importance of a data sharing agreement is to help determine First Nation priorities in data governance while working in partnership with government, universities, researchers, and other organizations.

It is important to develop a data sharing agreement that outlines the nature of the partnership with non-indigenous institutions as "cultural differences, unrealistic expectations, organizational constraints, and ongoing ethical and data sharing violations can create barriers that stifle or end effective partnerships" (Harding, et al 2011). Throughout our work at the Centre, we strive to promote a community-centered approach to information governance, data repatriation efforts, and battling information poverty. This is a tool for our First Nation partners to establish their sovereign rights as individual nations and become self-determining in their information governance.

Our framework is a template or guideline of considerations to follow when developing your own data sharing agreement. There are so many factors that will alter the agreement substantially that we cannot have a single template that will meet all situations. This document serves to outline factors to consider and include, but is not limited to the text herein.

There are so many factors that will alter the agreement substantially that we can't have just one template that meets all situations, factors to consider include, but are not limited to:

### **PARTIES:**

1. Is the provincial government a party? If the provincial government has control of data, we would include provisions that refer to Freedom of Information and Protection of Privacy Act (FOIPOP) and the "harm" clause.
2. If a University is a party, we would have to look at what province it is located in and if there is any applicable privacy or freedom of information legislation. In some provinces, universities fall under their provincial government FOIPOP legislation.

### **WHAT KIND OF SHARING?**

1. Is this a one-sided sharing where First Nations are sharing data but the other party isn't? Or does this involve the linkage of data from First Nation sources and from government or other sources?
2. If there is a linkage of data:
  - a. Both parties will have to establish their legal authority to share and the data then becomes blended. At that point, is the other party prepared to accept First Nation ownership of data that includes their own data? Or will each party maintain ownership of their 'part' of the data.
  - b. Who will be doing the linkage. Additional provisions will have to be included if one party is doing the linkage, and another Service Agreement would be required amongst the parties if an outside organization is doing the linkage.

## WHAT TYPE OF DATA:

1. Is this administrative data? Does it include personal information? Is personal health information involved? All of this impacts upon what legislation may be applicable and what type of sharing is authorized.

## IS THIS A ONE-TIME SHARING? WHAT IS THE SCOPE?

1. If this is an ongoing project where there may be continued or new use of data, or new insertions of data, then procedures for data access requests and approvals will have to be included. If this is a one-time sharing for very limited purposes, then those purposes can be pre-approved in the agreement itself.

## WHAT IS THE PURPOSE OF DATA SHARING?

1. Will the data be used for surveillance/program/policy purposes or is it for research purposes. Where research or interpretation is involved, you will have to include provisions for pre-publication review by First Nation parties, presentation to First Nation parties, etc. If the agreement is for surveillance/reporting purposes – where interpretation is not necessarily involved, pre-approvals may not be necessary.
2. Will the data include personal information? If so, different legislation will apply and parties may be restricted in what they can do with the data.

## WHAT IS THE DATA FLOW?

1. Parties must identify the flow of data from each organization, to any other service providers, the linkages and the ultimate data steward. The roles and responsibilities can not be defined until you know where the data is going.

### **WARNING:**

There are very many considerations that will impact upon the drafting of an appropriate data sharing agreement that protects the interests of First Nations. The notes and template provided are simply an outline and a basis for discussion amongst the partners. They must not be used as an alternative to seeking appropriate legal advice.

Agreement Text	Drafting Comments and Considerations
<p><b>BETWEEN:</b></p> <p>*** FIRST NATION, *** FIRST NATION, etc.</p> <p>(hereinafter referred to as the First Nation – or “the First Nation Parties” if more than one First Nation)</p> <p>and</p> <p>[the Government party or any other organization]</p>	<p><i>On the First Nation side, only First Nations and legal entities should be parties. Data Sharing Agreements are legally binding agreements and not Memorandum of Understandings. First Nation’s need a legal entity to enforce First Nation rights, so do not refer to a department or a committee – it has to be at the organizational level.</i></p> <p><i>Again, the other party must be a legal entity. In the case of an academic agreement with a researcher, it is recommended that the University be the primary party, to ensure accountability and responsibility for data security.</i></p> <p><i>A Data Sharing Agreement is not used if the other party is only providing data hosting, data cleaning, data matching, or other technological services. A Data Sharing Agreement is also not used if the other party is not using the data for their own purposes. That type of arrangement would require a service agreement.</i></p>
<p><b>PREAMBLE:</b></p> <p>WHEREAS [Description of First Nation Parties];</p> <p>AND WHEREAS [Description of other Parties];</p> <p>AND WHEREAS the Parties wish to work together to ... [Describe the purpose of the collaboration];</p>	<p>A Preamble is a part of the agreement that is NOT legally binding. It is typically used to provide a description of the parties, their relationship, and why they are entering into the agreement.</p> <p>The Preamble can also be used to describe the general intent of the parties, although because it is not legally binding, it should not contain definitions or anything that would be necessary to interpret the agreement.</p>

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<p>AND WHEREAS the parties wish to ensure that First Nations data is managed in a manner that meets applicable laws and standards regarding personal privacy, and meets the First Nations' expectations and interpretation of First Nations' Ownership, Control, Access and Possession (OCAP®) of First Nations' data;</p> <p>AND WHEREAS by this Agreement, the Parties will manage the use and disclosure of certain data, including First Nations data.</p> <p>THEREFORE THE PARTIES AGREE AS FOLLOWS:</p>	
<p>1. <b>DEFINITIONS</b></p> <p><b>"Anonymized Data"</b> means data that has been modified so that the identity of the subject individual cannot be readily determined by a reasonably foreseeable method. This involves removal of name and address; and may also involve converting date of birth to month and year of birth, age or age group; and reviewing the remaining data elements to ensure they do not permit re-identification of the subject individual by a reasonably foreseeable method.</p> <p><b>"Agreement"</b> means this data sharing agreement between the First Nation Parties and [other party] as it may be amended from time to time in accordance with its terms.</p>	

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<p><b>“Applicable Law”</b> means, with respect to the Parties, any law, statute, regulation, by-law, order, judgment, decree or other requirement having the force of law relating or applicable to all or any of the Parties.</p> <p><b>“Data”</b> shall mean ...</p> <p><b>“Data Steward”</b> shall mean the organization responsible for receiving and maintaining the Data and First Nation Data shared under this Agreement;</p> <p><b>“First Nations Data”</b> means</p> <p>(a) any and all data shared by the First Nations Parties under this Agreement;</p> <p>(b) any data formed by linking one or more data sets with data shared by First Nations Parties; and</p> <p>(c) any data held by the Data Steward pursuant to this agreement and any subsequent Service Agreement, which is capable of identifying First Nation communities, First Nation membership, Indian status or residence on an Indian reserve.</p> <p><b>“OCAP®”</b> refers to First Nations principles of OCAP®, which represent the assertion of First Nations rights to govern information collected from and pertaining to First Nations. OCAP® mandates that First Nations control why, how and by whom information is collected, used or shared. It respects community privacy rights in the same way that individual privacy rights are valued.</p>	<p><i>The definition for “applicable law” captures federal/provincial laws (as applicable), as well as First Nation law or by-laws, and rules of conduct for health professionals, etc.</i></p> <p><i>The definition of “First Nations Data” must be adjusted to fit the circumstances of the parties and the type of data being shared.</i></p> <p><i>Another definition should be included if the other party is also sharing data “[Organization’s] Data”.</i></p> <p><i>More definitions may be added, including acronyms for applicable legislation.</i></p>



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2.	<b>PURPOSE OF DATA SHARING</b>	<i>In this section the parties would outline the general reasons and benefits for sharing information – what they expect to achieve.</i>
3.	<b>AUTHORITY TO SHARE</b>	<i>In this section, the Parties indicate what legal authority that they have and require in order to participate in the data sharing.</i>
4.	<b>DESCRIPTION OF DATA</b>	<i>In this section, the Parties will describe which type of data will be shared. Specific data fields should be listed in an appendix or schedule.</i>
(a)	Data to be Disclosed by the First Nation Parties	
(b)	Data to be Disclosed by the [the other party]	
(c)	The Parties agree that the information shared in this Agreement may be collected, stored, disclosed and used strictly for the limited purposes set out in this Agreement.	
(d)	<p>For greater certainty, any Party may allow a third party contractor to access the data described herein for the purpose of assisting the Party to comply with its obligations under this Agreement, provided that the disclosing Party ensures, through contract with the third party, that:</p> <p>(i) Data, or any part or product thereof, provided to the contractor shall either be destroyed or returned to the disclosing Party upon the completion of any contract, including service contract; and</p>	<i>This section contemplates service agreements with consultants or technological service providers (i.e. to clean and match data).</i>

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<p>(ii) the contractor shall maintain in the strictest confidence all information made available by or acquired from the disclosing Party and shall not disclose to any third party, copy or use any data except in performance of the contract with the Party;</p> <p>(iii) the contractor shall maintain the same privacy and security standards as required by the disclosing Party under this Agreement.</p>	
<p>5. <b>DURATION OF AGREEMENT:</b></p> <p>This Agreement will commence on the date upon which the last of the Parties affixes the signature of an authorized representative and shall terminate on *** or earlier as provided herein.</p>	<p><i>When will the agreement terminate, or shall it be ongoing, unless terminated under the agreement?</i></p>
<p>6. <b>TRANSFER OF DATA:</b></p> <p>Data will be securely transferred in the following ways: ***</p>	<p><i>This section should reflect the dataflow and provide technical and physical requirements for the transfer of data to the data steward.</i></p>
<p>7. <b>AUTHORIZED USE &amp; DISCLOSURE OF FIRST NATIONS DATA</b></p>	<p><i>This is where you would provide details on the approved uses and disclosures of data. This must contain a lot of detail, so that the purposes cannot be expanded without First Nation consent.</i></p>
<p>8. <b>SUBSEQUENT USE &amp; DISCLOSURE OF FIRST NATIONS DATA</b></p>	<p><i>If the data might be used for future purposes or ongoing work that is not listed in the agreement, there must be a process to obtain authorization from the First Nation parties. Typically this would involve creation of a committee or some other body that will manage the requests and make recommendations to appropriate authorities.</i></p>
<p>9. <b>PRIVACY IMPACT ASSESSMENT</b></p>	<p><i>If a Privacy Impact Assessment is warranted or required, that should be added into the agreement as a condition for the sharing.</i></p>

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<p>10. <b>LIMITATION ON COLLECTION, USE, DISCLOSURE AND RETENTION</b></p> <p>(a) The Parties agree and warrant that the Data and the First Nations Data shall be used and disclosed only and strictly for the purposes specified in this Agreement.</p>	<p><i>If FOIPOP or other Access to Information is applicable, there may be significant limitations on the ability of a data steward to limit disclosure. A legislative review must be conducted and the data steward be carefully determined.</i></p> <p><i>Moreover, if FOIPOP legislation does apply and there is an exemption applicable to First Nations, another clause will be added that the First Nation is sharing on the basis that this clause is applicable.</i></p>
<p>11. <b>CONFIDENTIALITY &amp; SECURITY</b></p> <p>(a) All parties are responsible for the security of the Data entrusted to them under this Agreement and shall safeguard the Data against accidental or unauthorized access, disclosure, use, modification and deletion.</p> <p>(b) Upon request, each Party shall provide the other Parties with a description of how the security and confidentiality of the Data are protected.</p> <p>(c) The parties agree to respect and maintain the confidentiality, security and privacy of information according to applicable legislation, policy and standards.</p> <p>(d) The parties agree that First Nations Data shall be protected in the same manner, and according to the same privacy standards and security measures as if it were personal information.</p>	<p><i>The contents of this section depend heavily upon whether there is one Data Steward or several, whether the Data Steward is a party, whether the Data Steward is a government body, what regulations/legislation apply to the Data Steward, etc.</i></p>

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<p>12. <b>BREACH AND TERMINATION</b></p> <p><b>NOTICE OF BREACH</b></p> <p>(a) Mandatory Self-Reporting of Breach: If a Party breaches any term or condition contained in this Agreement, or becomes aware of any breach by its agents, representatives or third party contractors, it shall immediately notify the other Parties in writing, and the breaching Party shall immediately take steps to remedy the breach.</p>	
<p>(b) Notice by Non-Breaching Party to Remedy Breach: If a Party has breached this Agreement, any one or more of the non-breaching Parties may by notice in writing, require the breaching Party to immediately remedy the breach.</p> <p><b>TERMINATION FOR BREACH</b></p> <p>(c) Notwithstanding subsection (d), if the breaching Party does not remedy the breach to the satisfaction of the other Parties, any one of the non-breaching Parties may, by notice in writing, immediately terminate this Agreement.</p> <p><b>TERMINATION FOR CONVENIENCE</b></p> <p>(d) Any Party may terminate this Agreement at any time, without cause, upon delivery of not less than *** [insert time period in months] notice to the other Parties.</p>	

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<p>13. <b>RETURN OR DESTRUCTION of DATA</b></p> <p>(a) Upon expiry or termination of this Agreement [what happens to the data].</p> <p>(b) The Data Steward shall send a letter to the Parties confirming that the destruction/return of data has been completed according to this section.</p>	<p><i>Details for this section will depend upon the type of data, whether it has been linked to any non-First Nation data, who is the data steward, is there another data steward identified as the recipient upon termination, etc.?</i></p>
<p>14. <b>INTELLECTUAL PROPERTY, COPYRIGHT AND PUBLICATION</b></p>	<p><i>This section should address ownership of data. Typically, First Nation parties would retain ownership of data that they have contributed or authorized be contributed (such as Indian Registry System). The other party may retain ownership of their own data. This means that for a linked data set, each would own their part.</i></p> <p><i>This section should also deal with intellectual property rights over publications, reports, acknowledgements, etc., the requirement to present results/research to First Nation's first, pre-publication notices with the right of dissent, and correct attribution of First Nation data in publications and research.</i></p>
<p>15. <b>OTHER SECTIONS</b></p>	<p><i>Parties may wish to include sections regarding capacity building for First Nations, logging the use of data and reports to First Nation parties,</i></p>

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<p>16. <b>GENERAL</b></p> <p>(a) <b>SURVIVAL OF TERMS:</b> Terms and conditions relating to: creation, use, disclosure and destruction of First Nations Data; and Confidentiality and Data Governance, shall survive the termination and expiry of this Agreement.</p> <p>(b) <b>AMENDMENTS:</b> This Agreement may be amended or terminated upon mutual agreement, in writing, by the Parties.</p> <p>(c) <b>ASSIGNMENT:</b> No part or whole of this Agreement may be assigned by either Party.</p>	
<p>(d) <b>WHOLE AGREEMENT:</b> This Agreement, plus schedules, constitutes the whole Agreement between the Parties unless duly modified in writing and signed by both Parties.</p> <p>(e) <b>LIVING DOCUMENT:</b> The Parties recognize that this Agreement constitutes a living document, with the intention that necessary amendments be made according to the terms herein, as circumstances warrant.</p>	
<p>17. <b>NOTICES</b></p> <p>Every notice or written communication provided for or permitted by this Agreement shall be in writing and delivered to:</p> <p>[Insert Contact Information]</p> <p>IN WITNESS whereof, this Agreement has been executed by the Parties by their duly authorized representatives:</p>	

# References

Harding, Anna and Harper, Barbara and Stone, Dave and O'Neill, Catherine and Berger, Patricia and Harris, Stuart and Donatuto, Jamie, Conducting Research with Tribal Communities: Sovereignty, Ethics and Data-Sharing Issues (September 2, 2011). Environmental Health Perspectives, September 2011; Seattle University School of Law Research Paper No. 11-24. Available at SSRN: <https://ssrn.com/abstract=1934951>

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**AFNIGC Framework for a Data Sharing Agreement**