

IMPLEMENTATION TOOLKIT

MODULE 5

*Information Governance
& Data
Management*



Jordan's
Principle

**CHILD
FIRST
INITIATIVE**

TABLE OF CONTENTS

REVIEW OF MODULE 4	3
OVERVIEW OF MODULE 5	3
WHAT IS IT ABOUT?	3
WHAT CAN YOU EXPECT TO ACHIEVE?	3
PROGRAM STANDARDS	4
PROGRAM GUIDELINES	7
TOOLS AND TEMPLATES	13
APPENDIX A - COLLABORATIVE RESEARCH AGREEMENT	13
APPENDIX B - DATA SHARING PROTOCOL	19

Review of Module 4

By this time, you have identified how you will implement your JP-CFI Program, and you have identified shared team goals and performance indicators. You have designed an evaluation framework and identified the evaluation components most important for decision making and provision of care. Now, you have the basis for which to use the information governance and data collection protocols.

Overview of Module 5

What is it about?

This module will outline the process to develop information governance, data collection protocols and research protocols to manage the information for the JP-CFI Program. Information governance is about protecting the rights of the child and the family, while using the information to best serve the community and the families moving forward. Having the service providers and supports agree to a data collection protocol will assist in high quality coordination of care. Research protocols will assist the community to ensure that the community retains ownership, control, access, and possession of the information collected. The research protocols will assist in setting up mutually beneficial research relationships with external researchers.



What can you expect to achieve?

Through this module you can expect to develop three main components:

1. Information governance for the JP-CFI Program;
2. Data collection protocols; and
3. Research Protocols.

Program Standards

Target Outcomes for Module 5 are:

- 1) **Effective and Efficient Information Management and Data Governance**
- 2) **Every family has free prior informed consent for how the information will be used, stored securely, who will have access to the information and for what purpose.**
- 3) **Information is governed by the First Nation in accordance with OCAP principles: First Nations and their families own the data, First Nations and their families have control of the data, First Nations and their families will decide who has access to the information, First Nations and their families will possess the data in a secure manner.**
- 4) **Research partnerships will be based on mutual respect and will require formal research partnership agreements and data sharing agreements.**

Information Governance

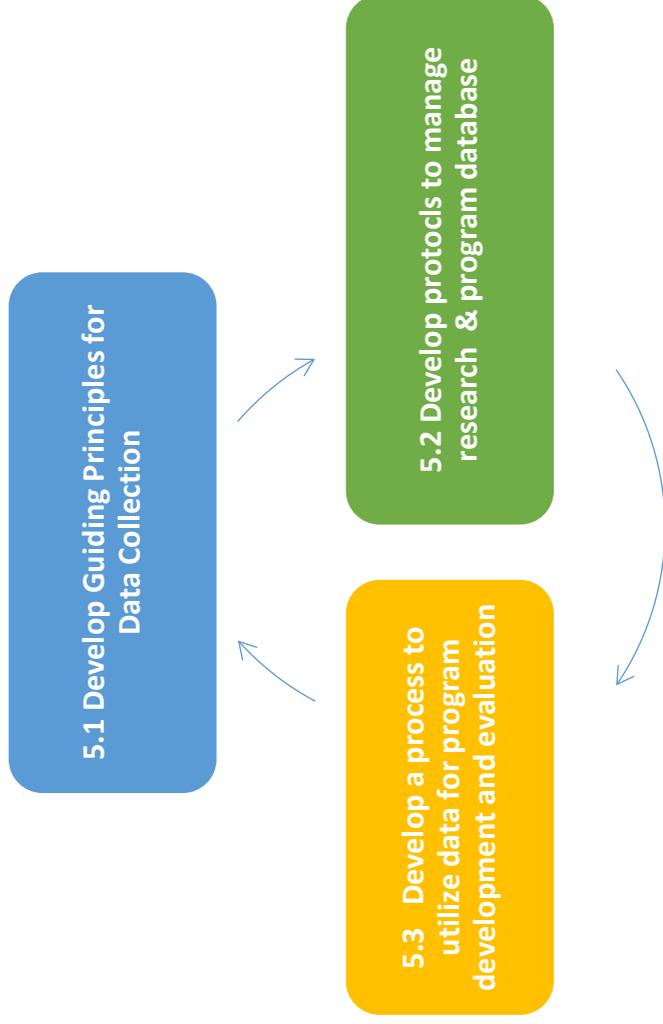
- 5.1 The committee and service providers will agree to use one electronic data system for all children and families involved in the program.
- 5.2 Information is accurately collected and recorded from children, families, partners, service providers, and community members to inform the design of services and supports.
- 5.3 Information is used to develop the care plan for the child with the family and will be updated as new information becomes available.
- 5.4 The committee and service providers will track all relevant information to provide an analysis on the gaps in services, ineffective services and ineffective processes to access services in order to make system wide improvements.
- 5.5 New standards of care will be shared electronically across the region of Manitoba.
- 5.6 All personal information gathered about children, parents and family will be confidential, only those providing care will have access to the information. A consent to share information will be signed by the parents prior to sharing any information.
- 5.7 Should it be necessary to discuss personal information with personal who are not part of the care team, the consent of the parents or guardians will be required.
- 5.8 Information (electronic and paper) will be protected and stored in a secure location accessible to the team members. Access will be determined by the role each team members plays in the care of the child and their family.
- 5.9 Parents or guardians can request to have access to all information regarding their child.

- 5.10 Parents or guardians will have free prior informed consent as to what the information collected about their child will be used for, who will have access to it, and where it will be stored.
- 5.11 Information will only be provided to other parties when consent is obtained or when required to do so by law.

Research

- 5.11 Education and training are provided to all team members on OCAP principles.
- 5.12 All researchers will be required to obtain ethical approval from the community research ethics committee and the leadership of the First Nation.
- 5.13 All research utilizing the child's information will include an advisory committee with representation from the children's families that will be involved in the research from start to finish.
- 5.14 All research utilizing the data will require the free prior informed consent of the families and community and the signing of a data sharing agreement which will outline the goals of the research, how First Nation and families will be involved in the decision-making structure for the research project, how the information will be used, analyzed and reported and who will have access to the data

Module 4 – Information Governance & Data Collection



5.1 Develop Guiding Principles for Data Collection	
1.	Engage Community Committee
2.	Develop Guiding Principles for Data Governance
3.	Develop Policies and Procedures for Guiding Principles
4.	Design and deliver training for Information Governance

5.2 Develop protocols to manage research & program database	
1.	Define what Data Management means to your community
2.	Define the Standard Operating Procedures
3.	Develop Training based on your customized Management Procures

5.3 Develop a process to utilize data for program development and evaluation	
1.	Obtain Community Approval
2.	Develop a Collaborative Research Agreement
3.	Develop a Data Sharing Agreement
4.	Monitor the Research Project
5.	Report back to the Community

Program Guidelines

5.1 Develop Guiding Principles for Data Governance	
Step 1	Engage Community Committee <p>Information governance is a community wide framework for managing information throughout the project and supporting the programs strategy, operations, regulatory, legal, risk and environmental requirements. This also includes standards, processes, roles and measurement that hold the program and people accountable to create, organize, secure and maintain the use of information in ways that align with and contribute to the program's goals.</p> <p>The Community Team will develop the guiding principles for data governance, informed by the standards that they seek to achieve and maintain.</p>
Step 2	Develop Guiding Principles for Data Governance <p>The following are some Guiding Principles for Data Governance:</p> <ol style="list-style-type: none">1. Accountability<ul style="list-style-type: none">• Establish an information governance structure for program development and implementation• Document and approve policies and procedures to guide the implementation• Enable reporting to the community that demonstrates the program is meeting its obligations to the families, the community, the funders and external partners.• Communicate and train all staff of the program on the policies and procedures to ensure standardization of practices.• Information is appropriately protected, accessed, stored, and released with proper documentation.• Information is available when and where it is needed.• Information is retained for the right amount of time and properly disposed of when no longer needed.2. Transparency<ul style="list-style-type: none">• The Information Governance program will be documented and shared to ensure its structure, processes, and practices are apparent, understandable, and available to families, community service providers and partners.• Documentation shall be available to the programs staff and other partner service providers regarding program operational policies, decisions made on the child and family's care, activities and services provided and outcomes.3. Integrity of accurate, complete, valid and reliable information is an expectation of the child their family, service providers, funders and external partners.<ul style="list-style-type: none">• The information provided by the program is reliable and valid.• Adherence to the programs policies and procedures.• Reliability of systems that control the information• Standardization in the way that information is collected, verified and securely

5.1 Develop Guiding Principles for Data Governance

stored.

- The program determines their responsibilities and processes for classifying and managing information they receive from secondary sources.
- Procedures are developed to incorporate information received from previous providers into the child and their family's file.
- Reliability of information should be built into the processes and systems used to collect the information. This will ensure quality of care, safety and efficiency of the program.
- The information system must be reliable to ensure the validity and integrity of the content. Hardware, network infrastructure, software, storage, and other components should be monitored for reliability and performance, and prompt action taken to mitigate identified problems and risks.

Step 3 Develop Policies and Procedures

Develop policies and procedures to implement the Data Governance Principles should include the following:

Protection - Every system, electronic or manual, that generated, collects, stores, transmits, uses the information must be governed with protection in mind. Information governance programs must ensure appropriate protection from breach, corruption and loss are provided for the confidential information collected. The following are suggested mechanisms to ensure **Protection**:

- Only staff members with appropriate levels of access may access information relevant to their roles and responsibilities. If staff transition in status or job function changes the respective levels of access to information is changed immediately to the new level appropriate for their roles and responsibilities.
- Ensuring that the electronic information cannot be inappropriately viewed, e-mailed, downloaded, uploaded, or otherwise reproduced – intentionally or inadvertently, even by individuals with approved access to the system.
- Appropriate safeguard will be clearly defined in the program policy and that compliance is monitored regularly.

Compliance;

- The Information Governance program complies with applicable laws, regulations, standards, and program policies.
- The information management system and processes explicitly declare how the program's activities are conducted in an ethical manner.

Availability;

- The program shall maintain information in a way that ensures timely, accurate and efficient retrieval for all those involved in providing care.
- To ensure critical information is available, the program must develop a system to back-up the electronic system and the information routinely.
- The program will develop a process to remove obsolete or redundant data and information.

5.1 Develop Guiding Principles for Data Governance

Retention & Disposition;

- Information is maintained for an appropriate time, taking into account the legal, regulatory, financial, operational requirements.
- Information is securely and appropriately disposed of when no longer required to be maintained.

Step 4 Design and deliver training for Information Governance

Provide Training to all those involved in data collection, data entry, data analysis, and data management on the policies and procedures.

Nanaandawewigamig – First Nations Health and Social Secretariat has a First Nations Research Unit that can provide assistance as well as linkages to:

- Manitoba First Nations Information and Research Governance Committee
- University of Manitoba
- University of Winnipeg
- Centre for Aboriginal Health Research
- National – First Nations Information Governance Centre (FNIGC)

5.2 Develop Data Management Protocols for the Program

Step 1 Define what Data Management means to your Community

Data management includes the generation, collection, organization, validation, analysis, storage, and integration of data as well as the dissemination, communication, presentation, utilization, transmission, and safeguarding of the information.

Define what data you will require for

- Providing services to the child and their family
- Reporting to community and funders
- Further program planning and development
- Identify gaps in services

Step 2 Define the standard operating procedures

Define your standard operating procedures by determining:

- ❖ Who will collect the information
- ❖ How it will be collected
- ❖ Who will input the data
- ❖ Who will have access to the data
- ❖ Where the data will be stored.

This will also include development of procedures that will ensure the following data quality characteristics are met.

Data Quality Characteristics:

- Accuracy
- Accessibility
- Comprehensiveness
- Consistency
- Currency
- Relevancy
- Timeliness

Data management protocols will define the following for the program to ensure the quality data that is consistently collected, reliable and valid. This will also include the development of a common data dictionary / code book for the JP-CFI program.

Step 3 Develop Training based on your customized Management Procedures

Develop training for all service providers and external partners on the standard operating procedures.

5.3 Develop Research Protocols to inform further Program Development

Step 1 Community Approval

Obtain approval from the community and the families to work with the research project. This process should be determined in collaboration with the Elders/Knowledge Keepers and the Leadership (Chief and Council) as deemed appropriate by the First Nation.

Step 2 Development of Collaborative Research Agreement

A collaborative research agreement (**Appendix A**) is a summary of the agreed terms of the research and can include the rights, responsibilities and expectations between those involved. The purpose of the research is usually included in the agreement to provide a balanced and transparent process.

A collaborative research agreement usually includes the following:

- Purpose, goals and duration of the research project
- Scope of the project, including the activities required to complete the research
- Expected outputs and products of the research
- Potential risks and benefits to the community
- Roles and responsibilities of each person
- Time commitments required from community members involved in the research and the amount of compensation to be paid to those involved
- Research methods and procedures
- Research capacity to be built in the community
- Process and form for obtaining informed consent from the individual participants and the community as a whole
- Reporting obligations by the research institution
- Communication plan
- Conflict resolution mechanism
- Measures to ensure confidentiality
- Access to, ownership of, and restrictions on the use of data during and after the project, including terms and conditions for future use of the data
- Involvement of the community in the data analysis, interpretation and dissemination of the research findings
- Conditions relating to formal publication (how acknowledgement and differences in interpretation of the data will be addressed)
- Financial and logistical responsibilities of the partners
- Provision of benefit-sharing in circumstances where intellectual property rights or other forms of economic gain may be negotiated
- Termination clause

The list of issues should be discussed, understood and agreed upon by both parties to ensure a successful and beneficial research project. It is intended to be a legal document and should be reviewed by legal counsel prior to signing.

<p>Step 3</p>	<p>Development of Data Sharing Agreement</p> <p>A data sharing protocol (<i>Appendix B</i>) is a formal agreement between the community and the research partner which summarizes the conditions and arrangements for sharing the community’s information or data.</p> <p>The agreement sets out the fundamental principles and obligations that the research partners must adhere to when they collect, use, store and disclose individual or aggregate data. It also describes why information or data is being shared, and when and how information or data is being shared.</p> <p>This kind of agreement is a useful tool in protecting individual and community interests, information and privacy. It is also important in clearly stating the standards and can be used to prevent misunderstandings. The template for a Data sharing agreement includes the following sections:</p> <ol style="list-style-type: none"> 1. Introduction 2. Definitions 3. Purpose 4. Information to be shared 5. Use of data or information 6. Mechanism for information sharing 7. Data ownership 8. Publication and dissemination 9. Data security and confidentiality 10. Retention and disposition of information 11. Intellectual property 12. Duration and renewal 13. Expiration or revocation of the agreement 14. Signing authorities
<p>Step 4</p>	<p>Monitoring of Research Project</p> <p>The monitoring of the research project should be determined by the Community Team with a research advisory committee in place. It is important to include Elder/Grandmother/Knowledge Keeper representation as well as family member participation on such an Advisory Committee.</p>
<p>Step 5</p>	<p>Reporting back to the Community</p> <p>Report the findings back to the program and community. Research should be celebrated!</p>

Tools and Templates

The templates are developed on the basis of OCAP. Some communities may use the templates as is, others may find it helpful to add to or modify the template to meet the needs of the community.

Appendix A – Collaborative Research Agreement

Collaborative Research Agreement¹

Project Title _____

THIS COLLABORATIVE RESEARCH AGREEMENT is made this _____ day of _____ 2017.

BETWEEN:

Principal Researcher(s)

Name(s):

Supporting Institution:

Address: _____, Telephone: _____, Email: _____

AND

_____ First Nation Community

Contact Person(s):

Organization:

Address: _____, Telephone: _____, Email: _____

The principal researchers, as named, and the _____ First Nation agree to conduct the named collaborative research project in accordance with the guidelines and conditions described in this document.

Purpose of the Research Project

This section should describe the general topic that is being researched, and also the purpose of doing the research (e.g. to increase awareness/understanding, enhance well-being, improve programs, etc), A statement of purpose is usually fairly brief (2-5 sentences) and not too specific.

Sample text: *The purpose of this research project, as discussed with and understood by the _____ First Nation in the community of _____, is to investigate*

The results of this research may be used to

Scope of the Project

This section provides more details about the project. It should include the following; specific research objectives or questions, and types of information that will be gathered (e.g. statistics, interviews).

¹ Template developed by the National Aboriginal Health Organization

Sample text:

The project aims to answer the following questions:

In order to meet the objective or answer the questions stated above, the following types of information will be gathered:

Methods and Procedures

This section describes how research data will be gathered, recorded, analyzed and reported. Issues that should be addressed in this section, but a separate section could be created to deal with that issue since it is usually an important considerations for communities.

- a) Research or data gathering methods; depending on the nature of the project, these might include: collecting information/statistics from databases; collecting environmental samples; collecting surveys, interviews or focus groups;
- b) The extent or amount of data to be obtained should be specified (e.g. statistical variables, number or interviews/surveys, number of samples, etc.) and explained.
- c) The role of the community members in the research or data gathering phase as participants in interviews etc. and or as paid researchers, fieldworkers or guides);
- d) Procedures for obtaining consent (individual or collective) must be described in detail;
- e) Methods to be used for recording and string data;
- f) Procedures for ensuring confidentiality and securing data;
- g) Methods of analysis or interpretation of data to generate findings and conclusions;
- h) Opportunity for community members or community researchers to participate in data analysis, or to verify the results of the analysis;
- i) Preparation of the final report; how will community members have an opportunity to revise and approve it before it is finalized; and
- j) Format for presenting findings to the general public and the community.

Sample Text

Data will be gathered using the following methods or procedures: (identify procedures)

The amount of data that is required for this project is...

The number / amount is required because...

Community members will assist or participate with the data- gathering phase in the following ways: (identify mechanisms)

Individual free prior informed consent to participate in the project will be obtained in the following ways:

(identify mechanisms)

Participants have the right to withdraw from the project at any time for any reason. In this case, that participant's data will be destroyed.

Research data will be stored in the following ways (OCAP compliant)

The following persons will have access to research data:

Confidentiality of research data (if desired) will be ensured in the following ways

Data will be analysed or interpreted through the following methods

Community researchers/participants will participate in the analysis of data, or the verification of results, in the following ways

The final research report will be submitted to the community for review and approval

Research findings will be presented to the community in a language and format that is clean and comprehensible to community members.

Expected Outcomes, Benefits and Risks

This section sets out the expected outcomes and benefits of the research project. It is important to be clear and honest about expected benefits for both the researcher and the community. Benefits for the principal researcher may include financial gain (from publication) or indirect financial benefit through enhancement of professional status (to an individuals or research institution). Benefits to the community may include the generation of information that will support future funding applications or that will enhance community programs/services; education and/or training for the community members; or direct financial compensation to community researchers and or participants.

Risks to the community as a result of the project should also be considered, as should any measure that could be taken to minimize those risks These may include: environmental impacts, invasion of personal or collective privacy; portrayal of the community in a negative way and; disruption of other important community projects or issues.

Sample Text

The expected outcomes of this research project are:

The project will benefit the principal (external) researchers in the following ways:

The project will benefit the community (individually or collectively) in the following ways:

The project poses the following risks to the community

Measure will be taken to minimize these risks are

Obligations and Responsibilities

This section is not specific to a particular research project. It describes obligations and responsibilities of each partner (community, external researchers, and community based researchers) in a community based research project through all phases including research design, implementation, data collection and analysis and the dissemination of information.

External Research Partner

- *Do no harm to the community*
- *To involve the community in active participation of the research process and to promote it as a community-owned activity*

- *To ensure the research's design, implementation, analysis, interpretation, reporting, publication and distribution of its results are culturally relevant and in compliance with the standards of competent research.*
- *To undertake research that will contribute something of value to the community.*
- *To ensure that new skills are acquired by community members, such as research design, planning, data collection, storage, analysis, interpretation and so on*
- *To promote the dissemination of information to society at large if desired and appropriate through both written publications and oral presentations*
- *To be involved in any future analysis of the data after the data is returned to the community, if requested.*
- *To abide by any local laws, regulations, and protocols in effect in the community or region, and to become familiar with the culture and traditions of the community.*
- *Within their respective roles as researchers and community representatives, to advocate and address health, social or other issues that may emerge as a result of the research.*
- *To ensure that the community is fully informed in all parts of the research process, including its outcomes through publications and presentations, and to promptly answer questions that may emerge regarding the project and its findings.*
- *To communicate equally with the other partners in all issues arising in the project.*
- *To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nation cultural perspective*
- *To support the community by providing resources as a matter of priority (e.g. research funding to support community research coordinator)*
- *To abide by their own professional standards, their institution's guidelines for ethical research and general standards of ethical research.*

Community Based Researcher

In addition to the obligations listed for the external research partners, the community researcher is obligated:

- *To provide a link between the research project team and other community members, and provide relevant, timely information on the project.*
- *To place the needs of the community as a first priority in any decision where the community researcher's dual roles of community member and researcher may be in conflict*
- *In situations where a research project is promoting healthy lifestyles practices, to promote the intervention objectives of the project by working closely with community health, social and/or education professionals.*
- *To be stewards of the data until the end of the project if requested or appropriate.*
- *Community Partner*
- *First and foremost, to represent the interests, perspectives and concerns of community members and of the community as a whole*
- *To ensure that research carried out is done in accordance with the highest standards, both methodologically and from a First Nations cultural perspective.*
- *To communicate the results of the research to other communities and to share ideas as well as programs and service development for mutual benefit and involvement.*
- *To serve as the guardian of the research data during and/ or after completion of the project.*
- *To offer the external and community researchers the opportunity to continue data analysis before the data are offered to new researchers.*

Funding

This section identifies funding sources and sets out the responsibilities of all partners with respect to funding requirements.

Sample Text

The principal researchers have acquired funding and other forms of support for this research project from these sources:

The funding agencies have imposed the following criteria, disclosures, limitations and reporting responsibilities on the principal researchers:

The community partner has the following responsibilities with respect to funding requirements:

Dissemination of Results

This section should identify all the stakeholder (e.g. communities, their academic sector, funding bodies, professional bodies, government departments, etc.), to which results will be disseminated. The methods for dissemination should also be described.

You may want to consider the degree of control that the community has over future publication or dissemination of research results.

Sample text:

Research results will be disseminated to the following stakeholders:

Research results will be disseminated in the following manner:

Any future publication or dissemination of research results, beyond what is described in this agreement, shall not be undertaken without consultation with the _____ First Nation community.

Data Ownership and Intellectual Property Rights

The data gathered or produced through the research project is distinct from the research results. The First Nation community should clearly affirm ownership of its data, as well as any associated intellectual property rights. Conditions of data stewardship and use of data after completion of the research project should be considered by the community, but do not need to be specified in the research agreement since this is an internal protocol to be determined at the community's discretion.

Sample Text

The individual owns his or her personal information while the _____ First Nation owns the collective data.

The _____ First Nation retains all intellectual property rights (including copyright), as applicable, to the data offered under this agreement.

Access and stewardship of the collective data are negotiated and determined by the First Nation and will be OCAP compliant.

Communication

Guidelines for internal and external communication should be established in this section. Internal communication means communication between research partners names in this agreement, while 'external communication refers to communication about the project to other interested parties such as the media.

Sample Text

Communication on all aspects of the research, including progress reports to the community, will be ensured in the following ways:

In case of media inquiries during or after the project, designated spokespersons are:

The community will be the first to receive research results and the first invited to provide input and feedback on the results. The results should be presented in a format that is language appropriate and accessible to the community. Results will not be released without the approval of the community.

At the end of the study, the research partners agree to participate in community meetings to discuss the results and their implications.

Dispute Resolution

This section sets out the process for addressing concerns over or resolving disputes related to the implementation, interpretation or release of research data and/or findings.

Sample Text

In the event that a dispute arises out of or relate to this research project, both parties agree first to try in good faith to settle the dispute by mediation administered by an agreed upon neutral party before resorting to arbitration, litigation or some other dispute resolution procedure. A mediator will assist the parties in finding a resolution this is mutually acceptable.

If a dispute cannot be resolved to the satisfaction of both parties, the research project may be terminated according to the terms described below.

Term and Termination

This section notes the duration of the project and sets out the course of action to be followed if either party to the agreement wishes to terminate the research project.

Sample Text:

This agreement shall have an effective date of _____ and shall terminate on _____. This agreement may be terminated by the written notifications of either party.

Appendix B - Data Sharing Protocol

DATA SHARING AGREEMENT²

THIS DATA-SHARING PROTOCOL is made this _____ day of _____, 2006.

BETWEEN:

_____ (First Nation community or organization)

AND

_____ (Research partner(s) or organization)

1. Introduction

In general, the introduction provides some background information leading to the development of the Data-Sharing Protocol.

What is the purpose of the Data-Sharing Protocol and why is it necessary?

The introduction should identify the parties to the agreement, their names, titles, contact information and the names of their organizations. It may also include relevant policy statements, a mission statement, or guiding principles.

Sample text:

The _____ First Nation promotes meaningful partnerships through working in collaboration with the _____ (research partner(s) or organization).

The _____ First Nation has agreed to enter into an agreement whereby the _____ (research partner(s) or organization) is authorized to use the _____ data (record level or aggregate data) from the _____ (name of past research conducted), as set out in this Agreement.

This Data-Sharing Protocol will maintain the values, principles and protect the rights of the First Nation. This Protocol should not be used for any other purpose.

2. Definitions

Relevant definitions may be included in this agreement for clarification of certain terms.

Sample text:

Information sharing: *The exchanging, collecting, using or disclosing of personal information by one organization with another organization for certain purposes, including First Nations, government bodies, educational institutions, non-profit organizations, etc. The sharing may be carried out using any transmission method and may take place over any time period.*

² Template developed by the National Aboriginal Health Organization

Data linkage or data profiling: This is a computerized use of personal data obtained from a variety of sources, including personal information banks, to merge and compare files on identifiable individuals or categories of individuals for administrative purposes. This linkage or profiling generates a new body of personal information.

Personal information: Recorded data or information that is related to an identifiable individual.

Record level data: Information that is specific to an individual or group of individuals, whether or not the person is identifiable by name.

Aggregate data: Aggregate data includes data collected from several sources that do not reveal the identity of any individual. It is collective data meant for developing statistics or for planning based upon that data (e.g., combining demographic data about clients from all primary care providers in a service area generates aggregate data about client characteristics).

3. Purpose

The purpose and reason for the data-sharing agreement should be identified. If individual data records are being shared, the applicable federal, provincial and territorial legislation regulating the use and release of individual client information should be specified (e.g., freedom of information and protection of privacy acts, health information acts or other community protocols, such as a Code of Research Ethics or Privacy Code). The purpose of the data-sharing arrangement must be understood and formally agreed to by those entering into it.

Sample text:

The purpose of this Data-Sharing Protocol is to:

- a) summarize the conditions and arrangements for data or information collection and sharing;*
- b) set out the fundamental principles and obligations that organizations must adhere to when they collect, use, store and disclose personal information about members of the First Nation;*
- c) describe why data or information is being shared, how and when data will be collected and shared, and by whom;*
- d) protect individual and community interests, information and privacy;*
- e) maintain appropriate standards and prevent misunderstandings over responsibilities; and,*
- f) clarify issues of data ownership, control and access, intellectual property, aggregate data, confidentiality, use of information and further disclosure.*

This Protocol provides a framework for the use of data that supports First Nations principles of OCAP in relation to research, and supports the data needs and capacity of the _____ First Nation and the _____ (research partner(s) or organization), with respect to the use of information for planning, advocacy, and determining community priorities and trends.

Ownership: Refers to the relationship of First Nations to their cultural knowledge/data/information. The principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.

Control: The principle of “control” asserts that First Nations people, their communities and representative bodies are within their rights in seeking to control all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project from conception to completion. The principle extends to the control of resources and review processes, the formulation of conceptual frameworks, data management and so on.

Access: First Nations people must have access to information and data about themselves and their communities, regardless of where it is currently held. The principle also refers to the right of First Nations communities and organizations to manage and make decisions regarding access to their collective information.

This may be achieved in practice through standardized, formal protocols.

Possession: While “ownership” identifies the relationship between a people and their data in principle, possession or stewardship is more literal. It refers to the physical control of data. Although not a condition of ownership per se, possession is a mechanism by which ownership can be asserted and protected.

4. Information to be Shared

Within the protocol, it is important to describe in detail the data to be shared.

Sample text:

[Record level or aggregate] data from the _____ First Nation will be shared for the purposes of this agreement.

The data to be shared consists of

_____.

5. Use of Data or Information

The agreement should clearly identify how the data or information shared under the arrangement will be used. For what purpose(s) are the data going to be used? It may state that the data will only be used for the stated purpose(s) and may not be used for any other purposes (further disclosure), without the explicit written approval, in advance, of the First Nation. The research partner(s) may not release the data for any purpose, unless agreed to in advance by all parties, and provided it is not in violation of provincial, territorial or federal legislation.

Sample text:

The research partner(s) will use the data for the purposes of _____

_____.

The research partner(s) will only use the data for the stated purpose(s) and the data may not be used for any other purposes (further disclosure) without the explicit written approval, in advance, of the _____ First Nation. The research partner(s) may not release the data for any purpose unless agreed to in advance by all parties, and provided it is not in violation of provincial, territorial or federal legislation.

6. Mechanism for Information-Sharing

The methods of data-sharing need to be identified. Some mechanisms for sharing include electronic transfer over a secure network or electronic transfer through password-protected external disks.

Sample text:

The data-sharing will involve electronic transfer over a secure network. Data matching and linkage will be used. (Note: this is only an example; your community may use a different mechanism for sharing.)

7. Data Ownership

The agreement should address control and access to data by the requesting party. The requesting party may be deemed custodians or stewards of the data under the conditions defined in the agreement and, depending upon the specifics of the project, may receive either individual records or aggregate data. Users may be expressly prohibited from use of the data in the pursuit of any commercial or income-generating venture, either publicly or privately.

Sample text:

The _____ First Nation owns the collective data. Access and stewardship are negotiated and determined by the First Nation.

8. Publication and Dissemination

Depending upon what kind of information you have allowed the research partner(s) to access, you may decide to specify that you are a co-author or a partner in the research project, particularly if the information is very sensitive. This may allow you to shepherd the information and retain some rights to the publication without sacrificing the integrity of the research results.

Sample text:

The research partner(s) will not release data received as part of this agreement to other local or research institutions or organizations without express written agreement from the _____ First Nation. Other interested research institutions or organizations shall contact the First Nation directly.

9. Data Security and Confidentiality

The data steward must maintain confidentiality and protect the data in a manner consistent with clearly defined principles, and according to formal and rigorous data protection standards and methods. The data steward will be responsible for upholding the principles, standards and methods. Custodians of data with personal identifiers must agree and take all steps necessary to ensure its privacy and security as described in relevant freedom of information and privacy acts, health information acts, or other legislation as well as their institution's protocols and community protocols, where applicable. If either party deems security and confidentiality inadequate, the stewardship should be revoked in favour of a more secure steward or destruction of the data.

Integrity and security of the data must be maintained by instituting regulatory controls, such as ensuring that only authorized users have access to the data and that electronic systems are properly maintained and managed.

Sample text:

All employees, agents and representatives of the _____ First Nation and the research partner(s) who will come in contact with data must take an Oath of Secrecy by completing and signing the standardized form. The First Nation shall record and document the names of all persons who have taken the oath and the date the oath was taken.

The following is an example of an Oath of Secrecy.

I _____, do solemnly swear (or affirm) that I will faithfully and honestly fulfill my duties as an employee/contractor of the _____ in relation to its participation in the _____ research study. I swear (or affirm) that I will protect the privacy of individual respondents, communities and First Nations collectively, and maintain the confidentiality of all research data and related information pursuant to the policies, rules, regulations and instructions provided to me by _____ and the _____ First Nation. I will respect the _____ First Nation Code of Research Ethics and the provisions of the protection agreement. I will not, without due legal authority, disclose or make known any matter or thing that comes to my knowledge by reason of my work on the _____ research study. I will not release data or statistical outputs without appropriate authorization from regional authorities.

I understand that maintaining confidentiality is critical to the credibility of the research and of the organizations taking part in the research, and that a breach of confidentiality may result, among other things, in the immediate termination of my contract and legal action against me for damages.

The _____ First Nation and the research partner(s) will each provide, for their own offices, all necessary equipment, supplies and policies to ensure the confidentiality of the survey data, including but not limited to:

- a lockable storage room and lockable filing cabinet;*
- password protection for computers containing confidential data or information;*
- controlled and restricted access, by lock and/or computer password, of all data or information, either hard copy or electronic; and,*
- a firewall or similar software or hardware to protect the data or information that is stored on a computer that has access, directly or indirectly, to the Internet or any other type of data-sharing networks.*

The _____ First Nation and the research partner(s) will ensure that at all times the data or information is either directly supervised by one of its employees or agents, or that it is safely locked in a secure cabinet.

10. Retention and Disposal of Information

The agreement should specify how long the shared data are kept or stored. Also, terms should be identified regarding the disposal of the data once the agreement has expired or been revoked. The data may be returned to the source or destroyed by the recipient, either physically or electronically.

Sample text:

The _____ (research partner(s)) will store and maintain the data in a manner that ensures its use remains consistent with the terms and conditions of this agreement.

Upon expiration or revocation of this agreement, the _____ (research partner(s)) will immediately and permanently remove and destroy all copies, both physically and electronically, of the data provided under this agreement in accordance with relevant laws and policies (e.g., band bylaws and policies or government laws).

11. Intellectual Property

Although this may not be consistent with some First Nations perspectives, intellectual property arising from research in Canada is normally vested in the organization(s) that conducts the research. As a result, in situations where data is provided to an organization that may conduct further research, it may be important to specify in an agreement that the First Nation retains all intellectual property rights (including copyright), as applicable, to the data offered under this agreement, and this agreement constitutes only a license to acquire and use these data products. Furthermore, it may be specified that no title or rights be conveyed by this agreement.

Sample text:

The _____ First Nation retains all intellectual property rights (including copyright), as applicable, to the data offered under this agreement, and this agreement constitutes only a license to acquire and use these data products. Furthermore, this agreement does not convey title or rights.

12. Duration and Renewal

A clause should include information on when the agreement will come into effect (e.g., the date of signing by the last of the parties), as well as how long the agreement will remain in effect. There can also be terms set out for renewal, extensions or amendments to the agreement, if necessary.

Sample text:

This agreement will commence on and come into effect from the date of signing by the last of the parties, and will remain in effect for the duration of five (5) years.

This agreement may be renewed, extended or amended with the written consent of both parties at least sixty (60) days prior to the expiration of the agreement.

Notwithstanding paragraph 12.1, either party shall be entitled to terminate this agreement in the event the other party fails to fulfill any of its obligations as stipulated in this agreement by providing a written notice to the other party sixty (60) days prior to termination. Data access privileges are terminated immediately. At the end of the notice period all copies of the data will be removed and destroyed, as described in section 10.

13. Expiration or Revocation of the Agreement

There should be a clause outlining the terms for the expiration or revocation of the agreement.

Sample text:

Upon expiration or revocation of this agreement, the research partners will immediately and permanently remove and destroy all copies, both physically and electronically, of the statistical outputs provided under this agreement in accordance with federal laws and Treasury Board Policy or any other federal government policy. (This refers to statistical outputs that may or may not be the subject of the agreement.)

In exceptional circumstances, such as discovery of repeated misuse or distortion of the statistical outputs, the _____ First Nation will advise the research partner(s) in writing of the inappropriate action and provide them with sixty (60) days to correct the said inappropriate action. In the event that the research partner (s) does not correct the said inappropriate action within the sixty (60) day period, the research partner's license to use the statistical outputs may be revoked by the _____ Band Council on behalf of the _____ First Nation. Upon revocation, all copies of the statistical outputs will be removed and destroyed.

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Acknowledgements

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