

Application Guide

First Nations Health and Social Secretariat of Manitoba Health Information Research Governance Committee (HIRGC)

The guide below provides details on how to properly complete the HIRGC Research Application for initial review of research involving First Nations in Manitoba. Incomplete applications will not be reviewed by the HIRGC; therefore, applicants are advised to follow the guide to ensure that their application packages are complete and accurate.

For questions that are not answered in this guide, please contact:

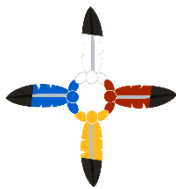
Sage Broomfield, Research Ethics Coordinator via hirgc@fnhssm.com and/or directly at sbroomfield@fnhssm.com

Date of Application: *The date of application submission.*

Project Information	
Project Title	<i>The project title should accurately reflect the study and correspond with the title presented on all project materials.</i>
Start Date	<i>The date the project will begin project activities.</i>
Estimated End Date	<i>The estimated date the project will complete project activities.</i>
Research Funder(s)	<input type="checkbox"/> Tri-Council Agency: <i>CIHR/NSERC/SSHRC</i> <input type="checkbox"/> Other: <i>Provide name of funder(s).</i>
Grant Number(s)	<i>The number given to the project by the funder (if applicable).</i>

Contact Information	
Name of Principal Investigator/Lead Researcher	<i>The individual who provides overall leadership of the research team and assumes the primary responsibility for the project, including ethical conduct. If two or more people are equally responsible, please name the researcher who will be the primary point of contact for administrative issues.</i>
Address	<i>Office address of lead researcher.</i>
Phone	<i>Office or cell phone number of lead researcher.</i>
Fax	<i>Fax number of lead researcher (if applicable)</i>
Email	<i>Email of lead researcher.</i>
Name of Primary Contact (If different from above)	<i>The individual who is the main point of contact if the lead researcher is unavailable – usually a co-lead researcher, project coordinator, or administrative assistant.</i>
Phone	<i>Office or cell phone of primary contact.</i>
Email	<i>Email of primary contact.</i>

Purpose of Application	
<input type="checkbox"/> Access to Manitoba First Nations Research File (MFNRF)	<input type="checkbox"/> Letter of Support (Regional)
Please explain:	
<i>You may check all that apply. In this section you can further explain the purpose of your application and why you are asking to access the MFNRF or receive a letter of regional support.</i>	
<i>By checking “Access to Manitoba First Nations Research File” you are requesting access to the linked file held at the Manitoba Center for Health Policy (MCHP) that is generated from the Indian Status Registry (ISR) and linked to the Manitoba Health Insurance Registry data.</i>	



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By checking “Letter of Support (Regional)” you are requesting support and general guidance on your research project on a regional level from the HIRGC.

Project Team

Name	Role/Responsibilities	How do they identify? (Settler, First Nations, Metis, Inuit)
Jane Smith	Project Coordinator	First Nations (Manitoba First Nation)

The project team includes co-researchers, and core research team staff such as coordinators, lead analysts, surveyors, and interviewers, as well as elders. Here you will also include a brief explanation of their roles and responsibilities for the project. In addition, we ask you to clarify how each team member identifies, and if possible, the Nation they identify with. This helps us better understand who the research team is.

See the example above. You may add additional lines as needed.

Project Partners

Contact	Organization/Nation	Do you have a BCR/Letter of Support? (Please Attach)
John Smith (Chief)	Manitoba First Nation	Yes, BCR

The project partners include but is not limited to First Nations, Provincial territorial organizations, tribal councils, non-profit and community organizations, businesses, health organizations and institutions, Metis and Inuit organizations, and academic institutions.

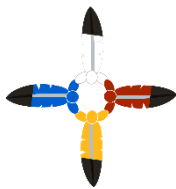
It is important that when you are requesting a Band Council Resolution (BCR) and/or Letter of Support, that the partners are aware of why these documents are being requested. Partner listed above may be contacted by HIRGC to confirm their understanding and involvement in this project. The contact will be the primary person involved in your project from that organization/institution.

Please attach any BCRs and/or letters of support from project partners.

See the example above. You may add additional lines as needed.

Ethics

	Name of REB(s)	Status (Not Applied, Applied and Waiting, Conditional Approval, Approved, Denied)
<input type="checkbox"/> HREB	University of Manitoba REB	Applied and waiting
<input type="checkbox"/> PHRPC		
<input type="checkbox"/> Other		
Have all research personnel completed the TCPS2/TCPS3 training course?		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In Progress
Have all research personnel completed the OCAP® training course?		<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> In Progress

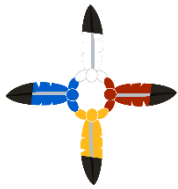


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Has your research team applied to any other Research Ethics Boards (REBs); and what are the status of those applications? This includes institutional REBs (HREB), the Provincial Health Research Privacy Committee (PHRPC, formerly HPIC), or any other REBs such as a First Nation REB, or REB of a Metis or Inuit Nation/organization if your research also includes those populations. In addition, we would also like to know if you and your research team have taken and completed the Tri-Council TCPS2 and OCAP® training course offered by the FNIGC. Please attach all other REB applications as well as your TCPS2 and/or TCPS3 and OCAP® training certificates.

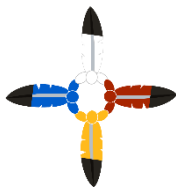
See the example above. You may add additional lines as needed.

Project Details
Summary/Abstract of Project
<i>In this section, please provide a summary of your research project, this includes your research questions and expected outcomes.</i>
Is this project closely linked to any other project(s)?
<input type="checkbox"/> Yes, this is a part of a larger project. <input type="checkbox"/> Yes, this is a continuation of a previous project. <input type="checkbox"/> No If yes, please provide details on the connected project(s): <i>If your project is connected (an off shoot, another phase, or a follow-up) to another project, please provide information on that project such as its name, its status (complete, in progress, etc.), and how your current research relates to it.</i>
Has the larger/previous project been reviewed by the HIRGC?
<input type="checkbox"/> Yes, it was reviewed by HIRGC but denied. <input type="checkbox"/> Yes, it was reviewed by HIRGC and approved. <input type="checkbox"/> No If yes, please provide details of the HIRGC review: <i>If your project is connected (an off shoot, another phase, or a follow-up) to another project that was previously reviewed by the HIRGC, please provide information on the status of that project (ongoing, ended, not approved).</i>
Has an amendment or new ethics submission been submitted for this new project?
<input type="checkbox"/> Yes, an amendment was made to the larger/previous project's application for this project. <input type="checkbox"/> Yes, a new ethics submission was made to the larger/previous project's application for this project (see the Ethics section). <input type="checkbox"/> No. If an amendment was made, please provide details: <i>If your project is connected (an off shoot, another phase, or a follow-up) to another project, and an amendment was made to that ethics submission to do this project. Please describe the conditions of that amendment.</i>



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Ethical Standards Involving First Nations
<p>HIRGC does not support pan-Indigenous research, how will the research consider the unique histories, cultural practices, and jurisdictional challenges of the First Nations peoples, their Nations, and representative bodies in your research?</p>
<p><i>The HIRGC only has the mandate to review Manitoba First Nations specific research. We do not speak or provide approval on behalf of Metis or Inuit, as we respect their Nations sovereignty and autonomy that the First Nation(s) that you are working with will be represented in your research within the context of their realities.</i></p> <p><i>If your research also includes Metis and Inuit populations, you must clarify how you will ensure that each Indigenous Nation is distinct within your research.</i></p>
<p>Where are your study participants located?</p> <p><input type="checkbox"/> Urban (MB city) <input type="checkbox"/> Rural (Outside of MB city, off-reserve) <input type="checkbox"/> On-Reserve</p> <p>Please provide if possible - city/Nation information (Names, Language Groups, Tribal Council Affiliations). In addition, please provide details on how they will be identified in the data (as Individuals, as a Nation, or at a regional or level).</p> <p><i>You may check all that apply.</i></p> <p><i>By checking “Urban (MB city)” you confirm that participants or the people within your research data sets reside in urban setting such as a Manitoba city, like Winnipeg.</i></p> <p><i>By Checking “Rural (Outside of MB city, off-reserve)” you confirm that participants or the people within your research datasets reside outside of a Manitoba city and off-reserve. This includes towns and municipalities.</i></p> <p><i>By Checking “On-Reserve” you confirm that participants or the people within your research data sets reside within a Manitoba First Nation.</i></p> <p><i>By providing this information, you are confirming your knowledge of the Nation(s) you are working with and how they will be represented in your research and the results.</i></p>
<p>Describe your relationship with the First Nation(s) you are working with?</p> <p><i>If you currently do not have a relationship with the First Nation(s), HIRGC will not approve this application and request you build a relationship first.</i></p> <p><i>If you currently do not have a relationship with the First Nation(s) due to working with regional level data is important that a relationship be formed in another way such as with regional, tribal, or community organizations to help guide this research.</i></p> <p><i>Please provide details of your relationship with the First Nation(s) you are working with. This includes how relationship started, the status of the relationship, information about current collaborations with the Nation and how the Nation was involved in the creation of this research project (Did they approach the research team? Did the research team approach the Nation? Did the project come out of conversations with the Nation?)</i></p>



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Describe the First Nations ethical standards and processes of the distinct cultural and language groups of the First Nation(s) group(s) you are working with and how you will establish, integrate, and abide those standards and processes.

Each First Nation, and individuals within those nations, have distinct ethical standards and protocols when it comes to building relationships and doing research within the Nation. Please provide details about those standards and protocols of the First Nation(s) you are working with and how your research team plans to integrate and abide by those standards. This can include information about how methods are developed, use of cultural protocols like ceremony and gifting, how information is gathered and shared, the involvement of elders and knowledge keepers, and the use and sharing of their language(s), cultural imagery, and stories.

Describe the historical, cultural, traditional, research, and colonial contexts of the First Nation(s) you are working with.

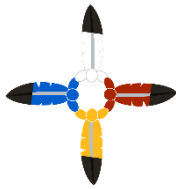
This is to ensure that important information such as colonialism, systemic racism, and other challenges, such as past research harms, are reflected and considered in your research and results. In addition, the distinct cultural contexts of the Nation such as language, relationship structures, and Nation context is important.

Does this project involve any other First Nations peoples, Nations, and representative bodies within or outside of Canada?

Yes No

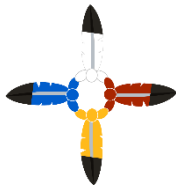
If yes, please provide details as to who and why they are involved.

We recognize that there are cases in which research connects to or involves those outside of Manitoba and Canada. If this is the case for your research project, please provide details about any other First Nations peoples, Nations, and representative bodies within or outside of Manitoba/Canada involved in the research. In this section, please explain how you will ensure they are involved, including considerations of ethical standards of all Nations involved (inside and outside of Manitoba and Canada).



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Methodology
What type of project is this? <input type="checkbox"/> Primary Research <input type="checkbox"/> Secondary Research <i>You may check all that apply.</i> <i>By checking “Primary Research” you acknowledge that you will be gathering new data or information from primary sources such as Nation members.</i> <i>By checking “Secondary Research” you acknowledge that you will be utilizing existing data or information such as public or private data sets.</i>
Will you be directly engaging with First Nation(s) or individuals at any point in your research activities? <input type="checkbox"/> Yes <input type="checkbox"/> No Please provide details on your prospective participants or sample group. <i>In this section you will describe your sample group – who is included, how many people/what is your sample size, etc.</i> <i>If you are engaging with people, please describe why this sample group was chosen and how you will be recruiting and engaging with participants.</i> <i>If you are not engaging directly with people, please describe how this sample group was chosen.</i>
Will you be engaging with specific demographics of First Nation peoples that may be systematically perceived as vulnerable? (Vulnerabilities can include pregnancies, substance use disorders, disabilities, houselessness, <input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please provide details on how you will do this in a safe and appropriate way. <i>It is important to acknowledge that specific demographics may be perceived as vulnerable by certain systems. Conducting research in a way that is safe and appropriate for this population that both meets research objectives and protects them from further harm during and after research processes. This includes but is not limited to proper consenting practices such as use of assent forms and powers of attorney, properly explaining the research process, being mindful of your use of honorariums, having supports present during interactions, being mindful of their state of mind, ensuring research methods ensuring research methods are appropriate, and appropriate aftercare.</i>
Please provide a description of your research methods. <i>In this section you will provide a descriptive summary of the research methods you plan to utilize during your project. This includes but is not limited to what information you will be gathering/what datasets you will be using? How will you be gathering information (1-on-1 interviews, surveys, sharing circles, etc.)? Who was involved in the development of the data gathering tools? What datasets you will be comparing and why? Will you be accessing/using biological samples and how will this process be done?</i> <i>If you have any data gathering tools (e.g., survey, interview, and focus group/sharing circle questions) developed, please provide details of those, and attach them to this application.</i>



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In this section you will provide a descriptive summary of the research methods you plan to utilize during your project. This includes but is not limited to what information you will be gathering/what datasets you will be using? How will you be gathering information (1-on-1 interviews, surveys, sharing circles, etc.)? Who was involved in the development of the data gathering tools? What datasets you will be comparing and why? Will you be accessing/using biological samples and how will this process be done?

If you have any data gathering tools (e.g., survey, interview, and focus group/sharing circle questions) developed, please provide details of those, and attach them to this application.

Free, Prior, and Informed Consent (FPIC)

What level(s) of consent will you be gathering?

Regional Consent (through HIRGC) Collective/Nation Consent Individual Consent

Please explain why you have chosen this/these level(s) of consent, why you will not be seeking other levels, and how and when you plan to gather consent:

You may check all that apply.

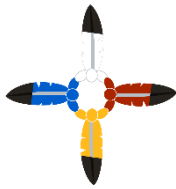
By checking “Regional Consent (through HIRGC)” you are acknowledging that this application is a request for consent to access the MFNRF or receive a letter of support stating our approval and consent of this project at a regional level.

By checking “Collective/Nation Consent” you are acknowledging that you will be seeking consent from the First Nation(s), Provincial territorial organization, tribal council, or other collective organization to do research within their Nation, territory, or jurisdiction via partnership, BCRs, and/or letters of support.

By checking “Individual Consent” you are acknowledging that you will be seeking consent from individual participants involved in this research via an Informed Consent process.

Please describe how consent will be gathered (written or oral), how you will ensure that participants understand the consent process (translation to an appropriate First Nations language/dialect, use of non-technical terms, guiding them through the consent form, etc.), and when you will gather consent.

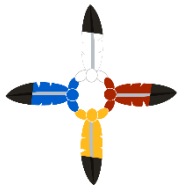
Please attach copies of consent materials to this application, including translated copies.



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Please describe the conditions of consent:
<i>In this section you will describe how you went about receiving Individual and/or Nation/Collective consent.</i>
<i>For individuals this includes but is not limited to when you will be seeking consent, how ongoing consent will be maintained, who will explain the consent form and how that will be done, where will consent be obtained and under what circumstances, if consent will be available in a First Nations language and/or in a way that is easily understood, if oral consent will be provided if requested, and if a participant does not have the capacity to give consent, how will consent be gathered on their behalf?</i>
<i>For Nation/Collective this includes but is not limited to when you sought consent, who you sought consent with and if they had the right to provide consent, how ongoing consent will be maintained, where will consent be obtained and under what circumstances, if consent was available in a First Nations language and/or a way that is understood, and if oral consent will be available if requested. If consent is collective/Nation based, was the Nation consulted and did they provide approval for consent to be provided on their behalf?</i>
<i>In addition, please describe the process for withdrawing consent.</i>

Privacy and Confidentiality
For primary data sources, will you be collecting personal identifiers?
<input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please provide details. <i>In this section, you will provide details on what identifiers you will be collecting, why they are being collected, and how you will protect the identities of participants.</i>
For datasets held at MCHP:
Is the data you are accessing identifiable? <input type="checkbox"/> Yes <input type="checkbox"/> No Is there a possibility that data linkages will generate identifiable information? <input type="checkbox"/> Yes <input type="checkbox"/> No Please provide details. <i>Please describe the data sets at MCHP you will be using.</i> <i>If data linkages generate identifiable information how you will protect the identities of those within the data sets.</i>
For other data sources (e.g. repositories, other databases, other projects, etc.):
Is the data you are accessing identifiable? <input type="checkbox"/> Yes <input type="checkbox"/> No Is there a possibility that data linkages will generate identifiable information? <input type="checkbox"/> Yes <input type="checkbox"/> No Please provide details. <i>Describe your data sources.</i> <i>If data linkages will generate identifiable information how you will protect the identities of those within the data sets.</i>
Will you be collecting biological data?
<input type="checkbox"/> Yes <input type="checkbox"/> No If yes, please provide details.



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In this section you will provide details on how you will be collecting, storing, protecting, and discarding biological samples. In addition, please describe any associated cultural protocols involved in the return or destruction of biological samples if applicable.

What is the process to ensure the privacy and confidentiality of the participants and data? What is in place in the chance a breach occurs?

In this section, please describe the protocols in place for ensuring privacy, confidentiality, and the steps to be taken if a breach were to occur. You can include here any institutional privacy and confidentiality protocols.

Benefit to First Nations Peoples and/or Manitoba First Nations

Please describe benefits of this project to First Nations people, their Nations, and representative bodies (Includes expected outcomes, impacts on practice/policy, etc.):

In this section, please share any of the potential benefits of this project to First Nations and/or the First Nation(s) you work with. This includes but is not limited to expected outcomes of the project, impacts on practice/policy, development of programming, supports, resources, and infrastructure in the Nation(s).

Which of the following committees/circles are involved in your project:

- Advisory/Guidance Committee/Circle
- Steering Committee/Circle
- Data Access Committee/Circle
- Other Committee/Circle

Please provide details on the committee(s), who will be involved, and what their role(s) in the project will be. Please note that if you do not form any of the above committees, HIRGC will not accept your application as it is imperative to do research in a good way to have a circle of stakeholders and knowledge keepers guiding your work.

An advisory committee is a collection of individuals who bring knowledge and skills that can guide the project. This committee serves to make recommendations and provide key information to the research team and can be involved in project creation and planning, implementation, reviewing project approaches, methods, and tools.

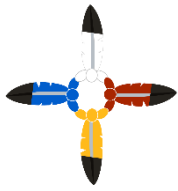
A steering committee is a collection of project stakeholders, experts, and authority figures who have a stake in how a research project is managed. They serve to provide governance and guidance as to the direction, scope, budget, timeline, and methods of a research project.

A data access committee is a collection of individuals who have a stake in how the research data is analyzed and findings are shared – either throughout or once a project is complete.

Other committees may be specific subcommittees that help guide certain aspects of the project. This can include youth, elders, participants, parents, and other committees.

How are First Nation(s) people and Nation members actively involved in your research?

In addition to building skills and capabilities to do research, it is important during the research process to involve First Nations or the First Nation(s) that you are working with in a meaningful way that acknowledges the knowledge and skills they carry. There are other ways that research can invest in



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the Nation whether that be through hiring local, fair, and equitable compensation for their knowledge-sharing, contributions, and support, mentoring or training, and investing in programming and infrastructure.

Have you worked with the First Nation(s) and/or your committee(s) to determine and define any potential harms that may be caused by participating in the research or from the data/results?

Yes No

Please describe this process and the outcomes.

In addition to identifying the benefits of research, it is important to identify the potential harms (mental, emotional, spiritual, cultural, and physical) and contributing contexts so that all involved can be aware of them and harms can be mitigated throughout and after the research process. It is also important that harms be defined from the perspective of those most impacted by the research, as there may be times where research is not deemed harmful from the researcher's perspective but harmful from an individual or First Nations perspective. By describing the potential harms from all perspectives, you are ensuring that your research is being done in a respectful way and from a harm reduction approach.

Describe the support systems in place for those that you will be engaging with before, during, and after the project.

Please describe what is being done to mitigate any potential harm and how you will go about resolving any issues that may arise. This includes the provision of and access to mental health supports or elders, counselling, cultural supports, trauma supports, ongoing resources, and support during the research and after it is complete – HIRGC does not approve research that only provides supports during the research process.

First Nations Principles of OCAP®

Ownership

Ownership states that a Nation or group owns information collectively in the same way that an individual owns his or her personal information. This is distinct from concepts of stewardship. Stewardship implies a caretaking or holding of rather than a legal right to data. It is important that you establish who owns the data and findings of this research as early in the research process as possible. Ownership of data and research findings includes the ability to access, create, modify, derive benefit from, and share. It implies both control of and responsibility over data and findings.

First Nations hold a collective ownership over their knowledge, data, and information derived from both. It is important that this collective ownership is acknowledged, recognized, and abided by at all stages of the research.

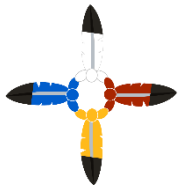
In the following Ownership sections, you will clarify how First Nations people, their Nations, and representative bodies hold ownership over research and its associated data and findings and how that ownership is acknowledged in knowledge translation and communications.

Have you established ownership of the data and findings from this project?

Yes No

If yes, who owns the data and findings and why? If not, how will you establish ownership and why?

In this section you will clarify what and how the research is owned by those involved (researcher, funder, institutions, organizations, Nations, and individuals).



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This includes how research data, findings, and publications will be owned in accordance with OCAP®, institutional policies, publication guidelines, and intellectual property rights such as copyright. Ownership over each area or the entirety of the project will determine who has rights to reproduce or disseminate this work.

For example, academic institutions may own the copyright in research data originated by research staff, with the author having the right to reproduce or disseminate the work. Students may own copyright to materials generated as part of their studies. Other parties, such as First Nations organizations or Nations, who participate in research collaboration may have ownership due to data sharing or other agreements. However, within First Nations-based research practices, individual and collective ownership is also incredibly important, therefore it is imperative to define what is owned by who within and throughout the research project.

If the First Nation(s) or individuals involved in this project have consented, how will you acknowledge them in publications, reports, and presentations? (Includes Nation, partners, and participants)

Contributor Co-Author/Co-Presenter

Please provide details.

This applies to First Nations, organizations, and individuals.

By checking “Contributor” you imply that the First Nation(s) you are working with contributed their knowledge and have given permissions to use and share it in findings. This includes those on your committees.

By checking “Co-Author/Co-Presenter” you imply the co-creation of knowledge with the First Nation(s) you are working with and that they have co-authorship, and therefore co-ownership, over the findings.

When naming First Nation(s) and individuals as contributors, co-authors, and co-presenters, you acknowledge their expertise.

It is important to recognize ownership by acknowledging them as contributors, co-authors, or co-presenters in findings. Active involvement in the sharing and dissemination of research findings communicates with those consuming your research the importance of First Nations ownership.

Control

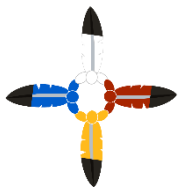
Throughout history, especially the history of research with First Nations people, their Nations, and representative bodies have had little control over their narratives, how information about them is collected, how it is used, and how it is shared.

In the following sections, you will clarify First Nations people, their Nations, and representative bodies will have control over all aspects of information and data management from collection to use, disclosure, and destruction.

If applicable, has a data/information sharing agreement been developed? (Please attach)

Yes No In Progress

If yes/in progress, please provide details. If not, why not?



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Data/information sharing agreements are necessary whenever you are planning to engage in sharing the data or information gathered in a research project with parties outside of the research team and partners.

It is good practice to have an information/data sharing agreement. It sets out the purpose of the data sharing, what happens at each stage, sets standards for data sharing, and helps all involved be clear about their roles and responsibilities to the information/data and to one another. This includes during and after data collection and the research project. Data includes but is not limited to documents, spreadsheets, audio and visual components, transcripts and codebooks, biological data, databases, models, intangible and tangible cultural heritages/knowledges, methodologies, and procedures and protocols.

If an information/data sharing agreement has been developed or is in progress, please provide a summary of the agreement such as who are the signatories, what is the purpose and aims of the agreement, why the agreement is necessary/important, the benefits of the agreement, what is being shared, and any other important or relevant governance arrangements.

If an information/data sharing agreement has not been developed share details on how you plan on developing an agreement such as what will be included and who will be involved.

If you have chosen not to develop one, please share why you have chosen not to. How will First Nations people, their Nations, and representative bodies control and govern their data? How will decisions be made for use, access, dissemination of, and destruction of data? Please elaborate.

Describe the tools or processes you will use to ensure accountability to the First Nation(s) so they are informed of the project details and are participants in the project development? (Includes but is not limited to reporting, Advisory groups, meetings, Nation feedback, decision-making, etc.)

In addition to information and data sharing agreements, there are other ways in which the First Nations people, their Nations, and representative bodies involved can have control over the research. This can occur through several accountability measures which hold researchers accountable to First Nations and their needs and goals within and throughout the research process. This includes, but is not limited to, how information is reported back to the Nation, involvement of committees, Nation meetings and opportunities for feedback, and other decision-making processes.

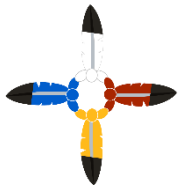
In this section you will provide details on any other accountability processes you plan to include in your research project that will allow for greater First Nations control over narratives, how information is collected, used, and shared.

For the removal, repatriation, or destruction of data:

Please describe the details of what will happen with data at the completion of the project.

If the First Nation(s) you are working with (collectively or individually) requests their data (including biological data) be removed from the research, repatriated, or destroyed, what will the process be to do so?

The request for research data to be removed, repatriated, or destroyed can be challenging for researchers but it is important to respect the decisions of First Nations people, their Nations, and representative bodies on how their data is used. This decision can include one or all (removal,



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repatriation, or destruction). Provide details on what will be involved if those you are working with request the removal, repatriation, or destruction of research data.

Removal means the omission of specified data from the data pool and overall findings.

Repatriation means the return of specified data in all forms (electronically and physically) to the First Nation – this may include the removal of the data from the data pool and overall findings.

Destruction means the electronic erasure and physical destruction of all the data in the hands of the researchers. This may happen after the repatriation of original copies to the First Nation at their request. This may also include the removal of the data from the data pool and overall findings. In addition, specific processes for destruction may be requested such as the use of ceremony.

Access

First Nations people, their Nations, and representative bodies must have access to information and data about them regardless of where it is held. It is within their rights to manage and make decisions about who else can access this information.

In the following sections, you will clarify how First Nations people, their Nations, and representative bodies will be able to access their information and data throughout and following the research process.

Clarify how the First Nation(s) you are working with will be informed of their ability to access their data, findings, and final products of the research?

It is important that First Nations people, their Nations, and representative bodies are made aware of how they can access their own information and data. Often, barriers exist that make access to their own information and data difficult. It is important that researchers make it known in a clearly understood way how those involved in research can access their data. This can be done during information sharing sessions, during the consenting process, and as an ongoing process throughout the research.

Clarify how the First Nations people, their Nations, and representative bodies will be able to access their data, findings, and other products of research (reports, presentations, publications)? Please describe your knowledge exchange/translation plan.

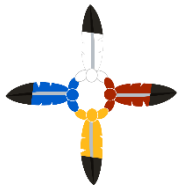
In addition to being aware of their ability to access data, findings, and other research products, the process of accessing is equally important. This includes both information requested, and information planned on being shared via your knowledge exchange and translation plan.

In this section you will provide further details on how you plan on sharing data, findings, and other products of the research.

Will there be secondary users of this data, or will the data be shared outside of the project?

Yes No

If yes, please provide details on how this was determined and who makes decisions around points of access.
Too often First Nations data (e.g., quantitative, qualitative, clinical, biological) is shared without consent.



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If the data collected is to be used outside of your research project, please provide details on who you expect to be a secondary user of this data, how this was decided, and who made the decision around this secondary use of data.

For example, First Nations may have their own protocols governing biological data, as such, the HIRGC also requires First Nations biological data protocols be included in the processes to determine if secondary use of biological data is appropriate.

Possession

Possession of data includes both the stewardship (caretaking of) and physical holding of data. While data is owned by First Nations people, their Nations, and representative bodies, there are cases in which the data cannot be held (electronically or physically) due to several reasons. Ideally First Nations data would be held by First Nations people, their Nations, and representative bodies as it puts data within First Nations jurisdiction and control.

In the following sections, you will clarify where data for your project will be held and the decision-making processes around possession.

Where will the data be held and how long will it be held? Please describe how these decisions were made.

Data can be held electronically or physically in several ways. Please describe the location of where the data for your project will be held, the mechanisms in place to protect the data, and how long the data will be held for. In addition, please provide details on who made these decisions and the reasoning behind the decisions.

If the data is not held by First Nations:

Will the First Nation(s) involved have stewardship of the data? Yes No

Is there a plan in place to repatriate any data back to the First Nation(s) you are working with? Yes No

Please elaborate:

Ideally, First Nations people, their Nations, and representative bodies would have physical possession over their own data, however, there are cases where this is not possible. If this is the case, please provide additional information on how they will be involved in the stewardship of the data despite not having physical possession over it.

In addition, it is important to engage in the process of repatriating data to First Nations possession. If there is a plan to repatriate data, please provide further details on how this will be done such as working with First Nations people, their Nations, and representative bodies to develop the capability to house their own data. If there is not a plan to repatriate the data, please describe why this will not be done.

If available, please include the following:

- Full project proposal
- Copies of REB submissions
- Copies of TCPS2/TCPS3 and OCAP certificates
- Copies of any Letters of Support or BCRs from partners and Nations
- Copies of any consent forms, surveys, question guides, or any other information gathering tools
- Copies of any Information Sharing Agreements