

<b>Title</b>	<b>Indigenous Research</b>
<b>SOP Code</b>	502.02
<b>Effective Date</b>	September 2023

### Site Approvals

<b>Name and Title</b>	<b>Signature</b>	<b>Date</b>
Dr. Craig Kuziemy, Associate Vice-President, Research	<i>original signed</i>	October 2020
Dr. Craig Kuziemy, Associate Vice-President, Research	<i>original signed</i>	December 2020
Dr. Craig Kuziemy, AVPR	<i>original signed</i>	September 2023

## 1.0 PURPOSE

This standard operating procedure (SOP) describes the review procedure for research involving First Nations, Inuit and Métis persons as research participants.

## 2.0 SCOPE

This SOP pertains to Research Ethics Boards (REB) that review human participant research in compliance with applicable policies and guidelines.

## 3.0 RESPONSIBILITIES

All Researchers, REB members, REB Office Personnel and Institutional representatives are responsible for ensuring that the requirements of this SOP are met.

Researchers are responsible for ensuring that research involving First Nations, Inuit or Metis persons as research participants involve community engagement and other procedures as per TCPS and this SOP.

The REB Chair or designee or REB member(s) is responsible for ensuring appropriate review of human research projects involving First Nations, Inuit and Métis persons.

Institutional representatives and REB Office Personnel are responsible for ensuring that sponsor/funder policies and research agreements are in place, as required, prior to commencement of the research project.

## **4.0 DEFINITIONS**

See Glossary of Terms.

## **5.0 PROCEDURE**

First Nations, Inuit and Métis communities have unique histories, cultures and traditions. They also share some core values such as reciprocity – the obligation to give something back in return for gifts received – which they advance as the necessary basis for relationships that can benefit both Indigenous and research communities.

Research involving Indigenous peoples in Canada has been defined and carried out primarily by non-Indigenous researchers. The approaches used have not generally reflected Indigenous world views, and the research has not necessarily benefited Indigenous peoples or communities. As a result, Indigenous peoples continue to regard research, particularly research originating outside their communities, with a certain apprehension or mistrust.

While the landscape of research involving Indigenous peoples is rapidly changing, building reciprocal, trusting relationships will take time. It is therefore necessary for Researchers and REBs to follow additional requirements and principles as set forth in TCPS2 Chapter 9, *Research Involving the First Nations, Inuit and Métis Peoples of Canada*. It has drawn on prior work, both within Canada and internationally, that recognizes the interests of Indigenous peoples who participate in research and are affected by its results.

The requirements outlined in this SOP are in addition to (not instead of) those required for all human participant's research.

### **5.1 Community Engagement and Collaboration in Indigenous Research**

- 5.1.1 Where the research is likely to affect the welfare of an Indigenous community, or communities, to which prospective participants belong, researchers shall seek engagement with the relevant community;
- 5.1.2 The nature and extent of community engagement in a project shall be determined jointly by the researcher and the relevant community, and shall be appropriate to community characteristics and the nature of the research;
- 5.1.3 Researchers shall advise their REB how they have engaged, or intend to engage, the relevant community. Alternatively, researchers may seek REB approval for an exception to the requirement for community engagement, on the basis of an acceptable rationale;
- 5.1.4 Researchers and REBs shall recognize Indigenous organizations, including First Nations, Inuit and Métis representative bodies, and service organizations and communities of interest, as communities. They shall also recognize these groups through representation of their members on ethics review and oversight of projects, where appropriate;
- 5.1.5 Where a proposed research project is to be conducted on lands under the



jurisdiction of a First Nations, Inuit or Métis authority, researchers shall seek the engagement of formal leaders of the community;

- 5.1.6 Where alternatives to securing the agreement of formal leadership are proposed for research on First Nations, Inuit or Métis lands or in organizational communities, researchers should engage community processes and document measures taken, to enable the REB to review the proposal with due consideration of complex community authority structures;
- 5.1.7 Researchers have an obligation to become informed about, and to respect, the relevant customs and codes of research practice that apply in the particular community or communities affected by their research. Inconsistencies between community custom and TCPS2 requirements should be identified and addressed in advance of initiating the research, or as they arise;
- 5.1.8 As part of the community engagement process, researchers and communities should consider applying a collaborative and participatory approach as appropriate to the nature of the research, and the level of ongoing engagement desired by the community.

## **5.2 Critical Inquiry**

- 5.2.1 Research involving Indigenous peoples that critically examines the conduct of public institutions, First Nations, Inuit and Métis governments, institutions or organizations or persons exercising authority over First Nations, Inuit or Métis individuals may be conducted ethically, notwithstanding the usual requirement of engaging community leaders.

## **5.3 Research Agreements**

- 5.3.1 Where a community has formally engaged with a researcher or research team through a designated representative, the terms and undertakings of both the researcher and the community should be set out in a research agreement before participants are recruited.

## **5.4 Mutual Benefits in Research and Strengthening Research Capacity**

- 5.4.1 Where the form of community engagement and the nature of the research make it possible, research should be relevant to community needs and priorities. The research should benefit the participating community (e.g., training, local hiring, recognition of contributors, return of results), as well as extend the boundaries of knowledge;
- 5.4.2 Research projects should support capacity building through enhancement of the skills of community personnel in research methods, project management, and ethics review and oversight.



## **5.5 Recognition of the Role of Elders and Other Knowledge Holders**

5.5.1 Researchers should engage the community in identifying Elders or other recognized knowledge holders to participate in the design and execution of research, and the interpretation of findings in the context of cultural norms and traditional knowledge. Community advice should also be sought to determine appropriate recognition for the unique advisory role fulfilled by these persons.

## **5.6 Privacy and Confidentiality**

5.6.1 Researchers and community partners shall address privacy and confidentiality for communities and individuals early on in the community engagement process. The extent to which limited or full disclosure of personal information related to the research is to be disclosed to community partners shall be addressed in research agreements where these exist. Researchers shall not disclose personal information to community partners without the participant's consent.

## **5.6 Interpretation and Dissemination of Research Results**

5.6.1 Researchers should afford community representatives engaged in collaborative research an opportunity to participate in the interpretation of the data and the review of research findings before the completion of the final report, and before finalizing all relevant publications resulting from the research.

## **5.7 Intellectual Property Related to Research**

5.7.1 In collaborative research, intellectual property rights should be discussed by researchers, communities and institutions. The assignment of rights, or the grant of licenses and interests in material that may flow from the research, should be specified in a research agreement (as appropriate) before the research is conducted.

## **5.8 Collection of Human Biological Materials**

5.8.1 As part of community engagement, researchers shall address and specify in the research agreement the rights and proprietary interests of individuals and communities, to the extent such exist, in human biological materials and associated data to be collected, stored and used in the course of the research.

## **5.9 Secondary Use of Information or Human Biological Materials Identifiable as Originating from Indigenous Communities or People**

5.9.1 Secondary use of data and human biological material identifiable as originating from an Indigenous community or peoples is subject to REB review.

5.9.2 Researchers shall engage the community from which the data or human biological materials and associated identifiable information originate, prior to initiating secondary use where:

- secondary use has not been addressed in a research agreement and has not been authorized by the participants in their original individual consent; or
- there is no research agreement; and
- the data are not publicly available or legally accessible.

5.9.3 Individual consent for the secondary use of identifiable information is required unless the REB agrees that consent may be waived.

## **5.10 Secondary Use of Anonymous Information or Human Biological Materials**

5.10.1 REB review is not required for research involving only anonymous data sets or anonymous human biological materials, and associated data, that cannot be identified as originating from a specific Indigenous community or a segment of the Indigenous community at large.

5.10.2 REB review is required where the researcher seeks data linkage of two or more anonymous data sets or data associated with human biological materials and there is a reasonable prospect that this could generate information identifiable as originating from a specific Indigenous community or a segment of the Indigenous community at large.

## **6.0 REFERENCES**

See References.

## **7.0 REVISION HISTORY**

<b>SOP Code</b>	<b>Effective Date</b>	<b>Summary of Changes</b>
502.00	October 8 2020	Original version
502.01	December 2020	Added direction regarding the secondary use of anonymous information
502.02	September 2023	Reviewed, no revisions needed