

Guideline for Research in Collaboration with Indigenous Peoples

Introduction

The Royal Commission on Aboriginal Peoples (1992) raised awareness within the academic research community that ethical review of research topics, methods, and dissemination strategies related to Indigenous research must go beyond what is normally required for academic study. This is critical to address power imbalances and a long history of problematic research, and to ensure respect for Indigenous knowledge in the research. It is important to ensure that the Ownership, Control, Access and Possession (OCAPTM) principals developed by The First Nations Information Governance Committee are respected.

In response to the experiences of Lambton College researchers working with Indigenous Peoples or [1] contexts, considering the Truth and Reconciliation Act (see definition below) and in light of the Tri-Council Policy Statement, 2nd Edition (hereafter “the policy”), the Lambton College Research & Innovation department took on the task of articulating research guidelines for implementation of Chapter 9 of the policy. A group of Indigenous Peoples and Indigenous researchers, including graduate students, met various times to discuss relevant issues including how to partner with First Nation communities in research in depth and to draft this set of guidelines related to research involving Indigenous Peoples of Canada. These guidelines are intended to inform researchers as they prepare for and review research to be conducted in an Indigenous Peoples context and/or with Indigenous Peoples.

Lambton College particularly recognizes the unique considerations necessary for conducting research in each, distinct Indigenous Peoples context. In addition, we are aware of the concerns of many Indigenous Peoples about the ways research has been done in the past and is taking place in their communities as it was not always done respectfully and with the permission and consultation/collaboration of the communities. As renowned decolonizing scholar, Linda Tuhiwai Smith has clearly stated in her 1999 text *Decolonizing Methodologies*, “The term “research” is inextricably linked to European imperialism and colonialism. The word itself, “research”, is probably one of the dirtiest words in the Indigenous world’s vocabulary.” Cognizant of this historical context, the guidelines are at least partly an attempt to redress this situation.

Indigenous Peoples, remain distinct within Canada and, for this reason, deserve separate attention when it comes to research. In light of their histories, intensive preparation and culturally appropriate protocol that is defined by each community are required of each researcher who chooses to do their work in indigenous contexts.

a) Definitions:

1. Indigenous Peoples and Communities

Indigenous is a collective name for the original peoples across the world. There are more than 630 First Nations communities in Canada, which represent more than 50 Nations and 50 Indigenous languages.

2. Lead Researcher

A Faculty or Adjunct Researcher of Lambton College who will oversee the activities of the applied research project and supervise the research team to carry out the project in collaboration

with the project partner. Lambton College prefers to have a person who is Indigenous as the research lead on projects involving Indigenous Peoples.

3. Research Student

A student of Lambton College who has been hired to work under the Lead Researcher to conduct the applied research project activities in collaboration with the project partner. Lambton College encourages the hiring of students who are Indigenous to participate in research projects involving Indigenous Peoples and there is a preference by the College to hire students who are Indigenous for these positions.

4. Tri-Council Policy Statement (TCPS)

All projects involving people must be approved through a Research Ethics Board and consultation is a requirement under Tri-Council Policy Statement (TCPS). The Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS or the Policy) is a joint policy of Canada's three federal research agencies – the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council of Canada (SSHRC), or “the Agencies.” Ethical Conduct for Research Involving Humans – Chapter 9, Research Involving Indigenous Peoples of Canada is the governing body of the Research Ethics Board.

Chapter 9 is designed to serve as a framework for the ethical conduct of research involving Indigenous Peoples. It is offered in a spirit of respect. It is not intended to override or replace ethical guidance offered by Indigenous Peoples themselves. Its purpose is to ensure, to the extent possible, that research involving Indigenous Peoples is premised on respectful relationships. It also encourages collaboration and engagement between researchers and participants.

Ethical Conduct for Research Involving Humans was launched in December 2010. TCPS 2, as it is commonly known, updated and expanded the original (1998) version of TCPS1. The Panel on Research Ethics (PRE) and the Secretariat on Responsible Conduct of Research that supports PRE, strive to ensure that TCPS 2 is current and that the guidance it provides is as clear as possible. In this, they have always received the full support of the federal research agencies (CIHR, NSERC and SSHRC) that are jointly responsible for the TCPS, and for PRE and the Secretariat.

5. Research Ethics Board (REB)

Lambton College has an internal Research Ethics Board (REB). The REB is comprised of internal Lambton College staff and faculty members, as well as members of the Sarnia-Lambton community. The Research Ethics Board currently has a member who is Indigenous and is involved in the evaluation of all REB submissions that include the involvement of Indigenous Peoples. If for any reason the REB member who is Indigenous is unable to continue on the board the REB will actively pursue a replacement who is Indigenous. The role of the REB is to ensure that the rights of human participants in research are respected and protected, through ensuring that individuals receive sufficient information, which can be easily understood, and ensuring that appropriate strategies are in place to protect participants from potential adverse consequences of the research. Lambton College and the Lambton College Research Ethics Board (REB) are committed to ensuring research at the College is conducted with the highest ethical standards. Together, they promote the ethical conduct of research and adhere to the federal mandate - Tri-council Policy Statement: Ethical Conduct for Research Involving Human (2014) or TCPS 2 and

College Research Practices - to ensure that the rights of human participants in research are respected and protected.

b) General Principles:

1. Indigenous communities need to be engaged

When conducting research involving Indigenous Peoples, Lambton College researchers will follow the First Nations Principles of OCAP®. “There are four components of OCAP®: Ownership, Control, Access and Possession. OCAP® respects that rights of First Nations communities to own, control, access, and possess information about their Peoples is fundamentally tied to self-determination and to the preservation and development of their culture.” [25]

One of the key principles of research involving Indigenous Peoples is the engagement of the community or communities within which the research will be conducted. Specifically, researchers conducting research where the research is likely to affect the welfare of an Indigenous community, or communities, to which prospective participants belong, researchers shall seek engagement and permission to conduct the research from the proper authorities with the relevant community.[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. [3] Indigenous communities who possess research guidelines and expectations will be consulted and adhered to.

Wherever possible and appropriate to the nature of the research, researchers should consider a collaborative and/or participatory action approach to their research. [4] Similarly, 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] The project should seek to strengthen capacity building within the community through the enhancement of the skills of community personnel in research methods, project management, and ethical review and oversight. [6]

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2. Researchers must recognize and engage Indigenous Peoples organizations, service organizations and communities of interest as communities.

For the purposes of community engagement and collaboration in research undertakings, researchers and REBs shall recognize Indigenous Peoples organizations, including Indigenous representative bodies, and service organizations and communities of interest, as communities. They shall also recognize these groups through representation of their members on ethical review and oversight of projects.

In engaging territorial or organizational communities, researchers should ensure, to the extent possible, that they take into consideration the views of all relevant sectors – including individuals and subgroups who may not have a voice in the formal leadership. Groups or individuals whose circumstances make them vulnerable may need or desire special measures to ensure their safety in the context of a specific research project. Those who have been excluded from participation in the past may need special measures to ensure their inclusion in research. [8] It is important to ensure that these groups have a say in the kind of research that is completed

3. A community engagement plan must be developed and provided to the REB for review.

When proposing research expected to involve Indigenous participants, researchers shall advise their REB how they have engaged, or intend to engage, the relevant community. Generally, it is advised that the REB be notified via a community engagement plan whereby the proposed methods of engagement are clearly articulated. [9]

In those communities which have a recognized governing authority and/or have community organizations with recognized authority, researchers may formalize their engagement with the community through a research agreement. 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. [10]

4. Indigenous governing authorities must be respected.

Where a proposed research project is to be conducted on lands under the jurisdiction of a First Nations, researchers shall seek the engagement of formal leaders of the community. In such instances, both review by the institutional REB and the responsible community body recognized by the First Nations, Métis or Inuit authority is required.[11] Where alternatives to securing the agreement of formal leadership are proposed for research on First Nations, Métis and/or Inuit 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. [12]

Further, 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. Researchers must first understand cultural protocol for engaging with Elders and if possible include some form of compensation for their participation. Community advice should also be sought to determine appropriate recognition for the unique advisory role fulfilled by these persons. [13]

It is important that researchers understand the community context within which they are conducting their research. 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 this Policy should be identified and addressed in advance of initiating the research, or as they arise. [14]

Note, however, that institutional REB review and approval will be required regardless of approval by Indigenous Peoples governing authorities' and/or organizations approval. Specifically, research ethics review by community REBs or other responsible bodies at the research site will not be a substitute for research ethics review by institutional REBs, and will not exempt researchers affiliated with an institution from seeking REB approval at their institution, subject to Article 8.1.

Additionally, governing bodies, Acts and The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) should be respected and followed.

5. Researchers who wish to be exempt from the requirement of community engagement must provide a written rationale to the REB for review.

There are circumstances when community engagement may not be possible or appropriate. Researchers who wish to proceed without a community engagement plan must provide a detailed rationale to the REB for review and consideration. [15]

Note, however, that a rationale need not be required for specific circumstances and/or research methods. For example, “...where research relies only on publicly available information or on legally accessible information as defined in Article 2.2 (TCPS), community engagement is not required. Where the information can be identified as originating from a specific community or a segment of the Indigenous Peoples community at large, seeking culturally informed advice may assist in identifying risks and potential benefits for the source community.” [16]

6. Research involving critical inquiry within or about Indigenous Peoples communities, may not require community engagement and/or community consent.

Research involving Indigenous Peoples that critically examines the conduct of public institutions, First Nations, Métis and Inuit governments, institutions or organizations or persons exercising authority over First Nations, Métis or Inuit individuals may be conducted ethically, notwithstanding the usual requirement of engaging community/organizational leaders. [17] However, irrespective of the fact that community engagement may not be required, researchers must remain respectful of the community as they conduct their research.

7. Research involving secondary data analysis – and in particular the use of biological materials – is subject to research ethics review.

Prospective research and secondary use of data and human biological materials for research purposes is subject to research ethics review. Regardless of the source, if researchers wish to conduct secondary data analysis on data that is “...identifiable as originating from a specific Indigenous Peoples community or segment of the Indigenous Peoples community at large, researchers shall, through community engagement as appropriate, address any potential inadvertent identification of communities, or misuse of traditional knowledge.” Thus, unless specifically authorized through an appropriate consent process, researchers cannot use data for secondary purposes without further community engagement, consent and ethics review and approval.

Specifically, if the data and/or biological materials are “identifiable as originating from an Indigenous Peoples’ community or peoples is subject to REB review” and/or there is no formal research agreement for additional use and/or the data is not publicly available researchers must engage the community and provide documentation of such engagement to the REB prior to use of said data. Further, individual consent for the secondary use of identifiable information is required unless the REB agrees that one of Articles 5.5 or 5.6 or Articles 12.3 or 12.4 may apply. [18]

Given the historical context, the collection of biological samples requires careful consideration by researchers and extensive engagement and consultation with the community from which the data and samples will be collected. Where collection of biological materials forms part of the research project, researchers shall engage the community to “...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.” [19]

Special care and consideration shall be given by researchers as it pertains to the privacy and confidentiality of the participants and their data. “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, as set out in Article 3.2(i).” [20]

Finally, REB review is required where the researcher seeks data linkage of two or more anonymous datasets 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 Peoples community or a segment of the Indigenous Peoples community at large. [21]

8. Researchers must address the issues of intellectual property, data interpretation and dissemination of results prior to commencement of research.

The issue of intellectual property [22] should be addressed during the process of community engagement. Ideally the issue should be addressed formally in either a research agreement or community engagement plan. “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.” [23]

Further, prior to the publication and dissemination of research, community members and the First Nation Council should be provided with the opportunity to review the research results. Specifically, “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.” [24] During this process it will be ensured that the community representatives possess the required skill set to analyze the results.

c) References

1. We use the term Aboriginal as in the 1982 Constitution of Canada. While we recognize its limitations, our intention is that it includes all those individuals and community members who claim ancestry based in the lands we now call Canada. We also look to the etymology of the word from the Latin a/ab meaning “out of” or “from”, and “origin” as it relates to the original peoples.
2. TCPS Article 9.1
3. TCPS article 9.2
4. TCPS article 9.12
5. TCPS article 9.13
6. TCPS article 9.14
7. TCPS article 9.4
8. TCPS article 9.6
9. Generally TCPS article 9.10
10. TCPS article 9.11
11. TCPS article 9.3
12. TCPS article 9.5
13. TCPS article 9.15
14. TCPS article 9.8
15. TCPS article 9.10
16. TCPS article 9.21

17. TCPS article 9.7
 18. TCPS article 9.20
 19. TCPS article 9.19
 20. TCPS article 9.16
 21. TCPS article 9.22
 22. With respect to the matter of intellectual property, for a more comprehensive statement on what intellectual property is or may be considered within the Indigenous Peoples' context, please consult the AFN guidelines on research ethics at: http://www.afn.ca/uploads/files/rp-research_ethics_final.pdf
 23. TCPS article 9.18
 24. TCPS article 9.17
 25. The First Nations Principals of OCAP® <https://fnigc.ca/ocap>
- Please note that the main part of the above guideline was adopted from York University's "Guidelines for Research Involving Indigenous Peoples" (date?). <http://research.info.yorku.ca/guidelines-for-research-involving-aboriginalindigenous-peoples/>