## TCPS 2 (2018) – Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada

# C. Applying Provisions of This Policy in Indigenous Contexts

Requirement of Community Engagement in Indigenous Research

#### Article 9.1

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. The conditions under which engagement is required include, but are not limited to:

- a. research conducted on First Nations, Inuit or Métis lands;
- b. recruitment criteria that include Indigenous identity as a factor for the entire study or for a subgroup in the study;
- c. research that seeks input from participants regarding a community's cultural heritage, artefacts, traditional knowledge or unique characteristics;
- research in which Indigenous identity or membership in an Indigenous community is used as a variable for the purpose of analysis of the research data; and
- e. interpretation of research results that will refer to Indigenous communities, peoples, language, history or culture.

Community engagement as defined in this Policy can take varied forms. In geographic and organizational communities that have local governments or formal leadership, engagement prior to the recruitment of participants would normally take the form of review and approval of a research proposal by a designated body. In less structured situations (e.g., a community of interest), a key consideration for researchers, prospective participants, and REBs is determining the nature and extent of community engagement required. In some situations, if the REB is satisfied that participants are not identified with a community or that the welfare of relevant communities is not affected, the REB may waive the requirement of a community engagement plan (<u>Article 9.10</u>). In these cases, consent of individuals is sufficient to participate.

## Nature and Extent of Community Engagement

Communities lacking the infrastructure to support pre-research community engagement should not be deprived of opportunities to participate in guiding research affecting their welfare (<u>Article 9.14</u>).

The following list, which is not exhaustive, provides examples to illustrate the forms of community engagement that might be appropriate for various types of research.

- 1. Research directly involving a community on First Nations, Inuit or Métis lands with a formal governance structure. For example, a project that examines the incidence of diabetes in Pond Inlet, Nunavut, or the impact on Inuit health of contaminants in animals and plants used for country food.
  - Permission of the Nunavut Research Institute that carries authority to approve research in Nunavut is required. Agreement of the hamlet council in Pond Inlet will normally be a condition of approval. The local health committee may co-manage the project.
- Research involving Indigenous people who comprise a sizeable proportion of the study or community and where Indigenous-specific conclusions are intended. For example, a comparative study of access to public housing in Prince Albert, Saskatchewan.
  - First Nations in the district, represented by their tribal council, the local Métis association, and urban Indigenous and women's organizations, may partner with the Prince Albert city council to sponsor, implement and use the results of the housing study.
- 3. Research focusing on a larger community that is known to include Indigenous people (regardless of their proportion), and where Indigenous-specific conclusions are anticipated. For example, a study of student retention in high schools in the Sault Ste. Marie district of Ontario.
  - A committee representing First Nations, Métis organizations and urban Indigenous people whose children may be affected by the study may be convened to advise the District Board of Education and the researchers involved.
- 4. Research involving First Nations, Inuit or Métis people who comprise a sizeable proportion of the larger community that is the subject of research even if no Indigenous-specific conclusions will be made. For example, research on employment development programs serving residents of the inner city of Winnipeg in Manitoba.
  - Indigenous service agencies or political organizations may be engaged to help recruit Indigenous participants and secure community representation on an oversight committee, and to ensure cultural sensitivity in collecting and interpreting data on employment program impacts.
- 5. Interviewing a sample of individuals of Indigenous ancestry across Canada on the impact of a policy on their lives, where the results are not attributable to, or likely to affect, the community or communities with which they may identify. For example, survey research on the implementation of *Indian Act* provisions requiring ministerial approval of an "Indian's" will.

- First Nations, Inuit and Métis persons, whether or not they identify as members of an Indigenous community, enjoy freedom of expression, as does any citizen. They are free to consent and to participate in research projects that they consider to be of personal or social benefit. If the project is unlikely to affect the welfare of the individuals' communities, local community engagement is not required under this Policy. The necessity or desirability of engaging regional or national representatives of Indigenous communities in policy research may, however, be determined by other considerations.
- 6. Natural sciences research on First Nations, Inuit or Métis lands where Indigenous people may act as co-investigators or benefit from findings. For example, research focusing exclusively on contaminants in animals or plants in Nunavik that does not make inferences regarding food intake.
  - Research that involves the collection and analysis of tissue samples from animals or plants, and not involving human research participants, is not covered within the scope of this Policy and does not require institutional REB review. However, funding program guidelines and licensing requirements in the North may impose obligations to engage communities. Community customs or codes of research practice may require securing regional and local permission and reporting findings to communities (see NSERC literature on the Northern Research Program for professors and students/fellows, and <u>Article 9.8</u>).
- 7. Research that incidentally involves a small proportion of Indigenous individuals but is not intended to single out, or describe, characteristics of Indigenous people, for example, a study of therapies to control high blood pressure in a sample of hospital outpatients, which is not designed to collect Indigenous-specific data.
  - Since Indigenous participation is incidental rather than scheduled, community engagement is not required. If Indigenous individuals selfidentify during the collection of primary data, researchers should inquire whether culturally appropriate assistance is desired to interpret, or support compliance with, the research project. However, it should be noted that including markers of Indigenous identity in data collection may reveal anomalies that warrant further, more targeted research, which, if followed up, would require community engagement.
- 8. Research based on publicly available information as defined by this Policy, for example, historical, genealogical or analytic research based on public records, or data available or accessible in accordance with legislation.
  - Such research does not involve the collection of data from communities directly or from living persons and is not subject to REB review (<u>Article 2.2</u>). Community engagement is not required. Findings of such research nevertheless may have an impact on the identity or heritage of persons or communities. In order to minimize any harm, researchers should seek culturally informed advice before the use of such data to determine if harms may result and if other considerations, such as sharing of the research results, should be explored with the original source community (<u>Article 9.15</u>).

## Respect for First Nations, Inuit and Métis Governing Authorities

#### Article 9.3

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 leaders of the community, except as provided under <u>Articles 9.5</u>, <u>9.6</u> and <u>9.7</u>.

Research ethics review by the institutional REB and any responsible community body recognized by the First Nations, Inuit or Métis authority (<u>Articles 9.9</u> and <u>9.11</u>) is required in advance of recruiting and seeking and obtaining consent of individuals.

#### Application

Formal leaders with governance responsibilities on First Nations, Inuit or Métis land are charged with protecting the welfare of the community. <u>Article 8.3(b)</u> applies in such cases, requiring ethics review of research proposals by both "(i) the REB at the Canadian institution under the auspices of which the research is being conducted, and (ii) the REB or other responsible review body or bodies, if any, at the research site." A local authority may approve research or delegate responsibility for reviewing research proposals to a local or regional body (e.g., the local health board or a body like the Mi'kmaq Ethics Watch).

Research involving multiple geographic communities raises complex issues of review and approval. Regional bodies or national organizations may facilitate research ethics review and make recommendations, but the decision to participate normally rests with the local communities.

Engagement with formal leadership is not a substitute for seeking consent from individual participants, as required by <u>Chapter 3</u>.

## Engagement with Organizations and Communities of Interest

#### Article 9.4

For the purposes of community engagement and collaboration in research undertakings, 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 ethical review and oversight of projects, where appropriate.

#### Application

Organizational communities and communities of interest may exist within the boundaries of territorial communities. Overlapping interests in these cases are considered in <u>Articles 9.5</u> and <u>9.6</u>. A majority of persons who self-identify as Indigenous

live in rural and urban communities outside of discrete First Nations, Métis or Inuit communities. Political organizations, friendship centres, housing associations, health access centres and other groups operating in rural or urban centres have been created to enhance the welfare of their own members or the populations that they serve. Organizations and communities of interest are potential partners in research on issues relevant to their communities, and are to be recognized as communities for the purposes of community engagement under this Policy.

An organization may participate in research focusing on its members (e.g., the board and staff of a friendship centre), or it may facilitate ethical engagement with the population that it serves (e.g., the clientele of a health access centre). A community of interest (e.g., Indigenous youth who use an urban service program) may designate a local organization to provide advice and ethical protection for a project in which they participate.

Prospective participants may not necessarily recognize organizational communities or communities of interest as representing their interests. Where researchers and organizational communities or communities of interest collaborate in research (e.g., through a research agreement), prospective participants shall be informed about the extent of such collaboration (including how data will be shared) as part of the initial and ongoing consent process (<u>Article 3.2[i]</u>).

## Respect for Community Customs and Codes of Practice

#### Article 9.8

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.

#### Application

First Nations, Inuit and Métis codes of research practice derive from procedures and customs of predominantly oral cultures. While some rules may be in written form, their interpretation is dependent on experiential knowledge acquired through interactions in the community. An example is the strict limitation on making publicly available sacred knowledge that might be revealed within a trusting relationship. In academic culture, rules regarding limits on disclosure of information would reasonably be incorporated into a research proposal and should be integrated into research agreements between communities and researchers where such exists.

The absence, or perceived absence, of a formal local research code or guidelines does not relieve the researcher of the obligation to seek community engagement in order to identify local customs and codes of research practice. First Nations, Inuit and Métis customs and codes of behaviour distinguish among knowledge that can be publicly disclosed, disclosed to a specific audience, or disclosed under certain conditions. Determination of what information may be shared, and with whom, will depend on the culture of the community involved. Any restrictions on access to, or use of, traditional or sacred knowledge shared in the course of the research project should be addressed in the research agreement.

In Indigenous communities, custom may restrict the observation, recording, or reporting of ceremonies or certain performances and require approval of appropriate individuals. <u>Article 10.3</u> addresses the requirement for ethics review of research involving naturalistic and participant observational studies, and associated ethical implications, which may include infringement on consent and privacy.

Many First Nations communities across Canada have adopted an ethics code originally developed to govern practice in the First Nations Regional Longitudinal Health Survey. The code asserts ownership of, control of, access to, and possession (OCAP) of research processes affecting participant communities, and the resulting data. OCAP addresses issues of privacy, intellectual property, data custody and secondary use of data, which are also covered later in this chapter.

Inuit communities and organizations are considering addressing similar concerns, including adoption or adaptation of OCAP. For example, possession agreements, which are distinct from research agreements, are set out in a memorandum of understanding between the researcher's institution and the community (usually represented by the land claim organization). The possession agreement covers the control and use of data and human biological materials collected over the course of the research. The agreement may continue to exist long after the research is completed, to allow control and use of data and human biological materials for Inuit-initiated research.

Researchers should consult their own institutions to ensure that the application of OCAP or other community-based ethics codes is consistent with institutional policies. Where divergences exist, they should be addressed and resolved prior to the commencement of the research.

First Nations, Inuit and Métis scholars attached to academic institutions as faculty members, students or research associates are increasingly engaged in research involving their own communities, and sometimes their own family members. They are generally exempt from restrictions on physical access to territory or personal access to community members. However, as members of institutions that adhere to this Policy, they are subject to the ethical duty to respect community customs and codes of research practice when conducting research in their own local or cultural communities, and to engage the relevant community as required by this Policy. In these cases, institutional REBs may be concerned about researchers being in a conflict of interest and should manage the conflict of interest in accordance with <u>Articles 7.2</u> and <u>7.4</u>.

Life history and language research are examples of research areas where insider relationships and cultural competencies provide unique opportunities to extend the boundaries of knowledge. Although it can be argued that recording the life history of an elderly relative is a family matter rather than a community matter, when undertaken as research, community engagement is important to ensure that the following

considerations are reviewed: the potential impact of such research on the wider community; conflicts between the individualist norms of the academic environment and the norms of the community; and the possibility of unclear or mistaken assumptions on the part of participant and researcher. During the consent process, researchers should give the participant the opportunity to identify the relevant form of community engagement, and at what stage such engagement should occur. This may include engaging with extended family members, peers of the participant with whom the researcher's interpretations can be validated, or Elders knowledgeable about cultural rules governing disclosure of privileged information.

### **Collaborative Research**

#### Article 9.12

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.

#### Application

While community engagement is appropriate in any research that affects Indigenous communities, the nature and degree of collaboration between the researcher and the community will depend on the nature of the research, and the community context. Collaborative approaches in research with Indigenous communities are a means of facilitating mutually respectful and productive relations (<u>Article 9.2</u>).

Collaborative research is generally understood to involve respectful relationships among colleagues, each bringing distinct expertise to a project. Collaboration often involves one of the partners taking primary responsibility for certain aspects of the research, such as addressing sensitive issues in community relations, or scientific analysis and interpretation of data.

In general, community-based research takes place at community sites. Some forms of research are community-centred in that the research focuses not only on individuals but also on the community itself and may become a project conducted by, for and with the community.

Participatory research is a systematic inquiry that includes the active involvement of those who are the subject of the research. Participatory research is usually actionoriented, where those involved in the research process collaborate to define the research project, collect and analyze the data, produce a final product and act on the results. It is based on respect, relevance, reciprocity and mutual responsibility.

Where participatory research is adopted, the terms and conditions should be set out in a research agreement (<u>Article 9.11</u>).