



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

[Introduction](#)

[A. Key Concepts and Definitions](#)

[B. Interpreting the Ethics Framework in Indigenous Contexts](#)

[C. Applying Provisions of This Policy in Indigenous Contexts](#)

Introduction

Preamble

This chapter on research involving Indigenous peoples in Canada, including Indian (First Nations ¹), Inuit and Métis peoples, marks a step toward establishing an ethical space for dialogue on common interests and points of difference between researchers and Indigenous communities engaged in research.

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.

The landscape of research involving Indigenous peoples is rapidly changing. Growing numbers of First Nations, Inuit and Métis scholars are contributing to research as academics and community researchers. Communities are becoming better informed about the risks and benefits of research. Technological developments allowing rapid distribution of information are presenting both opportunities and challenges regarding the governance of information.

This chapter 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.

Building reciprocal, trusting relationships will take time. This chapter provides guidance, but it will require revision as it is implemented, particularly in light of the ongoing efforts of Indigenous peoples to preserve and manage their collective knowledge and information generated from their communities. The Agencies – the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC) – are committed to the continued evolution of this Policy, as noted in the Introduction. As the Policy comes into effect, the approach of engaging communities will be applied not only to research projects but also to the further development of the Policy itself to ensure that it remains a living document.

This chapter forms an integral part of this Policy to which institutions eligible to administer and receive research funding from any of the three research agencies agree to adhere as a condition of funding. See the *Agreement on the Administration of Agency Grants and Awards by Research Institutions*. ² 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. Some of that work has been done by the three agencies responsible for this Policy. In particular, CIHR and its Institute of Indigenous Peoples' Health have engaged in extensive dialogue with community partners to develop the *CIHR Guidelines for Health Research Involving Aboriginal People*. The CIHR Guidelines remain an important source of additional guidance for health research involving Indigenous peoples in Canada.

SSHRC and NSERC, likewise, have developed program guidelines for research involving Indigenous peoples and issues. Indigenous entities at local, regional and national levels have published and implemented principles and codes governing research practice – including ethical protections – that emphasize collective rights, interests and responsibilities.

This Policy provides guidance for research involving humans, as defined in [Chapter 2](#). Other guidelines specific to particular programs, research domains and community settings may elaborate on the processes set out herein, or may address ethical concerns of broader scope than those covered in this Policy. Researchers and research ethics boards (REBs) are advised to consult reference documents that apply to their research undertakings. Examples of relevant resources are listed under References at the end of this chapter.

While this chapter is designed to guide research involving First Nations, Inuit and Métis peoples of Canada, its discussion of respectful relationships, collaboration and engagement between researchers and participants may also be an important source of guidance for research involving other distinct communities. The need to respect a community's cultural traditions, customs and codes of practice may extend beyond First Nations, Inuit and Métis

communities. REBs and researchers may draw on articles of this chapter that are of relevance for the particular community involved in the research.

Neither this Policy nor this chapter are meant to reflect or introduce any change to other Government of Canada policies with respect to the issues addressed in this chapter.

Context

The existing Indigenous and treaty rights of the Indigenous peoples of Canada, that is, the Indian, Inuit and Métis peoples of Canada, were recognized and affirmed in the *Constitution Act, 1982*.³

This chapter acknowledges the unique status of the Indigenous peoples of Canada. It interprets how the value of respect for human dignity and the core principles of Respect for Persons, Concern for Welfare, and Justice (as articulated in [Chapter 1](#)) apply to research involving Indigenous peoples. It accords respect to Indigenous peoples' knowledge systems by ensuring that the various and distinct world views of First Nations, Inuit and Métis peoples are represented in planning and decision making, from the earliest stages of conception and design of projects through to the analysis and dissemination of results. It affirms respect for community customs and codes of research practice to better ensure balance in the relationship between researchers and participants, and mutual benefit in researcher-community relations.

The purpose of this chapter specifically, and the Policy in general, is to provide guidance to researchers on the ethical conduct of research involving Indigenous peoples.

The desire to conserve, reclaim and develop knowledge specific to First Nations, Inuit and Métis communities, and to benefit from contemporary applications of traditional knowledge, is a motivating force in community initiatives to assume a decisive role in research. The guidance provided in this chapter is based on the premise that engagement with community is an integral part of ethical research involving Indigenous peoples.

This Policy acknowledges the role of community in shaping the conduct of research that affects First Nations, Inuit and Métis communities. The Policy also respects the autonomy of individuals to decide whether they will participate in research in accordance with [Articles 3.1 to 3.6](#). Articles in this chapter give guidance for balancing individual and collective interests. In light of the diversity within and among First Nations, Inuit and Métis communities, and the ongoing development of community codes of research practice by these communities at the local, regional and national level, ethical review of a proposed project shall be attentive to the specific context of the project and the community involved ([Articles 9.8 and 9.9](#)).

A. Key Concepts and Definitions

Definitions of key concepts used in this chapter are provided to assist in applying the guidance in this Policy (see [Chapter 1](#) regarding the scope of definitions used in this Policy) and to facilitate dialogue between researchers and Indigenous communities. Since there is not universal agreement on the meaning of some terms, the definitions provided are intended for the purposes of this Policy only. This terminology will require periodic revision, particularly in light of the ongoing debate on the terms of art used in international and domestic contexts. This is in keeping with a commitment to the continued evolution of this Policy.

- Aboriginal peoples – see Indigenous peoples.
- Community – describes a group of people with a shared identity or interest that has the capacity to act or express itself as a collective. In this Policy, a community may include members from multiple cultural groups. A community may be territorial, organizational, or a community of interest. “Territorial communities” have governing bodies exercising local or regional jurisdiction (e.g., members of First Nations who reside on reserve lands). “Organizational communities” have explicit mandates and formal leadership (e.g., a regional Inuit association or a friendship centre serving an urban Indigenous community). In both territorial and organizational communities, membership is defined and the community has designated leaders. “Communities of interest” may be formed by individuals or organizations who come together for a common purpose or undertaking, such as a commitment to conserving a First Nations language. Communities of interest are informal communities whose boundaries and leadership may be fluid and less well- defined. They may exist temporarily or over the long term, within or outside of territorial or organizational communities.

An individual may belong to multiple communities, both Indigenous and non-Indigenous (e.g., as a member of a local Métis community, a graduate students' society and a coalition in support of Indigenous rights). An individual may acknowledge being of First Nations, Inuit or Métis descent but not identify with any particular community. How individuals define which of their community relationships are most relevant will likely depend on the nature of the research project being proposed.

- Community customs and codes of research practice – may be expressed in written or oral form. Consistent with the world views of particular First Nations, Inuit and Métis peoples, community customs and codes of research practice may embody kinship networks and responsibilities that include multi-generational obligations to ancestors and future generations. Ethical obligations often extend to respectful relations with plant, animal and marine life.
- Community engagement – is a process that establishes an interaction between a researcher (or a research team) and the Indigenous community relevant to the research project. It signifies the intent of forming a collaborative relationship between researchers and communities, although the degree of collaboration may vary depending on the community context and the nature of the research. The engagement may take many forms including review and approval from formal leadership to conduct research in the community, joint planning with a responsible agency, commitment to a partnership formalized

in a research agreement, or dialogue with an advisory group expert in the customs governing the knowledge being sought. The engagement may range from information sharing to active participation and collaboration, to empowerment and shared leadership of the research project. Communities may also choose not to engage actively in a research project, but simply to acknowledge it and register no objection to it.

- First Nations, Inuit and Métis lands – include Indian reserves, Métis settlements, and lands governed under a self-government agreement or an Inuit or First Nations land claim agreement.
- Indigenous knowledge – see Traditional knowledge.
- Indigenous peoples – a term used in international or scholarly discourse. In the Canadian context, the term “Indigenous peoples” typically refers to persons of Indian, Inuit or Métis descent, regardless of where they reside and whether their names appear on an official register. Self-identification is a fundamental criterion for defining Indigenous peoples.⁴ The term “Indigenous” does not reflect the distinctions among First Nations, Inuit and Métis peoples, who have their own histories, cultures and languages, so an attempt has been made to limit use of the term in this Policy to instances where a global term is appropriate. Indian peoples commonly identify themselves by distinct nation names such as Mi’kmaq, Dene or Haida, and as First Nations. In Canada, a comparable term, “Aboriginal peoples,” is also used in certain contexts.
- Traditional knowledge – the knowledge held by First Nations, Inuit and Métis peoples, the Indigenous peoples of Canada. Traditional knowledge is specific to place, usually transmitted orally, and rooted in the experience of multiple generations. It is determined by an Indigenous community’s land, environment, region, culture and language. Traditional knowledge is usually described by Indigenous peoples as holistic, involving body, mind, feelings and spirit. Knowledge may be expressed in symbols, arts, ceremonial and everyday practices, narratives and, especially, in relationships. The word “tradition” is not necessarily synonymous with old. Traditional knowledge is held collectively by all members of a community, although some members may have particular responsibility for its transmission. It includes preserved knowledge created by, and received from, past generations and innovations and new knowledge transmitted to subsequent generations. In international or scholarly discourse, the terms “traditional knowledge” and “Indigenous knowledge” are sometimes used interchangeably.

B. Interpreting the Ethics Framework in Indigenous Contexts

Chapter 1 identifies three principles that express the core ethical value of respect for human dignity – Respect for Persons, Concern for Welfare, and Justice. The three core principles are interpreted in this chapter as follows:

Respect for Persons is expressed principally through the securing of free, informed and ongoing consent of participants. The concerns of First Nations, Inuit and Métis for their continuity as peoples with distinctive cultures and identities have led to the development of codes of research practice that are in keeping with their world views. Indigenous codes of research practice go beyond the scope of ethical protections for individual participants. They extend to the interconnection between humans and the natural world, and include obligations to maintain, and pass on to future generations, knowledge received from ancestors as well as innovations devised in the present generation.

Historically, the well-being of individual participants has been the focus of research ethics guidelines. In this Policy, the principle of **Concern for Welfare** is broader, requiring consideration of participants and prospective participants in their physical, social, economic and cultural environments, where applicable, as well as concern for the community to which participants belong. This Policy acknowledges the important role of Indigenous communities in promoting collective rights, interests and responsibilities that also serve the welfare of individuals.

Indigenous peoples are particularly concerned that research should enhance their capacity to maintain their cultures, languages and identities as First Nations, Inuit or Métis peoples, and to support their full participation in, and contributions to, Canadian society. The interpretation of Concern for Welfare in First Nations, Inuit and Métis contexts may therefore place strong emphasis on collective welfare as a complement to individual well-being.

Justice may be compromised when a serious imbalance of power prevails between the researcher and participants. Resulting harms are seldom intentional, but nonetheless real for the participants. In the case of Indigenous peoples, abuses stemming from research have included: misappropriation of sacred songs, stories and artefacts; devaluation of Indigenous peoples’ knowledge as primitive or superstitious; violation of community norms regarding the use of human tissue and remains; failure to share data and resulting benefits; and dissemination of information that has misrepresented or stigmatized entire communities.

Where the social, cultural or linguistic distance between the community and researchers from outside the community is significant, the potential for misunderstanding is likewise significant. Engagement between the community involved and researchers, initiated prior to recruiting participants and maintained over the course of the research, can enhance ethical practice and the quality of research. Taking time to establish a relationship can promote mutual trust and communication, identify mutually beneficial research goals, define appropriate research collaborations or partnerships, and ensure that the conduct of research adheres to the core principles of Respect for Persons, Concern for Welfare – which in this context includes welfare of the collective, as understood by all parties involved – and Justice.

Research Involving Indigenous Peoples in Other Countries

Although the present chapter addresses research involving Indigenous peoples in Canada, researchers, REBs, participants and the research community at large may find the guidance articulated here useful when undertaking research or reviewing a proposal involving Indigenous peoples in other countries who endorse collective decision making as a complement to individual consent. It is critically important, however, to seek local guidance in the application or adaptation of this Policy to Indigenous peoples outside of Canada.

For considerations that apply to research conducted in another country, see [Chapter 8, Section B](#).

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;
- d. 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.

Application

Paragraph (a) refers to First Nations, Inuit and Métis lands, which include Indian reserves, Métis settlements, and lands governed under a self-government agreement or an Inuit or First Nations land claim agreement. Researchers should become informed about formal rules or oral customs that may apply in accordance with a particular First Nations, Inuit or Métis authority. In different jurisdictions, research activities may be regulated in various ways.

Paragraph (c) refers to cultural heritage, which includes, but is not limited to, First Nations, Inuit and Métis peoples' relations with particular territories, material objects, traditional knowledge and skills, and intangibles that are transmitted from one generation to the next (e.g., sacred narratives, customs, representations or practices). Cultural heritage is a dynamic concept in that materials, knowledge and practices are continuously adapted to the realities of current experience.

Cultural heritage research such as archaeological research involving burial sites or sacred landscapes and handling of artefacts may raise ethical obligations important to the Indigenous community that may not be addressed in academic research proposals. Researchers and communities should agree in advance on how to reconcile or address these divergent perspectives ([Articles 9.8](#) and [9.12](#)).

Appropriation of collective knowledge, treatment of such knowledge as a commodity to be traded, or making unauthorized adaptations for commercial purposes, may cause offence or harm to communities from which the knowledge originates. Such conduct has prompted initiatives in various countries and international agencies to address unethical, unfair, and inequitable treatment of traditional knowledge and knowledge holders ([Article 9.18](#)).

Paragraph (e) refers to both primary collection of research data and secondary use of information collected originally for a purpose other than the current research purpose ([Article 2.4](#) and [Chapter 5, Section D](#)). [Articles 9.20](#) to [9.22](#) address community engagement and individual consent for secondary use of identifiable information and human biological materials for research purposes.

Nature and Extent of Community Engagement

Article 9.2

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.

Application

Diversity among and within communities makes generalizations about the form of community engagement inappropriate. Diversity within Indigenous communities may encompass differences in levels of formal education and employment, mobility, generational differences and intermarriage with non-Indigenous persons. This diversity increases the importance of clarifying mutual expectations and obligations with the community and incorporating them into a research agreement.

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 ([Article 9.10](#)). In these cases, consent of individuals is sufficient to participate.

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

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.
2. 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 [Article 9.8](#)).
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 self-identify 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 ([Article 2.2](#)). 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 ([Article 9.15](#)).

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 [Articles 9.5, 9.6 and 9.7](#).

Research ethics review by the institutional REB and any responsible community body recognized by the First Nations, Inuit or Métis authority ([Articles 9.9 and 9.11](#)) 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. [Article 8.3\(b\)](#) 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 [Chapter 3](#).

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 [Articles 9.5](#) and [9.6](#). 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 ([Article 3.2\(ii\)](#)).

Complex Authority Structures

Article 9.5

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.

Application

Researchers and REBs should not assume that approval of a project by formal leaders is the only avenue for endorsing a project. In some communities and some domains of knowledge, authority to permit and monitor research rests with knowledge keepers designated by custom rather than by election or appointment. In First Nations settings, a confederacy council spanning several communities may be recognized as having authority over its members’ traditional knowledge. In an Inuit community, the hamlet council, an Elders’ circle, and a hunters and trappers organization may have overlapping responsibility and expertise with respect to the knowledge being sought. Métis Elders dedicated to conserving Michif language may assert their autonomy from political leaders, but choose to collaborate with educational or cultural agencies (see also [Article 9.15](#)).

The preferred course is to secure approval for research from both formal leaders of a community and customary authority. This is especially important for outsiders to communities, whose presence or intentions might be challenged as inappropriate. Researchers should engage community processes, including the guidance of moral authorities such as Elders, to avert potential conflict. These measures should be documented to assist the REB in considering the community engagement processes proposed ([Article 9.10](#)). Where no agreement exists between formal community leadership and customary authority regarding the conduct of the proposed research, researchers should inform the REB. When alternative community engagement processes are followed to endorse a project, all other ethical safeguards set out in this chapter remain applicable.

Recognizing Diverse Interests within Communities

Article 9.6

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.

Application

Groups or individuals whose circumstances may make them vulnerable or marginalized within territorial or organizational communities should not be deprived of opportunities to participate in, and influence, research affecting their welfare. For example, people living with HIV/AIDS, impoverished youth or women who have suffered abuse may experience barriers to participation.

Gender-based analysis is being applied in First Nations, Inuit and Métis organizations and communities to promote or restore recognition of women's responsibilities in the conduct of community life – including decision making that directly affects their welfare. The legacy of patriarchal governance structures continues to pose challenges to women's full participation. Approaches that are attentive to cultural considerations help to ensure the equitable participation and benefit of women throughout the life cycle of a research project ([Article 4.2](#)).

Research undertaken secretly or as a direct challenge to legitimate authority may increase risks to participants whose circumstances make them vulnerable, may deepen rifts within the community, and may actually impede the advancement of social justice. Strategies that have proven effective to secure the inclusion and promote the safety of diverse sectors within a community include: advocacy by moral authorities in the community; special measures to protect the identity of participants in small communities; identifying research questions that include rather than divide interest groups; or expanding the coverage of a project to multiple communities. In some cases, the risks to participants and communities involved with, or affected by, the proposed research outweigh the potential benefits likely to be gained, and the research should not be undertaken.

Critical Inquiry

Article 9.7

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.

Application

Considerations in conducting critical inquiry are discussed more fully in [Article 3.6](#). As in the case of research involving groups whose circumstances make them vulnerable, or communities of interest within an Indigenous community ([Article 9.6](#)), researchers undertaking critical inquiry research will need to adopt appropriate approaches to ensure that cultural norms are respected, that the safety of participants is protected, and that potential harms to the welfare of the larger community are minimized to the extent possible. Researchers may need to consult culturally relevant regional or national Indigenous organizations for guidance.

For example, the Sisters in Spirit project of the Native Women's Association of Canada (NWAC) that was launched in 2005 for a five-year period illustrates research of a national scope that incorporated a critical dimension. The project involved interviewing families of missing and murdered First Nations, Métis or Inuit women in urban and rural settings, and on First Nations territory. It examined, among other matters, the adequacy of public institutions and services, Indigenous and non-Indigenous, to protect the women's well-being and support families in their efforts to deal with their losses. The objective was to effect policy change and improve the safety and well-being of Indigenous women in Canada. NWAC has published its commitment to participatory research and the principles and practices that protect the privacy and well-being of participants. The project built on NWAC's ongoing efforts to develop meaningful research relationships reflecting Indigenous ways of knowing.

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. [Article 10.3](#) 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 [Articles 7.2](#) and [7.4](#).

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.

Institutional Research Ethics Review Required

Article 9.9

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](#). Prospective research and secondary use of data and human biological materials for research purposes is subject to research ethics review.

Application

Applying this Policy in a way that accommodates the diversity of First Nations, Inuit and Métis cultures and mixed Indigenous communities in urban centres is complex. For example, the fit between institutional policies and community customs and codes of research practice may be unclear, requiring researchers to adapt conventional practice or negotiate a resolution. Consistent with [Article 8.3\(b\)](#), research conducted outside the jurisdiction of the researcher's institution shall undergo prior research ethics review 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."

[Article 8.1](#) permits review models for multi-site research that do not require separate research ethics review by each site involved in a research project. In cases where the community is the direct recipient of funding and has constituted a local REB that is party to an agreement with the researcher's institution, review by the institution's REB may not be required.

In accordance with [Article 8.4](#), communication between the institutional REB and the responsible agency in the community may assist in resolving inconsistencies between institutional policy and community customs and codes of research practice. Where a community research ethics review is required in addition to the mandatory institutional REB review, reconciling differences may require resubmission to one or both review bodies.

Researchers and REBs should recognize that research ethics review by community bodies will often pursue purposes and apply criteria that differ from the provisions of this Policy. The express purpose of most Indigenous community codes of research practice is to ensure the relevance of research undertakings to community needs and priorities, and respect for First Nations, Inuit and Métis identities, cultures and knowledge systems. While community codes of practice

and research agreements typically share many of the goals of institutional policies, the approaches to achieving those goals may differ significantly. It is therefore inappropriate to insist on uniformity between community practices and institutional policies. For example, when researchers seek to interview Elders willing to share their knowledge according to traditional customs of consent, REBs should not impose language and processes that may be experienced as culturally inappropriate or awkward ([Article 3.12](#)).

In cases where REB review of research on topics related to Indigenous peoples or affecting Indigenous communities is regularly required, the REB membership should be modified to ensure that relevant and competent knowledge and expertise in Indigenous cultures are available within its regular complement. Indigenous scholars or members drawn from First Nations, Inuit or Métis communities may fill this role ([Article 6.4](#)). For occasional review of Indigenous research that is likely to affect the welfare of a community or communities, consultation with ad hoc advisors or delegation to a specialized or multi-institutional REB may be appropriate ([Articles 6.5](#) and [8.1](#)).

The membership of community review bodies of First Nations, Inuit or Métis communities will not necessarily duplicate the membership criteria set out in this Policy. In the context of scarce resources in community organizations, the same personnel may be involved in reviewing the ethics of a proposal and co-managing the research project. An expectation that conflicts of interest will be managed by separating research ethics review and project management functions may impose unsupportable demands on small communities. In these circumstances, researchers and participating Indigenous communities should address the ethical safeguards of the community and its members that can be best achieved in circumstances when multiple roles are assumed by the same person ([Chapter 7](#) and, in particular, [Article 7.2](#)).

Requirement to Advise the Research Ethics Board on a Plan for Community Engagement

Article 9.10

When proposing research expected to involve First Nations, Inuit or Métis participants, researchers shall advise their REBs 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.

Application

In order for REBs to consider whether the form of community engagement chosen by the researcher is appropriate, they will require evidence in the form of one or more of the following: (a) a preliminary or formal research agreement between the researcher and the responsible body at the research site; (b) a written decision or documentation of an oral decision made in a group setting to approve the proposed research or to decline further participation; and (c) a written summary of advice received from a culturally informed advisory group or ad hoc committee (e.g., an urban community of interest). Where community engagement is not being proposed, perhaps due to the nature of the research and the community context ([Articles 9.1](#) and [9.2](#)), researchers shall provide a rationale acceptable to the REB.

Provision of a research agreement is particularly emphasized in health research funded by CIHR (see *CIHR Guidelines for Health Research Involving Aboriginal People* in References at the end of this chapter).

Where a researcher has an ongoing relationship with a community, a letter from formal or customary leaders in the relevant community may signal approval, and suffice to proceed with the research.

Where, under the provisions of [Articles 6.11](#) and [10.1](#), a community signals during preliminary discussions with researchers, prior to REB review, that the research may proceed but that it does not want further community engagement, researchers shall document and present to the REB the steps they took to invite and facilitate engagement by the community. See [Article 9.14](#) on how researchers may assist in capacity building.

Although researchers shall offer the option of engagement, a community may choose to engage nominally or not at all, despite being willing to allow the research to proceed. A community may, for example, support a research project carried out independent of community influence, or without any further collaboration of the community in the actual implementation of the research, in order to use scientifically defensible results to validate a negotiating position.

Research Agreements

Article 9.11

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.

Application

Research agreements serve as a primary means of clarifying and confirming mutual expectations and, where appropriate, commitments between researchers and communities. Research agreements, where applicable, shall precede recruitment of individual participants and collection of, or access to, research data. The scope of the agreement will depend on the level of engagement that the community desires and on the availability of resources to support community participation.

At a minimum, the agreement should address the ethical protections that would apply to securing individual consent for a comparable project, and should specify any commitments regarding collective community participation and decision making, sharing of benefits and review, and updating of the agreement. Expanding on information normally provided to an individual participant ([Article 3.2](#)), agreements typically set out the purpose of the research and detail mutual responsibilities in project design, data collection and management ([Article 5.3](#)); analysis and interpretation; credit due to knowledge holders; protection (and non-disclosure) of restricted knowledge; sharing of benefits or royalties flowing from intellectual property where applicable; production of reports; co-authorship; dissemination of results; and a conflict resolution process. Provisions for any anticipated secondary use of the information or human biological material, and associated data collected, should also be addressed at that time, and documented in the research agreement ([Article 9.20](#)). Where a community has adopted or adheres to a code of research practice, the agreement may set out responsibilities in accordance with that code and the specific requirements of the research project. In less formal circumstances, the agreement may be relatively brief, and subject to clarification as the project unfolds. The CIHR *Guidelines for Health Research Involving Aboriginal People* provide examples of elements that may be included in research agreements (see References at the end of this chapter).

Research agreements are increasingly being recognized by academic institutions (and the researchers associated with them) as providing reference points for research ethics review process and approval on such elements as consent, confidentiality, and access to and use of information. Agreements that specify procedures for community research ethics review, included as part of the institutional ethics application, can provide contextual information and guidance for REBs conducting initial review of applications, and continuing research ethics review throughout the project. Researchers should check with their institutions regarding signing authority for research agreements ([Article 9.18](#)).

Building relationships, clarifying the goals of a project, and negotiating agreements requires substantial investment of time and resources on the part of the community and the researcher. Development and participation costs incurred by the community and the researcher should be factored into proposals to the extent possible within funding guidelines.

Community agreement that a research project may proceed is not a substitute for securing the consent of individuals recruited to participate in that project, in accordance with [Chapter 3](#). Consent of prospective participants shall precede collection of, or access to, data or human biological materials. Consistent with the provisions of [Article 3.12](#), if signed written consent is not culturally appropriate, the researcher shall inform the REB of alternative processes employed for seeking and documenting consent.

Consent shall be given in accordance with the research agreement where one exists. Where research agreements provide that community partners will have limited or full access to identifiable personal data, the consent of participants to this disclosure shall form part of the consent process. Access to confidential information provided by an individual is subject to privacy law.

Researchers should be aware of the first language of Indigenous participants, and if it is an Indigenous language, researchers should make available translation by a knowledgeable person during the consent process, and during the conduct of research in accordance with the wishes of the participant ([Article 4.1](#)). Researchers should be aware of the official status of Inuit languages in Inuit regions.

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 ([Article 9.2](#)).

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 action-oriented, 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 ([Article 9.11](#)).

Mutual Benefits in Research

Article 9.13

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.

Application

To benefit the participating community, a research project should be relevant to community priorities and have the potential to produce valued outcomes from the perspective of the community and its members.

Relevance and community benefit can take a number of forms depending on the type of research being conducted, and the forms of community engagement. For example, genetic research on diabetes in a First Nations community is unlikely to benefit the community in the short term, but collaboration may facilitate increased knowledge of the condition, and what changes can be made to improve health outcomes. Collaborative research can thus accommodate basic, as well as applied, research, and include short-term and long-term benefits. In another example, a community invites a researcher to collaborate in a research project about housing and homelessness in an Inuit community. Using participatory research methods and social science tools, the nature, extent and consequences of the local housing shortage are documented, enabling the community to effectively communicate its needs to non-Inuit (*Qallunaat*) authorities. Other benefits include training workshops that provide employment and transfer skills to Inuit youth involved in data collection, field experience in community-based research for university student assistants, and materials useful to other Inuit communities in subsequent research.

Collaborative research approaches provide the community with the opportunity to discuss risks and potential benefits, and to minimize risks. Where participatory research is undertaken, the research report might also formulate recommendations on how to implement interventions resulting from the research for the benefit of the participating community.

A possible outcome of collaborative research, and in particular participatory research, is increased capacity to carry out research that can more readily be conducted in Indigenous languages and oral modes. The exploration, articulation and application of knowledge specific to a community or communities are thus advanced, potentially benefiting other First Nations, Inuit or Métis communities through knowledge transfer.

Researchers should provide communities access to research data that will allow them to address pressing issues through community-generated policies, programs, and services ([Article 9.8](#) and the Application of [Article 9.11](#)). Territorial and organizational communities and communities of interest may also seek to share in the benefits of research activities, which may include direct research grants, release time for project personnel, overhead levies on shared projects and commercialization of research discoveries.

Strengthening Research Capacity

Article 9.14

Research projects should support capacity building through enhancement of the skills of community personnel in research methods, project management, and ethical review and oversight.

Application

Collaborative research approaches provide for reciprocal learning and for transfer of skills and knowledge between the community and the researcher. Researchers should foster education and training of community members to enhance their participation in research projects. Employing Indigenous research assistants and translators is already common practice in community-based projects. Extending skills transfer through a program of training will support collaboration with institutions, and advance the capacity of communities to initiate and implement their own research. Collaborative research can also support building capacity of the research community to conduct culturally relevant research.

Lack of engagement by communities may be due to inadequate financial or human resources. Communities vary widely in the level of human and material resources they have available to collaborate with research initiatives. Structural barriers may prevent access to, and participation in, research. For example, small, remote communities and many urban communities of interest have limited organizational resources to advise or collaborate in research. The least organizationally developed communities are the most vulnerable to exploitation. Research undertaken in these circumstances should strive to enhance capacity for participation.

Funding programs that target the development of Indigenous research and capacity building seek to generate significant research training opportunities. Funding criteria allow researchers to include in their grant applications stipends for undergraduate, master's or doctoral students, or post-doctoral researchers, as appropriate, with priority given to Indigenous candidates. The time required to establish collaborative relationships may be difficult to accommodate in the programs of students. Mentorship by experienced researchers who introduce students to communities and monitor their ethical practice can facilitate the trust-building process and advance student progress.

Recognition of the Role of Elders and Other Knowledge Holders

Article 9.15

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.

Application

Within First Nations, Inuit and Métis communities, persons with special gifts carry varied roles and responsibilities in conserving and transmitting traditional knowledge and expressions of culture. They often are fluent in their traditional language. They model respectful relationships and may conduct ceremonies, pass on oral history, and offer guidance in community affairs. Their gifts are normally refined over a lifetime. Thus, Elders who have followed a rigorous path of learning over a long period are highly respected. Younger persons may also gain recognition as gifted knowledge holders.

High regard by the community that knows the Elder or other knowledge holder is the most reliable indicator of an individual's authority. Each community or nation has particular ways of approaching Elders or knowledge holders respectfully. In many First Nations, this involves the presentation and acceptance of tobacco to symbolize entering into a relationship. In some communities, feasting or gift-giving is appropriate.

Elders are now being recognized in research proposals and grant applications as providers of access to community networks, ethical guidance to researchers, and advice in interpreting findings in the context of traditional knowledge ([Article 9.17](#)). Researchers should seek advice from the community and the Elders regarding the appropriate recognition of the contribution of Elders and knowledge holders, which may include providing honoraria, acknowledging contributions by name or, as directed, withholding the Elder's identity in reports and publications.

Privacy and Confidentiality

Article 9.16

Researchers and community partners shall address privacy and confidentiality for communities and individuals early on in the community engagement process. Research agreements, where they exist, shall address whether part or all of the personal information related to the research will be disclosed to community partners. Researchers shall not disclose personal information to community partners without the participant's consent, as set out in [Article 3.2\(i\)](#).

Application

Researchers and community partners should consider early in the design of the research how community codes of research practice fit with provisions for privacy and confidentiality as set out in [Chapter 5](#). Where inconsistencies exist, they should be resolved in advance of starting the research. The research agreement should address how inconsistencies will be addressed if they arise over the course of the conduct of the research project.

In First Nations communities, privacy and confidentiality of identifiable personal and community information may be affected by the application of the principles of ownership, control, access and possession (OCAP). The First Nations Regional Longitudinal Health Survey administered by regional First Nations organizations has addressed balancing confidentiality and access by having communities designate a regional organization to hold data, while local authorities make decisions on who can access the data, and under what conditions. In practice, the organization that serves as data steward evaluates requests for information, and its recommendations to community authorities have considerable influence.

Whatever the nature of the research, it shall be designed to include safeguards for participant privacy and measures to protect the confidentiality of any data collected. Small Indigenous communities are characterized by dense networks of relationships. As a result, coding individual data is often not sufficient to mask identities, even when data are aggregated. Some Indigenous participants are reluctant to speak to interviewers from their own community because of privacy concerns. Communities themselves have distinguishing characteristics, which in some cases has compromised efforts to disguise the research site, and has led to the stigmatization of entire communities.

On the other hand, in some social sciences and humanities research, the significance of information is tied to the identity of the source. In these cases, individual attribution, with consent, is appropriate. When individual participants waive anonymity, researchers should ensure that this is documented ([Application of Article 5.1](#) and [Article 9.11](#)). Communities partnering in research may wish to be acknowledged (e.g., in the research report) for their contribution to the research effort.

Research undertaken with participants who have suffered traumatic experiences (e.g., former residential school students) poses a risk of re-traumatizing participants. Researchers should anticipate such risks in the research design, and adhere to cultural protocols for determining participant needs and access to trauma counselling.

Privacy protections in research are evolving. Respect for, and accommodation of, First Nations, Inuit and Métis priorities on joint ownership of the products of research and maintaining access to data for community use should guide research practices – with appropriate deference to applicable federal, provincial and territorial privacy legislation.

Interpretation and Dissemination of Research Results

Article 9.17

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.

Application

Where collaborative approaches are followed, researchers should ensure continuing communications with the participating community. Territorial or organizational communities or communities of interest engaged in collaborative research may consider that their review and approval of reports and academic publications are essential to validate findings, correct any cultural inaccuracies, and maintain respect for community knowledge (which may entail limitations on its disclosure). Researchers should integrate suggestions from the community representatives in the publication. If disagreement about interpretation arises between researchers and the community and it cannot be resolved, researchers should either (a) provide the community with an opportunity to make its views known, or (b) accurately report any disagreement about the interpretation of the data in their reports or publications. This should not be construed as giving the community the right to block the publication of findings. Rather, it gives the community the opportunity to contextualize the findings.

Final reports shall be made available to the territorial or organizational community or community of interest participating in the research. Researchers and communities should clarify the extent to which research findings will require translation, plain language summaries or oral presentations to community members, in order to make the research findings accessible to the community.

An Indigenous community, and those who participated in the research, should have the option to participate in deciding how collective or individual contributions to the research project will be acknowledged and credited in the dissemination of results (e.g., acknowledgement of co-authorship in research reports or at conferences and seminars).

Intellectual Property Related to Research

Article 9.18

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

Application

Researchers, communities and institutions should be aware that all knowledge and information is not necessarily protected under the existing law. Existing intellectual property legislation generally protects works and inventions. Strict criteria are used to define intellectual property rights. It is the joint responsibility of communities, researchers and institutions to understand and communicate what qualifies as intellectual property for the purposes of research under this Policy.

When undertaking research guided by community engagement, researchers, institutions and communities may need to first address issues regarding access to data, and the use of data for the purpose of the research or in the dissemination of research findings. Regarding access to and use of data, a research agreement may set out any limits on the disclosure of personal or privileged information (subject to applicable legal and regulatory requirements and the guidance in [Chapter 5](#)). It might include provisions to review reports and publications regarding the research prior to publication, or limits on the release of, or access to, research results (subject to applicable laws). Provisions for any anticipated secondary use of information or human biological materials, and associated data collected, should also be addressed and documented in this agreement. It may also set out any interests, licences or assignments in copyright flowing from publications about, or based on, the research ([Articles 9.8, 9.11 and 9.16](#)).

Some knowledge collected as a result of the research may have commercial applications and lead to the development of marketable products. With respect to commercialization of results of collaborative research, researchers and communities should discuss and agree on the use, assignment or licensing of any intellectual property (e.g., any patents or copyright), resulting from the marketable product, and document mutual understandings in an agreement. If the proposed research has explicit commercial objectives, or direct or indirect links to the commercial sector, researchers and communities may want to include provisions related to anticipated commercial use in research agreements. These provisions should be clearly communicated to all parties in advance, consistent with the consent process.

Researchers should consult the research office of their institution before entering into a research agreement that includes intellectual property provisions. Researchers should also consult the program literature or policies on intellectual property and copyright adopted by the federal research agencies CIHR, NSERC and SSHRC (available on their websites) and seek legal advice where appropriate.

Collection of Human Biological Materials Involving First Nations, Inuit and/or Métis Peoples

Article 9.19

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.

Application

Canadian law does not provide clear recognition of property rights in human biological materials. Researchers should be aware, however, that Indigenous people and communities may seek to maintain control over, and access to, data and human biological materials collected for research. This is in accordance with Indigenous world views about “full embodiment,” in which every part and product of the human body is sacred and cannot be alienated. Consistent with [Articles 9.8](#) and [9.11](#) and [Chapter 12](#), researchers and communities should address and specify in the research agreement:

- the objectives for collection, use and storage of human biological materials;
- the roles and responsibilities regarding custodianship of the data and the human biological materials; and
- any future use of these human biological materials and associated data, including material transfer agreements to third parties, and any subsequent requirements for community engagement.

Researchers must seek consent, in accordance with [Articles 12.1](#) and [12.2](#), from individuals who are invited to donate their biological materials.

Secondary Use of Information or Human Biological Materials Identifiable as Originating from First Nations, Inuit and/or Métis Communities or Peoples

Ongoing sensitivity about secondary use of data collected for approved purposes arises from experiences with misrepresentation of Indigenous peoples; use of data or human biological materials without appropriate engagement with the source community or consent of participants; and lack of reporting to communities on research outcomes. For example, members of Nuuchah-nulth communities in British Columbia provided blood samples for research on rheumatic disease. They vigorously protested the use of their blood components for subsequent unauthorized genetic research. In addition, there are fears in First Nations communities that access to health data for purposes other than treatment will facilitate unauthorized government surveillance.

When seeking to undertake research involving secondary use of data identifiable as originating from a specific First Nations, Inuit and/or Métis community or segment of the Indigenous community at large, researchers shall, through community engagement as appropriate, address any potential inadvertent identification of communities, or misuse of traditional knowledge. Requirements regarding the participant's consent for secondary use of identifiable information are addressed in [Articles 9.20](#) and [9.21](#).

Article 9.20

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

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

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

Individual consent for the secondary use of identifiable information is required unless the REB agrees that one of [Articles 5.5A](#) or [Article 12.3A](#) applies.

Application

Where the researcher can satisfy the REB that secondary use is consistent with an existing research agreement, the REB may require that the researcher engage the community from which the data or human biological materials and associated identifiable information originate – in accordance with the terms of the research agreement. New consent from individuals for secondary use is not required where the proposed secondary use is authorized by the REB in accordance with this Policy.

Article 9.21

Where research relies only on publicly available information that is protected by law, or on information that is in the public domain with no expectation of privacy as defined in [Article 2.2](#), community engagement is not required. Where the information can be identified as originating from a specific community or a segment of the Indigenous community at large, seeking culturally informed advice may assist in identifying risks and potential benefits for the source community.

Application

Research based only on publicly available information that is protected by law or on information that is in the public domain with no expectation of privacy as defined by this Policy, does not involve the collection of data from communities directly, or from living persons. As indicated in [Chapter 2](#), REB review for this type of research is not required. Community engagement is not required. Examples are historical or genealogical research or statistical analysis.

In these cases, researchers may not have any direct relationship with communities, but their findings may, nevertheless, 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 ([Article 9.15](#)).

Where access to publicly available information that is protected by law or information that is in the public domain with no expectation of privacy leads to new research initiatives to collect additional information from identified communities or individuals, REB review is required. The provisions set out in Article 5.6 apply for new initiatives of this kind.

Article 9.22

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.

Application

The REB may determine that community engagement is required to seek guidance on secondary use. [Articles 5.5A](#) and [5.6](#) or [Articles 12.3A](#) and [12.4](#) may apply.

Consistent with [Article 2.4](#), 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. Community engagement is not possible given that the data or human biological materials cannot be linked to a specific Indigenous community or specific individuals. Where the researcher seeks data linkage of two or more anonymous sets of information or human biological materials, and there is a reasonable prospect that this could generate identifiable information, then REB review is required.

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Endnotes

- 1 The *Constitution Act, 1982* contains the following definition: "In this Act, 'aboriginal peoples of Canada' includes the Indian, Inuit and Métis peoples of Canada." (35[2])
Indian peoples commonly identify themselves as "First Nations"; a term that came into common usage in the 1970s to replace the word "Indian," which some people found offensive. Although the term "First Nation" is widely used, no legal definition of it exists. Among its uses, the term "First Nations peoples" refers to the Indian peoples in Canada, both Status and non-Status. Some Indian peoples have also adopted the term "First Nation" to replace the word "band" in the name of their community.
- 2 Government of Canada, *Agreement on the Administration of Agency Grants and Awards by Research Institutions*, Effective April 1, 2018 to March 31, 2023. Retrieved on May 31, 2018.
- 3 *Constitution Act, 1982*, s. 35.
- 4 United Nations, Permanent Forum on Indigenous Issues, *Who are Indigenous Peoples?* Factsheet [PDF (196 KB) - external link]. Retrieved on August 2, 2018.

[Previous](#)

[Table of contents](#)

[Next](#)

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