

First Nation, 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 Aboriginal 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 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 institution of the researcher 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 Aboriginal 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 Aboriginal 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 (see Article 3.12).

In cases where REB review of research on topics related to Aboriginal peoples or affecting Aboriginal communities is regularly required, the REB membership should be modified to ensure that relevant and competent knowledge and expertise in Aboriginal cultures are available within its regular complement. Aboriginal scholars or members drawn from First Nations, Inuit or Métis communities may fill this role (see Article 6.4). For occasional review of Aboriginal 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 (see Articles 6.5 and Article 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 Aboriginal 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 (see Chapter 7 and, in particular, Article 7.2).

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Requirement to Advise the REB 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 REB how they have engaged, or intend to engage, the

relevant community. Alternatively, researchers may seek REB approval for an exception to the requirement for community engagement, on the basis of an acceptable rationale.

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 taken 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 (see 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 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 which the community desires, and 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 (see Article 3.2), agreements typically set out the purpose of the research and detail mutual responsibilities in project design, data collection and management (see 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 (see 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 (see 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 Aboriginal participants and, if an Aboriginal 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 (see 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 Aboriginal 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 Aboriginal communities are a means of facilitating mutually respectful and productive relations (see 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 or another 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 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 (see Article 9.11).

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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 Aboriginal 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 (see 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 Aboriginal 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 Aboriginal 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 Aboriginal 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 (see 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. The extent to which limited or full disclosure of personal information related to the research is to be disclosed to

community partners shall be addressed in research agreements where these exist. Researchers shall not disclose personal information to community partners without the participant's consent, as set out in Article 3.2(i).

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 – see definition in Application of Article 9.8). 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 Aboriginal 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 Aboriginal participants are reluctant to speak to interviewers from their own community because of privacy concerns. Communities themselves have distinguishing characteristics, which in some cases have 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 (see 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.

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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 is 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 Aboriginal 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. Understanding and communicating what qualifies, or does not qualify, as intellectual property for the purposes of research under this Policy is a joint responsibility of communities, researchers and institutions.

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 of this Policy). 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 the information or human biological material, 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 (see 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.

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Collection of Human Biological Materials Involving Aboriginal 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 Aboriginal 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 Aboriginal 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 Aboriginal Communities or Peoples

Ongoing sensitivity about secondary use of data collected for approved purposes arises from experiences with misrepresentation of Aboriginal 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 Nuu-chah-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 Aboriginal community or segment of the Aboriginal 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 Aboriginal 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 5.5 or 5.6 or Articles 12.3 or 12.4 may apply.

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, or on legally accessible information 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 Aboriginal 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 or legally accessible information 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 (see Article 9.15).

Where access to publicly available information or legally accessible information 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 datasets or data associated with human biological materials and there is a reasonable prospect that this could generate information identifiable as originating from a specific Aboriginal community or a segment of the Aboriginal community at large.

Application The REB may determine that community engagement is required to seek guidance on secondary use. Articles 5.5 and 5.6 or Articles 12.3 and 12.4 may apply.

Consistent with Article 2.4, REB review is not required for research involving only anonymous datasets or anonymous human biological materials, and associated data, that cannot be identified as originating from a specific Aboriginal community or a segment of the Aboriginal community at large. Community engagement is not possible given that the data or human biological materials cannot be linked to a specific Aboriginal 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.

Endnotes

[1] Indian peoples commonly identify themselves as “First Nations.” First Nation: 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. See Indian and Northern Affairs Canada, Terminology, available at

