



Indigenous Community Research Partnerships

A List of CIHR Guideline Articles and Key Features

Canadian Institutes of Health Research, 2007

A Demonstration of Principled Research Practices

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Principle #1: Reconciliation of Ethical Spaces

- Protection of Aboriginal Ethical Space involves a series of stages of dialogue starting with before the design of research, and with a continued questioning of “is this ethical?” (p. 17) (Canadian Institutes of Health Research, 2007)
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Principle #2: Sacred Space and Traditional Knowledge

Article 1

A researcher should understand and respect Indigenous world views, including responsibilities to the people and culture that flow from being granted access to traditional or sacred knowledge. These should be incorporated into research agreements, to the extent possible.

Key Features: Possible Ways to Demonstrate Principles

- **Spend time in the community:** volunteer, attend community events, meet with Elders, demonstrate intent for longer-term relationship (extends before and after the research).
- **Establish common ground:** make efforts to understand what matters to collaborators, including what and how knowledge can be collected and shared.
- **Show public accountability:** articulate why the research is urgently needed, with clear implications for the future. It is important to do this research for now and the future.

Example:

In a paper by Baydala et al. (Baydala et al., 2014), the ways for which co-learning, co-creation, and community based participatory research approach are used in a partnered research project is presented. Authentic partnering in research often requires (if not already formed) significant amounts of time building relationships, trust, and developing a research plan in which the community is invested.

Principle #3: Community Control and Approval Process

Article 2

A community's jurisdiction over the conduct of research should be understood and respected. This article should be read in the context of the discussion in Section 1.5, which addresses the application of this document.

Key Features: Possible Ways to Demonstrate Principles

- **Identify community processes:** who decides and guides research data responsibilities and processes.
- **Develop agreement(s)** such as MOU, Terms of Reference, Traditional agreements, or other ways to explicitly demonstrate consensual agreement between parties.
- **Be open to an evolving process:** a community may not have specific research protocol but members may want to explore, consult, and guide research.

Example:

In a study by Pahwa et al. (Pahwa et al., 2015) that explored respiratory health of First Nations people living on reserves, housing inadequacies were identified to be a key underlying determinant of respiratory ill health. As a result, the research agenda turned to addressing housing design issues.

Principle #4: Participatory Research

Article 3

Communities should be given the option of a participatory-research approach.

Key Features: Possible Ways to Demonstrate Principles

- **Ensure opportunities for communities to define what is participatory:** communities decide how much community participation is desired and reasonable, especially human and in-kind resources. Researchers bring some skills and knowledge, they rarely have expertise on context and values.
- **Show clear evidence of collaboration and partnership in the research process:** there must be a shared responsibility in identifying the importance of an issue as well as planning, conducting, and disseminating results.
- **Show respect for community and other stakeholder values:** this can include revisiting and checking in on the research process, adherence and respecting local traditional values in the research work.
- **Develop capacity for community and others to be partners if desired by community:** ensure others benefit from research, and plan to share fairly in gains from work.

Example:

Jull, Giles, Minwaashin Lodge, Boyer and Stacey (2015) (J. Jull, Giles, Boyer, & Stacey, 2015), describe the process for how a predetermined collaborative research approach was established. This is a demonstration of the terms of the research study in multiple ways such as in an ethical framework, research agreements, inclusion of Minwaashin Lodge on ethics, and a co-published protocol. In addition, the researcher was encouraged to be an active member of the community and hired a community-recommended member as research assistant.

Principle #5: Community and Individual Consent

Article 4

A researcher who proposes to carry out research that touches on traditional or sacred knowledge of an Indigenous community, or on community members as Indigenous people, should consult the community leaders to obtain their consent before approaching community members individually. Once community consent has been obtained, the researcher will still need the free, prior and informed consent of the individual participants.

Key Features: Possible Ways to Demonstrate Principles

- **Identify local community governance structures and processes** for gaining approval for engaging community members.
- **Present research idea(s)** to community leaders.
- **Create opportunities** for community leaders and members to learn about the researcher(s) and the research as well as respond.
- **Articulate how research and researchers aim to have the process and outcome(s) benefit the community or individuals involved in a study** - a higher bar than the common favourable risk-benefit expectation in research involving people

Example:

In a paper by Brunger and Wall (2016), the ways that taken-for-granted assumptions by researchers who follow research ethics guidelines can reinforce colonialist power relations are critically examined. In this paper, the findings from a study on how research that engaged Southern Inuit and NunatuKavut members is used to describe and operationalize the concept of research collaboration.

Principle #6: Confidentiality/Privacy

Article 5

Concerns of individual participants and their community regarding anonymity, privacy and confidentiality should be respected and should be addressed in a research agreement.

Key Features: Possible Ways to Demonstrate Principles

- **Identify concerns** around individual and community protections of information.
- **Ensure agreements** are stated and addressed, ideally in research agreements.

Example:

In a study to evaluate potential health determinants, a project was conceptualized and developed through two years of dialogue with participating First Nations communities. An agreement that addressed issues on co-ownership of data between researchers and community and how confidentiality and privacy would be respected (Pahwa et al., 2015).

Principle #7: Inclusion and Protection of Cultural Knowledge in Research

Article 6

The research agreement should, with the guidance of community Knowledge Holders, address the use of the community's cultural knowledge and sacred knowledge.

Key Features: Possible Ways to Demonstrate Principles

- **Discuss and agree on co-authorship and acknowledgments in academic forms of dissemination**, early in the study: dissemination may include papers, reports, and other forms of dissemination early in the study.
- **Come to agreement with community stakeholders on how and who to acknowledge** in future work by researcher.

Example:

In a study by Castleden, Morgan, and Neimanis (2010), 15 researchers at Canadian universities that conducted community-based participatory research with Indigenous communities were interviewed. The study reports on the diverse practices of acknowledgments

and co-authorship, including the benefits and risks of co-authorship with collectives or community partners.

Article 7

Indigenous people and their communities retain their inherent rights to any cultural knowledge, sacred knowledge, and cultural practices and traditions, which are shared with the researcher. The researcher should also support mechanisms for the protection of such knowledge, practices and traditions.

Key Features: Possible Ways to Demonstrate Principles

- **Be transparent in the use and development of knowledge** (inclusion/provide access to community partners on ethics applications, academic and community papers, reports, presentations).
- **Agree on co-authorship and other research and community-based opportunities** (for example, engage a community-based research assistant, conduct community presentations et cetera).
- **Demonstrate evidence of guidance about knowledge use** - Knowledge holder or Elder consultations and/or participation to ensure ongoing permissions; community guidance on use of knowledge.

Example:

In a paper by Kelley et al. (2013), the Tribal board protocols for reviews of how Indigenous knowledge is used, shared, and incorporated into research practices in the United States are examined and discussed. Written documentation between researchers and a Tribal board include 1) clear language descriptions of the study, 2) how cultural knowledge, language, and practices are to be incorporated into the study, and 3) the resource allocation to support the involvement of Tribal community Elders and community members.

Principle #8: Intellectual Property Rights and Indigenous Knowledge

Article 8

Community and individual concerns over, and claims to, intellectual property should be explicitly acknowledged and addressed in the negotiation with the community prior to starting the research project. Expectations regarding intellectual property rights of all parties involved in the research should be stated in the research agreement.

Key Features: Possible Ways to Demonstrate Principles

- **Plan for outcomes** (products, sustainability) clearly articulated at start of research.
- **Ensure there is evidence that community wishes were sought and honoured.**
- **Confirm and re-confirm permissions and keep community collaborators informed.**
- **Explore using a participatory research approach** – fair benefits in sharing of research.

Example:

Baydala et al. (2014) culturally adapted a life skills training program aimed at school-aged children and youth in a First Nation community and that was evaluated, using community-based participatory research methods. In the paper that describes the positive aspects of the program, the authors highlight the ways in which Elders were central to the program adaptations, and how the process of evaluation involved community researchers in all phases, from data collection to dissemination.

Principle #9: Benefit Sharing

Article 9

Research should be of benefit to the community as well as to the researcher.

Key Features: Possible Ways to Demonstrate Principles

- **Specify who the beneficiaries** of research will be.
- **Assess importance of the health issues investigated and prospective values of research for beneficiaries.**
- **Enhance value of research for each of the beneficiaries**, through discussion of knowledge, products, long-term research collaboration, health system improvements.

Example:

In a study by Tobias, Richmond, and Luginnah (2013), a community-based approach revealed environmental and health issues among Anishinabe communities in a region of Ontario, Canada. The authors describe how commitment to reciprocity and relational accountability meant making all attempts to meet community needs throughout all stages of the research process.

Principle #10: Empowerment and Research Capacity Development

Article 10

A researcher should support education and training of Indigenous people in the community, including training in research methods and ethics.

Key Features: Possible Ways to Demonstrate Principles

- **Explain how research benefits community and researcher.**
- **Researcher(s) spend time in the community and with community members,** evidence that they build their understandings of community and readiness.
- **Researcher(s) build capacity in the community,** for example hires community research assistant, trains community members.
- **Publish/disseminate research findings in accessible ways** to community, such as publishing in open access journals and using different formats (such as in-person communications) that suit different communication styles.

Example:

A study by Allen et al. (J. Allen et al., 2006) describes how Alaskan Native co-researchers without specialist research training were involved in all stages of the study. As a result, the co-researchers insisted on effective ways for research findings to be shared within the community, co-researchers were valuable to the community with new skills, and academic researchers benefitted from having credible and valid findings that were valued by the Alaskan Native communities and other researchers alike.

Principle #11: Cultural Protocol, Language and Communication

Article 11

11.1: A researcher has an obligation to learn about, and apply, Indigenous cultural protocols relevant to the Indigenous community involved in the research.

11.2: A researcher should, to the extent reasonably possible, translate all publications, reports and other relevant documents into the language of the community.

11.3: A researcher should ensure that there is ongoing, accessible and understandable communication with the community.

Key Features: Possible Ways to Demonstrate Principles

- **Reflect community communication preferences** and evidence of application of local cultural protocols and language.
- **Facilitate accessible and ongoing communications** with community partners.

Example:

In a study called the *Indigenous Red Ribbon Storytelling Study* by Nowgeseic, Meili, Stack, and Myers (2015), small tobacco bundles were offered to each research participant in addition to hosting a traditional Indigenous feast to a sharing circle of participants.

Principle #12: Initial and Secondary Use, Proprietary Interest, Storage and Transfer of Data and Biological Samples

Article 12

12.1: A researcher should recognize and respect the rights and proprietary interests of individuals and the community in data and biological samples generated or taken in the course of the research.

12.2: Transfer of data and biological samples from one of the original parties to a research agreement, to a third party, requires consent of the other original party(ies).

12.3: Secondary use of data or biological samples requires specific consent from the individual donor and, where appropriate, the community. However, if the research data or biological samples cannot be traced back to the individual donor, then consent for secondary use need not be obtained from the individual. Similarly, if research data or biological samples cannot be traced back to the community, then its consent for secondary use is not required.

12.4: Where the data or biological samples are known to have originated with Indigenous people, the researcher should consult with the appropriate Indigenous organizations before initiating secondary use.

12.5: Secondary use requires REB review. The guidelines set out basic principles for the collection, disclosure, use and transfer of data and biological samples.

Key Features: Possible Ways to Demonstrate Principles

- **Show evidence of agreed-upon approach** such as a set of criteria or agreement (for example, OCAP^{®1}).
- **Have evidence that agreements that are adhered to** and if changed, there is evidence that agreements were adjusted (including changes related to publications, use of reporting guidelines, et cetera)
- **Demonstrate respect for recruited participants and study communities** by developing and implementing procedures to protect confidentiality; provide participants with information that arises in study; ensure enrolled participants cared for, mitigating harms from the study; inform participants and community of results.
- **Concepts of data sovereignty are explicit and adhered to.**
- **Provide description of anonymization process.**
- **Provide documentation such as reports** to institutional and community ethics boards.
- **Document that evidence that the consultation took place.**
- **Document evidence of process and agreements**, such as meeting notes and agreements.
- **Make reference to processes** (such as OCAP[®]) or other community-endorse policies.

Example:

A study by Hudson et al. (Hudson et al., 2016) is about how research with Māori explored how to consider and include the rights and interests in research that involves biobanking and genomics. In their paper, the authors highlight six key areas of consideration regarding biobanking and genetic research – with particular emphasis on Māori participation in research governance, transparency and accountability to communities and sharing how Māori rights and interests are to be protected.

Principle #13: Biological Samples on Loan

Article 13

Biological samples should be considered "on loan" to the researcher unless otherwise specified in the research agreement.

¹ OCAP[®] is a registered trademark of the First Nations Information Governance Centre (FNIGC)

Key Features: Possible Ways to Demonstrate Principles

- **Evidence of data sharing agreements** and reference to the use of process that follow community endorsed policies and principles.

Example:

A paper by Kowal et al. (2012) presents a review of the literature and ethical issues relevant to genetic research in Indigenous populations. The ways in which these issues are negotiated within a particular genomic research project that involves the rural community of Aboriginal and Torres Strait Islanders are discussed. Outlined in the paper are the process and details of a Memorandum of Understanding between the research team, Aboriginal health services, and a community-owned education group.

Principle #14: Interpretation and Dissemination of Research

Article 14

An Indigenous community should have an opportunity to participate in the interpretation of data and the review of conclusions drawn from the research to ensure accuracy and cultural sensitivity of interpretation.

Key Features: Possible Ways to Demonstrate Principles

- **Encourage co-authorship/co-presentations to community**, researcher and other identified stakeholders (by Indigenous and Western-oriented researcher partners)
- **Ensure evidence that final results were viewed and agreed upon by all in the research partnership.**
- Show evidence that at the start of the project, **all in the research partnership understand that they have the opportunity to be involved in data interpretation.**
- **Confirmations with Indigenous community partners for permissions**, during data interpretation, dissemination.

Example:

In an evaluation study on how a Community Action Research Team (CART) and mentors experienced their role in a study addressing the high rates of sexually transmitted infections in four communities within Northwest Territories, Hopkins (Hopkins, 2012) describes a model for place- based knowledge exchange was developed. The work of the CART is community

driven, builds capacity and offers mutual support, and originally comprised of young Tłı̨ch̨q parents who wanted to improve the health and well-being of Tłı̨ch̨q community members.

Article 15

An Indigenous community should, at its discretion, be able to decide how its contributions to the research project should be acknowledged. Community members are entitled to due credit and to participate in the dissemination of results. Publications should recognize the contribution of the community and its members as appropriate, and in conformity with confidentiality agreements.

Key Features: Possible Ways to Demonstrate Principles

- **Encourage co-authorship/co-presentations to community**, researcher and other identified stakeholders (by Indigenous and Western-oriented researcher partners)
- **Ensure that dissemination is planned by and with community** (for example, in research agreement, protocols)
- **Identify and document clear roles for those in the research partnership identified.**
- **Offer opportunities for community stakeholders involved in research to co-publish, co-present, and use research.**

Example:

In a study by Bisset et al. (Bisset, Cargo, Delormier, Macaulay, & Potvin, 2004), Indigenous co-researchers played a key role in ensuring that research findings led to applied practice. The study was on the prevention of Type 2 diabetes and used a participatory action research approach that involved many key community stakeholders throughout the study.

Principle #15: Memoranda of Understanding and Research Agreements

- Agreements will reflect the spirit of OCAP®* principles of care for data and information obtained from research with Aboriginal people.