

First Nations Children's Action Research and Education Service

Guidelines for Ethical Research

“The most essential component of successfully applying First Nations research principles and guidelines is to accept them as a valued philosophy of research versus as a sidebar to western research ethics” (Blackstock, 2009, p. 113).

Introduction

The First Nations Children's Action Research and Education Service (FNCARES) translates research on the structural drivers of disadvantage for First Nations children and families into pragmatic, community-based solutions. FNCARES is committed to ethical research driven by, and for, First Nations communities. This document summarizes principles and practices for ethical research that FNCARES will rely upon in working with First Nations communities and organizations. It is arranged in chronological order according to major phases of a research project: I. Research Idea, II. Design/Planning, III. Action/Information Gathering, IV. Analysis/ Interpretation, V. Final Report and Dissemination, and VI. Follow Up. This summary incorporates principles and practices outlined in the documents listed below, giving precedence to the principles articulated by First Nations themselves:¹

- Assembly of First Nations, Environmental Stewardship Unit. (2009). [*Ethics in First Nations Research*](#)
- Blackstock, C., Cross, T., George, J., Brown, I., & Formsma, J. (2006). [*Reconciliation in child welfare: Touchstones of hope for Indigenous children, youth, and families*](#). Ottawa, ON, Canada: First Nations Child & Family Caring Society/Portland, OR: National Indian Child Welfare Association
- Blackstock, C. (2009). [*When everything matters: Comparing the experiences of First Nations and Non-Aboriginal children removed from their families in Nova Scotia from 2003 to 2005*](#)
- Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. (2010). [*Chapter 9: Research Involving the First Nations, Inuit and Métis Peoples of Canada. Tri-council policy statement: Ethical conduct for research involving humans*](#)
- Schnarch, Brian. (2004). [*Ownership, Control, Access, and Possession \(OCAP\) or Self-Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and some Options for First Nations Communities*](#). *Journal of Aboriginal Health*, 1(1), 80-95.

I. Research Idea

From the earliest stages of conception, researchers (First Nations and Non-Aboriginal) are required to respect and support First Nations self-determination in research by engaging with the community they hope to work with in order to do the following:

- Ensure that research goals are determined by First Nations priorities and interests, and that the research process and outcome will benefit the community in discernible ways

¹ For example, many of the principles and practices outlined in the Canadian Institutes' Chapter 9 of the *Tri-council policy statement* are recommended, but not mandatory. If these same principles are considered mandatory by First Nations, they are articulated as mandatory in this document.

- Ensure that the research will enhance the community's capacity to maintain their culture, language and identity as First Nations
- Establish relationships and communication practices that promote mutual trust and enable that community to be involved as partners in the research throughout each phase to the level they desire
- Undertake measures (including financial support) to identify and support the participation of Elders and other recognized knowledge holders to assist in research idea formation and guidance through all phases of the project
- Researchers must ensure non-discrimination by "respect[ing] First Nations ontology and practice, and view[ing] it on equal footing to Western knowledge" (Blackstock, 2009, p. 112)
- Identify research goals and appropriate collaborations or partnerships
- Ensure knowledge of local research ethics guidelines and processes, as well as community and cultural "protocols and customs for establishing a consensual research process" (Assembly of First Nations, 2009, p. 10)
- Be attentive to the diversity within and among First Nations communities, and ensure that researchers who are not insiders in the community take responsibility for learning as much as they can about that community, from credible community sources and literature, and be open to guidance from members of that community (without burdening the community).

II. Design/Planning

Before proceeding to the design phase, researchers must ensure free, informed and ongoing communal consent for further development of the project. This involves consent from local leadership and governing authorities, and any partners or collaborators identified during the Research Idea phase. Once consent is received, researchers must:

- Ensure that First Nations distinct worldviews, knowledge systems and codes of research practice are integrated into the design of the project, and carried throughout all phases
- Identify local research ethics and processes; note any discrepancies between the community's customs and codes of research practices and institutional policy and negotiate, with community, how these discrepancies will be resolved.²
- Acknowledge the unique status of First Nations as nations, and the implications of their inherent, Constitutional and treaty rights for the research. First Nations collectively own their cultural knowledge/data/information, and researchers must negotiate, with the community, ownership and property rights of any materials flowing from the research
- Jointly determine the various responsibilities and roles of the researchers, community and all collaborators for carrying out the project, including community's role in analysis/interpretation of data and review of reports and publications prior to dissemination
- Jointly determine what role the community will play in the analysis/interpretation of data, and in the review, report and dissemination of research findings
- Consult with community about how participants will be approached and compensated, and how language and cultural differences will be accommodated

² Researchers bound by the Tri-council Policy must ensure "that, at minimum, the provisions of [the] Policy are followed" (Canadian Institutes, 2010, p. 103)

- Consult with community about how the information will be disseminated, and agree on how contributions will be acknowledged
- Discuss and agree on how the information or data collected will be used, and ensure that the community has full access to information and data
- Ensure that protocols are in place for First Nations communities and organization to "manage and make decisions regarding access to their collective information" (Schnarch, 2004, p. 81); "community level data and statistics should not be released without the explicit permission of community authorities" (Assembly of First Nations, 2009, p. 12)
- Decide how privacy and confidentiality of information collected will be ensured on both the individual and the collective level; "research design must safeguard participant privacy and include measures to protect the confidentiality of any data collected" (Canadian Institutes, 2010, p. 127)
- Commit to building local capacity for research through training to enhance skills of research personnel in research methods, project management, ethical review and oversight, etc. (Canadian Institutes, 2010, p. 125)
- Clarify how findings will be made accessible to the community, i.e., language, format, etc.
- Write up a Research Agreement that specifies the terms and undertakings of both the researcher(s) and community before individual participants are approached; the Research Agreement will be used by Research Ethics Boards (REBs) to provide context and reference points for review and approval
- Once design is in place, seek ethics reviews from institutional REBs and from community REBs (where they exist). At this point, researchers must advise institutional REBs on the plan for community engagement, and provide evidence that the plan is appropriate in one or more of the following ways: a) preliminary formal Research Agreement (as above); b) "a written decision or document of an oral decision taken in a group setting to approve or decline further participation"; c) "a written summary of advice from a culturally informed advisory group or ad hoc committee." If a researcher has "an ongoing relationship with a community, a letter from formal or customary leaders may signal approval and suffice" (Canadian Institutes, 2010, p. 121)
- Write a memorandum of understanding (MOU) between the institution of the researchers and the community that outlines the "possession agreement," which "covers the control and use of data and human biological materials collected over the course of the research" (Canadian Institutes, 2010, p. 118)

III. Action/Information Gathering

Prior to information gathering, participants must be fully informed of the following: how their privacy will be protected, how information will be used, who will have access to information, how data will be shared, and if there is compensation for participation (e.g., transportation costs covered, share of royalties). Researchers must also:

- Ensure that there is "free, informed and ongoing consent from individual participants" (Canadian Institutes, 2010, p. 109) throughout the process
- Ensure data and information collection approaches respect cultural norms, safety of participants, and minimize potential harms to the welfare of the community (Canadian Institutes, 2010, p. 116)

IV. Analysis/Interpretation

During this phase, researchers must:

- Seek community's participation in analysis/interpretation of data as specified in the Research Agreement to ensure accuracy, validate findings, "correct any cultural inaccuracies, and maintain respect for community knowledge (which may entail limitations on its disclosure)" (Canadian Institutes, 2010, p. 128)
- Ensure that "[i]f disagreement about interpretation arises between researchers and the community and it cannot be resolved, researchers . . . either (a) provide the community with the opportunity to make its views known, or (b) accurately report any disagreement about the interpretation of the data in their reports and publications" (Canadian Institutes, 2010, p. 128)

V. Final Report and Dissemination

During this phase, researchers must:

- Integrate community's suggestions into the final report and into any material designed to disseminate research findings
- Acknowledge contributions to research in all reports and publications as specified in the Research Agreement
- Make final reports available to the community based on accessibility agreement as specified in Research Agreement

VI. Follow Up

- Researchers must remain available to the community "after the research project is finished to ensure the research manifests in discernible benefit to community members" (Blackstock, 2009, pp. 112-113)