Health research involving First Nations, Inuit and Métis children and their communities

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Canadian and international guidelines address the ethical conduct of health research in general and the issues affecting Indigenous populations in particular. This statement summarizes, for clinicians and researchers, relevant ethical and practical considerations for health research involving Aboriginal children and youth. While not intended to duplicate findings arising from lengthy collaborative processes, it does highlight 'wise practices' that have successfully generated knowledge relevant to, respectful of and useful for Aboriginal children, youth and their communities. Further research on current health issues and inequities should lead to practical, effective and culturally relevant applications. Expanding our knowledge of ways to address the health disparities facing Canada's Aboriginal children and youth can inform health policy and the provision of services. Community-based participatory research is proposed as a means to achieve this goal.

Key Words: *Aboriginal; Community-based participatory research; Indigenous; Research methods; Social determinants of health*

La recherche en santé auprès des enfants et des communautés issus des Premières nations et d'origine inuite ou métisse

Les lignes directrices canadiennes et internationales portent sur la tenue éthique de la recherche en santé en général et les problèmes touchant les populations autochtones en particulier. Le présent document de principes contient un résumé des considérations éthiques et pratiques pertinentes liées à la recherche en santé auprès des enfants et des adolescents autochtones, à l'intention des cliniciens et des chercheurs. Il ne vise pas à doubler les résultats découlant de longs processus coopératifs, mais il expose les « pratiques judicieuses » qui ont suscité des connaissances pertinentes, respectueuses et utiles pour les enfants, les adolescents et les communautés autochtones. D'autres recherches sur les enjeux et les inégalités en matière de santé devraient donner lieu à des applications pratiques, efficaces et pertinentes sur le plan culturel. Le fait d'accroître nos connaissances sur les moyens d'éliminer les disparités en santé dont sont victimes les enfants et les adolescents autochtones du Canada peut étayer les politiques en santé et la prestation des services. Les recherches participatives menées dans les communautés sont présentées comme un moyen de réaliser cet objectif.

DEFINITIONS

The term 'Aboriginal', as used in this document, is intended to be consistent with definitions used by the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada, and the Social Sciences and Humanities Research Council of Canada. The term 'Aboriginal peoples' includes "persons of Indian, Inuit or Métis descent regardless of where they reside and whether or not their names appear on an official register",⁽¹⁾ and should be used only where a global term is appropriate. Researchers must consider the distinct characteristics of Aboriginal groups in Canada before making unsubstantiated generalizations. In Canada, the term 'Indian' is used more historically to describe members of a variety of First Nations groups. Internationally, the word 'Indigenous' is used to describe descendants of the original inhabitants of a geographical region, and some researchers consider it the most inclusive descriptor of all Canada's First Nations, Inuit and Métis peoples.

BACKGROUND

Many Canadian paediatric health care providers participate in planning, conducting and disseminating research involving First Nations, Inuit and Métis children and youth. Even if they are not directly involved in research, front-line clinicians bring considerable insight to the medical and sociopolitical issues affecting the health of their Aboriginal patients. Paediatricians are uniquely positioned to identify situations in which thoughtful research may improve the health status of Aboriginal children and youth. This statement highlights how a community-based participatory research (CBPR) approach can serve to identify and address the social determinants of health impacting the health of Aboriginal

children, youth and their communities. The basic premises of CBPR can be applied to any research project designed to support disadvantaged, marginalized or minority groups.

Conducting research that involves children entails a certain 'moral duty' and conduct based on ethical principles such as beneficence, nonmaleficence and distributive justice.⁽²⁻⁴⁾ The latter principle best describes physician responsibilities to children who are members of a vulnerable group. Epidemiological and population health studies repeatedly show that Aboriginal children and youth are one of the most vulnerable populations in Canada. They lag behind their non-Aboriginal peers on almost every measure of health,⁽⁵⁾ including infant mortality,⁽⁶⁾ early childhood development, acute health care needs, chronic medical conditions and mental health.⁽⁷⁻¹⁰⁾ Increased rates of substance abuse (ie, tobacco, prescription drugs and alcohol)⁽¹¹⁻¹³⁾ and suicide⁽¹⁴⁾ reflect the more pressing disparities facing Aboriginal adolescents in this important transitional phase of life.⁽¹⁵⁾

Analyzing the social determinants of health and well-being is one way to understand the root causes of inequality affecting children and youth.⁽¹⁶⁻¹⁹⁾ For Aboriginal young people, additional determinants include kinship and support networks, racism, and the loss of traditional language, land and social identity.^(20,21) These unique determinants must be considered in any culturally relevant model used to evaluate health patterns and the circumstances perpetuating them. In many Aboriginal communities in Canada, traditional ways of life have been marked indelibly by colonial practices,⁽²²⁾ most notably by the residential school system, which has created a legacy of mental health and addiction problems with damaging intergenerational effects.⁽²³⁾

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Because colonization and related research practices have, at times, caused harm to Aboriginal peoples,(24,25) special care must be taken to safeguard children and youth from involvement in projects that do not serve their best interests in every respect. Some projects have been criticized for approaching Aboriginal researchers as informants rather than as colleagues; other studies have either publicized or profited from sensitive cultural information. There are significant challenges in collecting and analyzing Aboriginal public health data due to issues with accurately identifying Aboriginal persons, and with including both on- and off-reserve populations in single studies.(20) Concerns have also been raised that research to date has not examined the health needs of Aboriginal peoples proportionately, that is, with a depth and focus proportionate to their share of the population, particularly with respect to Métis groups, urban Aboriginals, First Nations persons living off reserve, women and children.(26) A comprehensive review of recent publications points to a failure to examine key determinants and indicators of health that capture and reflect the profiles of Aboriginal youth in Canada, either demographically or geographically.(27)

Responding to concerns that Aboriginal communities have been “researched to death,”(28) today’s investigators are challenged to find study methods or approaches that avoid misrepresentation or stigmatization, especially when research involving individual children is perceived to confer ‘risk by association’ by extrapolating results to a larger group.(29,30) Approaches have been proposed that enable Aboriginal communities to ‘come to life’ through mutually beneficial relationships with researchers.(28) At the heart of such proposals is a core tenet of Aboriginal ideology: that children’s success is a source of perpetual, living hope for future generations.

WHAT GUIDELINES GOVERN CANADIAN HEALTH RESEARCH?

The 2010 edition of the Tri-Council Policy Statement: Ethical conduct for research involving humans (or TCPS 2)(1) guides the conduct of research supported by three major Canadian research funding bodies. Chapter 9 focuses on research work that explores issues pertinent to Canadian Aboriginal peoples. It incorporates and replaces the CIHR’s 2007 Guidelines for health research involving Aboriginal people.(31) TCPS 2 was written and reviewed through a collaborative process that involved representatives from academia and Aboriginal groups. The core principles of TCPS 2 apply to all human research projects, but some points are especially salient for work with Aboriginal populations and are highlighted below.

The principle of ‘respect for persons’ requires that the welfare and integrity of individuals must take priority over every other research consideration: it is unacceptable to treat individuals as means to an end. Researchers must respect the autonomy of participants and especially their capacity to make voluntary and informed decisions. Materials used in obtaining informed consent must give an accurate account of the anticipated risks and potential benefits of participation. To ensure that participants fully understand these materials, they must be presented in a language and format suited to the participants. In Aboriginal communities, this may require translating materials into a traditional language or presenting them both orally and in a written form, depending on the age and literacy levels of study recipients. Following appropriate cultural protocols in a particular community (vis à vis the community as a whole and with individual participants) is also essential.(29)

Discussions regarding autonomy typically focus on the rights of individuals to make appropriate personal choices. In Aboriginal cultures, a sense of community, whether geographical or more widely social, is an essential consideration in decisions that are

observed to affect a group or to depend on knowledge residing in the community as a whole. Researchers must acknowledge the importance for many Aboriginal people of honouring multigenerational obligations, both to ancestors and to future generations. When considering a community project, it may be appropriate to approach community leaders, representatives or Elders first, before the individual study participants, to obtain informed consent.(32) In some cases, the approval of esteemed members in a given community may be a requirement for larger participation. Community engagement is important at every stage of a research endeavour. However, a decision made on behalf of a community can never override an individual’s right to autonomous decision making. Collective welfare should always be regarded as a secondary complement to individual well-being.

Researchers must demonstrate concern for participants’ welfare in any research study. Groups that may be affected by a research project must be consulted individually before a study is conducted to assess the risk of negative impacts, such as stigmatization, discrimination and the loss of control over research outcomes. Research that focuses on problems in a specific population should also propose ways of addressing disparities and building on existing strengths. In small Aboriginal communities, efforts must be made to protect the anonymity of participants. Disclosure to specific audiences should be made beforehand to participants and presented in a way that is acceptable to them as holders of this information. This approach may involve interpreting and contextualizing research findings for and with the source community (or an advisory board of community members) before publication, a step that challenges traditionally ‘objective’ arm’s-length relationships between academics and research participants.(33)

The principle of distributive justice asserts that researchers have an obligation to treat individuals fairly and equitably. No population group should be unfairly burdened with the risks for harm of research, nor should any individual or group be neglected or discriminated against so that others benefit from knowledge generated by research. Some authors and community leaders have noted that Aboriginal people have had minimal experience of actual advances relating to their participation in many research projects. There is ample opportunity to strengthen communities through projects based on goals defined by the participants themselves. Researchers may regard community engagement and shared decision making as onerous processes, but research conducted along these premises can address concerns identified by the community more directly and specifically (eg, reducing child health disparities and building community capacity to engage in health promoting activities).

In any research activity, possible imbalances of power between participants and researchers must be considered. This precaution particularly holds true for research involving children, and the Canadian Paediatric Society’s Bioethics Committee has explored the topic in some detail.(2) Considering power relationships becomes even more important in the ethical treatment of Aboriginal children in research. (23) Researchers must also appreciate how negative experiences of research in the past and an all-too-frequent failure to return results to the community have led to mistrust and hesitancy in sharing sensitive health information. In the future, researchers need to strive for equitable, collaborative relationships that value traditional and sacred knowledge held by Elders and other community knowledge holders alongside academic contributions.

CBPR AND HEALTH DISPARITIES

CBPR is an approach to research that emphasizes shared power and decision making. Community representatives are involved in all stages of research, from identification of the research question, to

Box 1: Ownership, control, access and possession (OCAP) principles for self-determination in research involving First Nations

<u>Ownership</u>	A First Nations community or group owns information collectively in the same way that an individual owns their personal information. Ownership is distinct from stewardship, although an institution may act as a caretaker of information if it is accountable to the group.
<u>Control</u>	First Nations people are within their rights in seeking to control all aspects of research and information management processes which impact them, including the control of resources and review processes, the formulation of conceptual frameworks, and data management.
<u>Access</u>	First Nations people must have access to information and data about themselves and their communities, regardless of where it is held.
<u>Possession</u>	Although not a condition of ownership per se, the possession (of data) is a mechanism by which ownership can be asserted and protected.

Based on reference 25

designing appropriate methods for collecting and interpreting data, through to applying and disseminating research findings.(34) CBPR in Aboriginal communities involves projects conducted by, for, and with Aboriginal people. Equitable engagement ensures that a given study addresses the needs of communities and builds the capacity of community members and leaders (as well as academic researchers) to develop responsive and effective health interventions.

CBPR supports the desire of some Aboriginal groups to maintain 'ownership, control, access and possession' of research projects and data.(25) The 'ownership, control, access and possession' principles (Box 1) were developed originally for conducting the First Nations Regional Longitudinal Health Survey. They have since been recommended as a necessary component of any research project involving First Nations communities. In particular, traditional knowledge must be respected as the birthright of Aboriginal children, and researchers must devote attention to intellectual property rights and use appropriate acknowledgement when citing or attributing research work. Developing genuine, collaborative partnerships based on reciprocal communication will help ensure that the research being conducted and the information to be generated will be culturally sensitive and relevant, while offering benefits to all involved.

Research based on authentic relationships among academics and Aboriginal community members can better meet community-identified needs. Aboriginal researchers reiterate the importance of including traditional 'wise practices' in CPBR, a best practice approach to "locally appropriate actions, tools, principles or decisions that contribute to the development of sustainable and equitable social conditions".(35) Many innovative CBPR projects have helped Aboriginal communities to explore their own health-related needs and strengths.(36-38) Equitable collaborations based on authentic and trusting partnerships lead to better health research. In Aboriginal communities, this research will not only address the social determinants of health explicitly but also generate results that help to reduce health disparities for Aboriginal children and youth.(33,39)

RECOMMENDATIONS

The Many Hands, One Dream initiative, spearheaded by national organizations concerned with Aboriginal child and youth health, articulated nine principles that should help guide approaches to the health of First Nations, Inuit and Métis children and youth. (40) CBPR is consistent with these principles. The following core

best practices should apply whenever health research involving Aboriginal children, youth, families or communities is being planned or conducted:

- Aboriginal children and youth must have the same right of access to the benefits of health research as other Canadians.
- A CBPR approach to research should be the first, preferred option for all research involving Aboriginal peoples and communities, especially when social determinants of health are at issue.
- It is the ethical responsibility of researchers to ensure knowledge of or otherwise inform Aboriginal peoples and communities concerning research principles defined in the Tri-Council Policy Statement: Ethical conduct for research involving humans, December 2010: www.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf. Participants should be fully aware of their options for collaboration and input at all stages of the CBPR process.
- Gathering, restoring and exploring knowledge gained from research must occur through community partnerships, and the use of such knowledge must build on community strengths. Open dialogue and capacity building that respects differences and explores similarities across ethical, procedural and cultural boundaries are required.
- To reduce the serious health disparities faced by First Nations, Inuit and Métis children and youth in Canada, governments at every level must prioritize funding for CBPR projects and programs.

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