ABSTRACT

Participatory research requires ethical guidelines to incorporate the needs of the partners, i.e., the researchers and the community. This paper describes the background, development and implementation of an innovative Code of Research Ethics developed for a participatory research project with a Native community in Canada. The document ensures that responsibility and control will be shared by both researchers and community throughout the project including joint publication of the results. It defines community control of data, means of resolving dissension at time of publication, incorporation of new researchers and the differences between community-based and academic researchers.

ABRÉGÉ

La recherche participative exige des balises déontologiques afin d'assurer que les besoins de tous les partenaires, autant ceux des chercheurs que ceux des membres de la communauté impliquée, puissent être pris en considération. Cette article décrit le contexte et la mise en application d'un code innovateur en matière de déontologie de recherche. Ce code a été créé dans le contexte d'une intervention et d'une évaluation d'un projet de prévention du diabète dans une communauté autochtone du Canada. Ce code de déontologie délimite les obligations et les responsabilités de chacun des partenaires pour la durée du projet. Il y est question des distinctions dans les rôles des chercheurs universitaires et communautaires, de la propriété des données recueillies lors du projet, du rôle des partenaires dans les divers types de publication, du processus de résolution des dissensions possibles lors de la publication, ainsi que de l'intégration de nouveaux chercheurs en cours de projet.

Participatory Research with Native Community of Kahnawake Creates Innovative Code of Research Ethics

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All research requires ethical guidelines to protect the research subjects and guide the researchers. In the past, researchers frequently had exclusive control of the research process and use of the results. Participatory research attempts to break down the distinction between researcher and subjects and to build collaboration between the parties. This article describes an innovative Code of Research Ethics which offers new direction for participatory research projects.

Participatory research can be applied to numerous forms of research¹ with varying degrees of intensity.² The term usually defines a research inquiry which involves: 1) some form of collaboration between the researchers and the researched; 2) a reciprocal process in which both parties educate one another; and 3) a focus on the production of local knowledge to improve interventions or professional practices.^{3,4} The ultimate aim of participatory research is to empower research subjects to assume ownership of the research process and to use

the results to improve their quality of life.⁵ Some authors argue that participatory research is a health-promoting endeavour in itself.^{3,6} There are advantages to involving beneficiaries in conducting health promotion programs.⁵ The relevance of the research questions and data collection methods agreed to by participants are more likely to be accepted by the study subjects and to lead to useful results for the target community.⁷ Involving participants in interpretation of the results usually brings richer contextual information and increasingly meaningful conclusions. Mittlemark² provides examples of the types of partnership that can be established between academic researchers and communities. In his work, the organizing principle is the location of project leadership. When the community is the senior partner, projects are designed and implemented by community groups and the academic partner is contracted to assist with particular problems. If academic groups are senior partners, authority begins with them and is gradually transferred to community groups. Finally, programs with balanced partnerships occur when leadership shifts back and forth, depending on which group has expertise for a given problem.

Ethical guidelines for participatory research need to reflect this sharing of leadership, power and decision making. Both partners should be involved at all stages: design, implementation, data analysis and publication of the results. In the past two decades, international,⁸ national,^{9,10} and professional organizations¹¹ and Native groups¹²⁻¹⁶ have reflected on these needs. The Council of International Organizations of Medical Sciences states: "the community to be studied should be represented in the ethical review process...it

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should not be considered that lack of formal education disqualifies community members from joining in constructive discussion on issues relating to the study and application of its findings;⁸ this is echoed by the Medical Research Council of Canada, "it needs the participation of communities in all phases of research, as appropriate to the questions under study."¹⁷

In 1982, one of the first documents to sensitize researchers to Native communities in Canada¹¹ stated that the community needs: 1) explanations of research objectives, methods, findings and interpretations, 2) a description of the data and knowledge of where the data are filed, 3) the opportunity to comment before publication, and 4) ways to suspend research if the community decides the project becomes unacceptable. In the last decade, Native organizations¹²⁻¹⁶ and experts in participatory research⁴ have continued to develop research agreements. These transform the principles of participatory research into practical tools and checklists. The latter appraise the extent to which each proposal is aligned with the principles of participatory research, clarify the roles and educate the partners of each other's needs. They require researchers and communities to negotiate written agreements, using an appropriate literacy level,¹⁸ prior to undertaking the research.

Code of Research Ethics for the Kahnawake Schools Diabetes Prevention Project

This Code of Research Ethics was developed in partnership with the Native Mohawk community of Kahnawake in Canada. It demonstrates new concepts in the sharing of power and decision making for both researchers and the community. The seven-page document contains a policy statement, the principles of participatory research, the differences between community-based and academic researchers, the obligations of the researchers and the community, data ownership, the process of incorporating new investigators and most importantly, the procedure for joint dissemination of results, including dissension if necessary.

The Kahnawake Schools Diabetes Prevention Project (KSDPP) is a participa-

tory research health promotion project.¹⁹ The long-term goal is the primary prevention of non-insulin-dependent diabetes mellitus through the short-term goals of healthy eating and daily physical activity of elementary school children. Kahnawake, population 7,000, is 15 kilometres south of Montreal, Quebec. For the KSDPP there are three partners: the community of Kahnawake through the Community Advisory Board (CAB), the community-based researchers and the academic researchers. The CAB, with 40 volunteers from community organizations and the private sector, is a full partner at all stages of the research from design to publication of results.

Developmental process

Researchers and project staff first reviewed existing codes of ethics and recommendations for research with Native communities.²⁰⁻²³ After several drafts, a working document was circulated to all members of the CAB. Two researchers and the CAB met for half a day to discuss and review the document. The resulting comments were incorporated into the revised document, which was circulated back to the CAB and researchers for final modifications. This process took approximately eight months.

Description and use of Code of Research Ethics

The Policy Statement (Figure 1) ensures that the cultural values, perspectives and wishes of this Mohawk community are firmly incorporated and emphasizes the need for community empowerment. The KSDPP originated from community requests for diabetes prevention²⁴ and during the design phase, the community decided that diabetes prevention should focus on the elementary school children.

The Principles of Participatory Research (Figure 2) clearly define the roles of the partners who are collaborating for the benefit of the community. These principles have ensured that the CAB plays an important role in developing policies for the research project, as well as providing guidance for interventions and evaluations, i.e., developing culturally appropriate telephone interviews. The CAB is taking an

active role in questioning, discussing and interpreting the results.

Obligations of all researchers. Obligations such as written permission from the research subjects, anonymity, confidentiality and scientific accuracy are common to all ethical guidelines. Other obligations pertain specifically to participatory research: these include continuous consultation and collaboration on all aspects of the research, community involvement through active participation rather than passive acceptance, transfer of new skills to the community during the research process, and help to address any health or social issues raised as a result of research. Some of these obligations are used in agreements with other Native communities.^{12-16,25}

Obligations of community-based researchers. A new development is the delineation of the community-based researchers, who have the additional obligation of maintaining a long-term relationship of trust in their dual role as caregivers/educators and researchers: "This is possible if the needs of the community are always considered as the first priority in any decision."

Obligations of community. These are to meet regularly with the researchers, to promote the objectives of the project, to offer advice for the intervention and interpretation of the evaluation, to control the data after the project ends, and to write dissenting opinions, if needed, at the time of publication.

Control of data. The Code of Research Ethics ensures that the community controls the data both during the research and after the research ends. There are several clauses in the document to protect this control.

During the project the academic researchers are appointed guardians of the data. At the end of the project the data must be returned to the community, who will decide on any further use of the data. However, the community is obligated to offer the original academic and community researchers the opportunity to continue the analysis, before the data are offered to new investigators.

During the research any new researchers, such as graduate students or established

"The sovereignty of the Kanien'keha:ka (the people) of Kahnawake to make decisions about research in Kahnawake is recognized and respected. The benefits to the community as a whole and to individual community volunteers should be maximized by the researchers. Research should empower the community to support community goals of health and wellness, to promote healthy lifestyles, improve its self-esteem and to fulfill its traditional responsibility of caring for the Seventh Generation." (*In Mohawk tradition, the Seventh Generation represents those as yet unborn*).

Figure 1. Policy Statement

"The Kahnawake Schools Diabetes Prevention Project is a partnership of the Kanien'keha:ka (Mohawk) community of Kahnawake, community-based researchers and academic researchers. In this document these three groups are referred to as the three partners. The three partners will work cooperatively and collaboratively in the design, implementation, analysis, interpretation, conclusion, reporting and publication of the experiences of the project. Each partner provides ideas and resources that come from the experience, knowledge and capability of all its members. Together, through respect for each other, consultation and collaboration, they significantly strengthen the project and its outcomes. All three partners of the project share an understanding that community-based research is a powerful tool for learning about health and wellness, while contributing to the health of the community in which it is being conducted."

Figure 2. The Principles of Participatory Research

"No partner can veto a communication. In the case of disagreement, the partner who disagrees must be invited to communicate their own interpretation of the same data as an addition to the main communication, be it oral or written. All partners agree to withhold any information if the alternative interpretation cannot be added and distributed at the same time, providing the disagreeing partner(s) do not unduly delay the distribution process."

Figure 3. Dissemination of Results

investigators, must first apply to all three partners. They will only be accepted if all three partners agree and if the incoming researcher agrees to follow the Code of Research Ethics. The CAB has been a full partner in incorporating two Masters students and one established investigator into the evaluation team.

Dissemination of results (Figure 3). The most unique feature of the Code of Research Ethics is the continued sharing of power and control for dissemination of the results (Figures 2 and 3). The community remains a full partner at this final stage, including publication in scientific journals.

If one of the partners disagrees with the interpretation of the data or the dissemination of the results, it will be resolved as per the clause in Figure 3. There are only a few examples of significant community representation for dissemination of the data.^{15,16} To our knowledge, this is the first time the right to dissent is written into a code of ethics.

During the project, the researchers first discuss the results with the CAB. Next, articles, some co-authored by researchers and CAB members, are published in the local newspaper. Before attending conferences or submitting articles for scientific

publication, the researchers discuss their papers and articles with the CAB, which has led to modification and strengthening of the final products.

DISCUSSION

Although guidelines exist, there have been few reports on the application of codes of ethics in empirical research projects. The KSDPP is an example of participatory research where there is a balanced partnership between the researchers and the community.² The Code of Research Ethics has reinforced this shared leadership throughout the project, including with respect to scientific publications. The developmental process was, in itself, an exercise in participatory research. The consultations promoted discussion on the general topic of ethics and increased the level of trust between the partners. Participation in the developmental process fostered a sense of ownership in the CAB. The eight months required to develop the document seemed unduly long, but on reflection it gave everyone the opportunity to define their roles.

The document meets the recommendations of international, national and Native organizations. The policy statement ensures that the cultural values, perceptions and expectations of this Mohawk community are firmly incorporated to respect Native sovereignty. The role of the community-based researchers is recognized as being different from that of academic researchers.

Community ownership of data, both during and after the research process, prevents potential misuse of the results. Managing dissent at the time of publication is an innovative feature which provides a framework for discussion and negotiation and aims to avoid extreme solutions and unresolved disagreements. Sometimes researchers have published without consulting the community, resulting in negative consequences from publications where communities had "no opportunity to correct misinformation or to challenge ethnocentric and racist interpretations."¹⁰ At the opposite end of the scale, communities have had power of veto at the time of publication, or researchers have agreed not to

publish beyond reporting requirements to the funding agency.²⁵ Joint publication requires close collaboration and the clause for dissension offers compromise. To date, there has not been a need to use this clause.

This Code of Research Ethics, developed for participatory research with a Native community, is attracting interest from universities,²⁶ government organizations²⁷ and Native groups. We believe the principles are equally applicable to both Native and non-Native research; indeed they have the potential to strengthen all participatory research.²⁸ As stated by previous organizations, we do not believe that these recommendations should be imposed on all research; rather that these ideas be discussed and individualized for each project.

For a copy of Kahnawake Schools Diabetes Prevention Project Code of Research Ethics, please send \$5.00 to Edward J. Cross, Kahnawake Education System, P.O. Box 1000, Kahnawake, Quebec, J0L 1B0, Canada.

REFERENCES

- Reason P. Three approaches to participative inquiry. In: Denzin NK, Lincoln YS (Eds.), *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications, 1994; 324-39.
- Mittlemark M. Balancing the requirements of research and the needs of communities. In: Bracht N (Ed.), *Health Promotion at the Community Level*. Newbury Park, CA: Sage Publications, 1990; 125-39.
- McTaggart R. Principles for participatory research. *Adult Educ Q* 1991;41:168-87.
- Green LW, George MA, Daniel M, et al. Study of Participatory Research in Health Promotion. The Royal Society of Canada, 1994.
- Israel BA, Cummings KM, Dignan MB, et al. Evaluation of health education programs: Current assessment and future directions. *Health Educ Q* 1995;22:364-89.
- Labonte R. Health promotion and empowerment: Reflections on professional practice. *Health Educ Q* 1994;21:253-68.
- Potvin L. Methodological challenges in evaluation of dissemination programs. *Can J Public Health* 1996;87 Suppl.2:S79-S83.
- Council of International Organizations of Medical Sciences. International Guidelines for Ethical Review of Epidemiological Studies. Geneva: CIOMS, 1991.
- Code of Conduct for Research Involving Humans. Tri-Council Working Group. Ottawa: Draft Document, 1996.
- Royal Commission on Aboriginal Peoples. Appendix B; Ethical Guidelines For Research. Integrated Research Plan. Ottawa: RCAP, 1993.
- Association of Canadian Universities for Northern Studies. Ethical Principles for the Conduct of Research in the North. Ottawa: ACUNS, 1982, reprinted 1988.
- Dene Tracking (Masuzumi B, Quirk S.). A Participatory Research Process for Dene/Metis Communities: Exploring Community-Based Research Concerns for Aboriginal Northerners. September 1993. Dene Nation, Box 2338, Yellowknife, NWT, X1A 2P8, Canada.
- Inuit Tapirisat of Canada, Research Department. Negotiating Research Relationships in the North. Background paper for the workshop on guidelines for responsible research, Yellowknife, September 1993.
- American Indian Law Center. Model Tribal Research Code with materials for tribal regulation for research and checklist for Indian Health Boards. Albuquerque, NM, 1994.
- Matsunaga DS, Enos R, Gotay CC, et al. Cancer Supplement, Participatory Research in a Native Hawaiian Community. 1996;78(7):1582-86.
- Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research. National Health and Medical Research Council, Commonwealth of Australia, 1991.
- Investing In Health: Sharing the Vision. Report of the Task Force on Health Research to the Medical Research Council of Canada. Ottawa: Medical Research Council of Canada, 1994;15.
- Freeman WL. Making research consent forms informative and understandable: The experience of the Indian Health Service. *Cambridge Q Healthcare Ethics* 1994;3:510-20.
- Macaulay AC, Paradis G, Potvin L, et al. The Kahnawake Schools Diabetes Prevention Project: Intervention, evaluation, and baseline results of a Diabetes Primary Prevention Program with a Native community in Canada. *Prev Med* 1997;26:779-90.
- Freeman WL. Research in rural Native communities. In: Bass MJ, Dunn EV, Norton PG, Stewart M, Tudiver F (Eds.). *Conducting Research in the Practice Setting*. Newbury Park, CA: Sage Publications, 1993;179-96.
- Macaulay AC. Ethics of research in Native communities. *Can Fam Phys* 1994;40:1888-90.
- Scott K, Receveur O. Ethics for working with communities of indigenous peoples. *Can J Physiol Pharmacol* 1995;73:751-53.
- O'Neil JD, Kaufert JM, Kaufert PL, Koolage WW. Political considerations in health-related participatory research in Northern Canada. In: Dyck N, Waldram JB (Eds.), *Anthropology, Public Policy and Native Peoples in Canada*. Kingston: McGill-Queen's University Press, 1993;215-32.
- Montour LT, Macaulay AC. Returning research results to the Mohawk community. *CMAJ* 1988;139:201-2.
- Herbert CP. Community-based research as a tool for empowerment: The Haida Gwaii Diabetes Project example. *Can J Public Health* 1996;87(2):109-12.
- Hennen B. Demonstrating social accountability in medical education (Editorial). *CMAJ* 1997;156:365-67.
- Research Division of Indian Health Service, USA. Dr. William Freeman - personal communication, 1997.
- Maddocks I. Ethics in Aboriginal research: A model for minorities or for all? *Med J Austr* 1992;157:553-55.

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