HEALTH SCIENCES RESEARCH AND ABORIGINAL COMMUNITIES: PATHWAY OR PITFALL?

Janet Smylie, MD, CCFP, MPH,[1,2] Nili Kaplan-Myrth, PhD,[3] Caroline Tait, PhD,[4] Carmel Mary Martin, MD, PhD, MRCGP,[1,2] Larry Chartrand, LLB, LLM,[5] William Hogg, MD, CCFP, MSc, MCISc,[1,2] Peter Tugwell, MD, MSc, FRCPC,[2] Gail Valaskakis, PhD,[6] Ann C. Macaulay, MD, CCFP[7]

[1]Department of Family Medicine, University of Ottawa, Ottawa ON
[2]Institute of Population Health, University of Ottawa, Ottawa ON
[3]Department of Public Health Sciences, University of Toronto, Toronto ON
[4]Culture & Mental Health Research Unit, Sir Mortimer B. Davis – Jewish General Hospital, Montreal QC
[5]Faculty of Law, University of Ottawa, Ottawa ON
[6]Aboriginal Healing Foundation, Ottawa ON
[7]Department of Family Medicine, McGill University, Montreal QC

Abstract

Objective: To provide health researchers and clinicians with background information and examples regarding Aboriginal health research challenges, in an effort to promote effective collaborative research with Aboriginal communities.

Methods: An interdisciplinary team of experienced Aboriginal-health researchers conducted a thematic analysis of their planning meetings regarding a community-based Aboriginal health research training project and of the text generated by the meetings and supplemented the analysis with a literature review.

Results: Four research challenges are identified and addressed: (1) contrasting frameworks of Western science and indigenous knowledge systems; (2) the impact of historic colonialist processes upon the interface between health science research and Aboriginal communities; (3) culturally relevant frameworks and processes for knowledge generation and knowledge transfer; and (4) Aboriginal leadership, governance, and participation.

Conclusion: Culturally appropriate and community-controlled collaborative research can result in improved health outcomes in Aboriginal communities and contribute new insights and perspectives to the fields of public health and medicine in general.

Résumé

Objectif : Offrir, aux cliniciens et aux chercheurs du domaine de la santé, des renseignements généraux et des exemples en ce qui a trait aux défis de la recherche sur la santé des Autochtones, et ce, en vue de promouvoir une pratique de collaboration efficace pour la recherche auprès des communautés autochtones.

Méthodes : Une équipe interdisciplinaire de chercheurs expérimentés du domaine de la santé des Autochtones a mené une analyse thématique de leurs réunions de planification (lesquelles visaient la mise sur pied d'un projet communautaire de formation en recherche sur la santé des Autochtones) et des procès-verbaux de celles-ci. Cette analyse a par la suite été étoffée à l'aide d'une revue de la littérature.

Résultats : Quatre défis en matière de recherche ont été identifiés et traités : (1) le contraste entre les principes de la science occidentale et les systèmes de connaissance indigènes; (2) l'effet des procédés colonialistes historiques sur l'interface entre les chercheurs en sciences de la santé et les communautés autochtones; (3) la conception de structures et de procédés pertinents sur le plan culturel afin de procéder à la production et au transfert des connaissances; (4) le leadership, la gouvernance et la participation des autochtones.

Conclusion : L'adoption d'une pratique de collaboration en recherche, qui est appropriée sur le plan culturel et régie par la communauté, peut entraîner une amélioration des résultats pour la santé au sein des communautés autochtones, ainsi qu'apporter de nouvelles connaissances et perspectives aux domaines de la santé publique et de la médecine en général.

J Obstet Gynaecol Can 2004;26(3):211–6.

Key Words

Aboriginal health research, participatory research, indigenous knowledge, Aboriginal communities, knowledge translation, health services research, cross-cultural comparison, information dissemination, Aboriginal, First Nations, Metis, Inuit, Maori, Pacific Islander, Aborigine

Competing interests: None declared.

Received on September 18, 2003
Revised and accepted on December 2, 2003

INTRODUCTION

The health status of Aboriginal communities in Canada falls well below that of other Canadians.[1-3] Life expectancy of Aboriginal peoples is approximately 5 to 7 years less than that of the general Canadian population.[4] Chronic diseases, postneonatal mortality, accidental deaths, infectious diseases, and mental health problems continue to be disproportionately common among Aboriginal peoples.[2,3] Despite some improvements in the health of Aboriginal peoples over the past decades, healthcare and social support systems have yet to succeed in eliminating

this disparity. The gaps in current health information are a major barrier to the effective planning and implementation of health-care services within Aboriginal communities.[5] The poor heath status outcomes of Aboriginal peoples occur in a context of the adverse sociodemographic realities facing many Aboriginal individuals and communities.[6-8]

Through working together to design a training program for Aboriginal community members learning how to conduct participatory Aboriginal health research, we identified 4 research challenges from the current landscape of Aboriginal health research in Canada: (1) the contrasting frameworks of Western science and indigenous knowledge systems, (2) the impact of historic colonialist processes upon the interface between health science research and Aboriginal communities, (3) culturally relevant frameworks and processes for knowledge generation and knowledge transfer, and (4) Aboriginal leadership, governance, and participation.

It is our belief that the successful navigation of each of these thematic areas is fundamental to achieving effective collaborative research with Aboriginal communities, and has the potential to contribute profoundly to health research in general.

CONTRASTING FRAMEWORKS OF WESTERN SCIENCE AND INDIGENOUS KNOWLEDGE SYSTEMS

An emerging body of literature on indigenous knowledge has been produced by Aboriginal scholars in Canada over the past 30 years.[9-14] Most of this work has its academic links to departments of Native studies, social sciences, and law, with a few exceptions that are linked to health.[11,14] Indigenous knowledge systems have been described as being ecologic, holistic, relational, pluralistic, experiential, timeless, infinite, communal, oral, and narrative-based.[13,15-17] Bearing in mind the limitations of a dichotomous framework, and recognizing that there is also considerable overlap in some areas, Western science has been described as reductionist, linear, objective, hierarchical, empirical, static, temporal, singular, specialized, and written (Table).[16,18-21]

Inherent methods of indigenous knowledge generation and application are participatory, communal, experiential, and reflective of localized geography. Practitioners of both scientific and indigenous knowledge systems organize information to condense experience and beliefs into "knowledge."

Comparison of Characteristics of Indigenous Knowledge Systems and Western Science

Indigenous Knowledge	Western Science
Ecologic/holistic	Reductionist/linear
Relational	Objective
Pluralistic	Hierarchical
Timeless/Infinite	Static/temporal
Communal	Singular
Oral	Written

In Western knowledge systems, this process involves the organization of data into abstract theoretical systems composed of multiple components, each of which requires a "specialist" to be fully understood (Figure 1). Western scientists give low priority to translating their knowledge for the benefit of members of the larger society. Furthermore, by employing processes of self-authentication, they set science apart from other forms of knowledge production.

In indigenous knowledge systems, generation of knowledge starts with "stories" as the base units of knowledge, then proceeds to "knowledge" as an integration of the values and processes described in the stories, and finally culminates in "wisdom" as a distillation of experiential knowledge. This process can be viewed as being cyclical, since keepers of "wisdom" in turn generate new "stories" as a way of disseminating what they know (Figure 2). Traditionally, localized forms of knowledge dissemination were interwoven with social, political, and kinship structures to reinforce individual and collective well-being and to ensure the protection and sustainability of the physical environment.

Although, for the most part, indigenous knowledge systems have been systematically marginalized,[18] indigenous perspectives of health as a balance of physical, mental, emotional, and spiritual elements almost certainly shaped the broader definition of health that was adopted by the World Health Organization at Alma-Ata, USSR, 1978.[23]

The emerging explication of indigenous paradigms by indigenous scholars[11-15,18,21] provides researchers with a set of conceptual tools that were previously difficult to access. This advancing epistemologic base sets the stage for an exciting

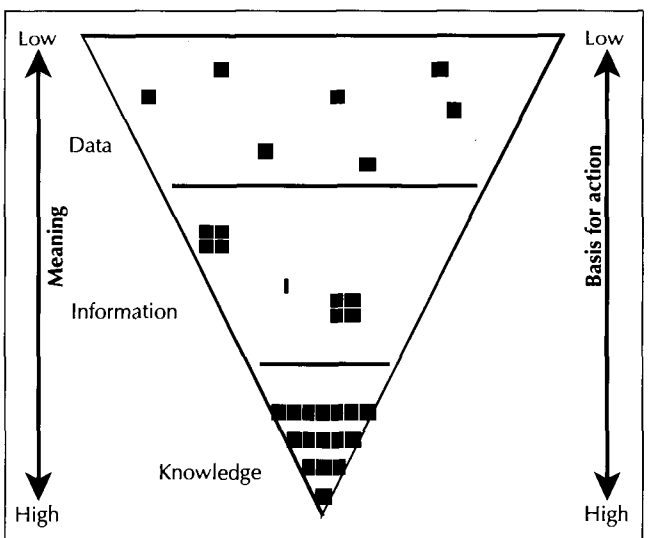

Figure 1. Relationship between data, information, and knowledge – Western science. Dion Stout and Kipling,[14] adapted from Burton-Jones.[22] Reprinted with permission of the copyright holders, the National Aboriginal Health Organization.

dialogue on quantitative and qualitative research methodologies that acknowledges not only the differences, but also the convergence, between Western science and indigenous thought.

THE IMPACT OF HISTORIC COLONIALIST PROCESSES ON THE INTERFACE BETWEEN HEALTH SCIENCE RESEARCH AND ABORIGINAL COMMUNITIES

The processes and outcomes of European colonization of the Americas have had a major ongoing effect on the physical, mental, emotional, and spiritual well-being of Aboriginal peoples in Canada, and continue to influence the relationships that Aboriginal individuals and communities have with health research and researchers. Health researchers, therefore, need to have a basic sense of the history of Aboriginal–European relations over the past 500 years and must be careful not to perpetuate colonial policies and attitudes.

Indigenous knowledge systems were systematically marginalized through government policies of assimilation that included the outlawing of Aboriginal cultural traditions, the abduction and forced assimilation of Aboriginal children through the residential school system, and a reservation system, which gave non-Aboriginal Indian agents authority over both the distribution of food and material goods and off-reserve travel by reserve members. At the community level, stories recounting experiences associated with past research projects and their respective researchers are often intertwined with stories about other forms of colonization and injustice.[18]

Health researchers are often reluctant or unable to leave the academic setting for the periods of time that are needed to develop meaningful community partnerships. Trained and confident in Western scientific knowledge systems, many researchers are unfamiliar with and disrespectful (intentionally or unintentionally) of the values and protocols of Aboriginal communities. Historically, researchers adopted a "helicopter" style of research: they arrived in the community, collected information with minimal community interaction, and then returned to the university and published the information in scientific journals to which the Aboriginal community had little access. This methodology deviates sharply from acceptable customs in most Aboriginal communities and has contributed to a deep distrust of and resistance to university-based researchers.

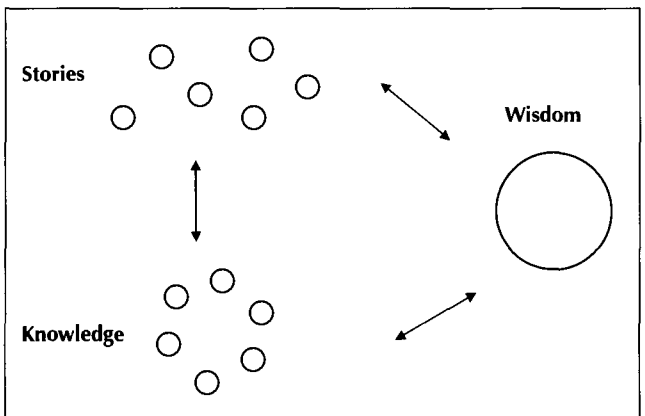

Figure 2. Indigenous knowledge generation process.

Governmental policy, published literature, and research have increasingly acknowledged and documented the historic injustices experienced by Aboriginal peoples in Canada over the past decade. The programs, exhibits, and publications of the Aboriginal Healing Foundation (accessible at <http://www.ahf.ca>) provide researchers with access to a body of information that was previously unavailable. Making use of these resources to better understand the disruptive impact of colonization provides an invaluable opportunity for researchers to enhance their understanding of local processes.

CULTURALLY RELEVANT FRAMEWORKS AND PROCESSES FOR KNOWLEDGE GENERATION AND KNOWLEDGE TRANSFER

"Fundamental to the exercise of self-determination is the right of peoples to construct knowledge in accordance with self-determined definitions of what is real and what is valuable."[21] The colonization process described in the preceding section not only denied Aboriginal peoples access to their land, but also denied them the tools to assert and implement their knowledge.[21]

Western scientific concepts and research that have been developed outside Aboriginal communities may be of little relevance from an Aboriginal community's perspective. For example, "infant mortality rates" and "birth weight" are commonly used indicators of "infant health." Both indicators focus on the individual infant and do not reflect the importance of kinship and community roles in understanding health and wellness. Also, both indicators focus on physical illness and do not reflect a definition of health that includes "a balance of physical, mental, emotional, and spiritual elements."[15] "Infant mortality" is catastrophic, but it is a downstream and rare outcome. As such, it may be of less immediate relevance and utility to Aboriginal community members working towards improved infant health than more proximal indicators such as "breastfeeding participation rates" and "maternal food security." Further, in Aboriginal communities coping with endemic type 2 diabetes, birth weight is a questionable measure of maternal and infant health, since maternal disorders of glucose metabolism tend to increase rather than decrease birth weight.[24] Finally, the external processes of indicator development and utilization may contribute to a distrust of and resistance to academic- or government-based measurement and evaluation of community health.

With respect to knowledge translation, with a few exceptions,[25] activities involving the health of Aboriginal communities have been overlooked. When such activities do occur, there appears to be little adaptation of mainstream knowledge or

translation of mainstream approaches into a context specific or meaningful to the Aboriginal community. For example, despite the hundreds of clinical practice guidelines published for health-care practitioners in Canada, there is only one that includes specific recommendations for Aboriginal peoples.[26] Interestingly, due to the lack of Aboriginal-specific research data, this set of recommendations was necessarily graded "D" (weakest evidence-based ranking).[27] The challenge facing Aboriginal-health researchers and policy makers is not only to expand dramatically the scope of Aboriginal research in Canada, but to develop, in collaboration with Aboriginal peoples, new research frameworks, protocols, and dissemination activities that are both scientifically sound and culturally relevant to Aboriginal communities. The "participatory" research that has been done in Aboriginal communities provides some of the best examples, as in the case of the Kahnawake Schools Diabetes Prevention Project, which incorporated traditional learning styles of Aboriginal children into 3 scientific models of health promotion in order to reduce the prevalence of obesity, improve nutrition, and increase physical activity levels among Mohawk children.[28] Community participants and project researchers have also collaborated to produce a benchmark project code of research ethics that supports an interface between community values and protocols and scientific approaches.[29]

ABORIGINAL LEADERSHIP, GOVERNANCE, AND PARTICIPATION

In the past decade, Aboriginal communities and organizations in Canada have begun to develop clearer guidelines and protocols for researchers working with Aboriginal communities.[2,29-32] It is important that researchers be aware of the unique ethical standards that exist with respect to conducting research involving Aboriginal peoples and communities. The Tri-Council Policy Statement *Ethical Conduct for Research Involving Humans* provides a useful list of "good practices" that will assist readers in complying with ethical standards in this area.[33]

From a global perspective, the International Working Group on Indigenous Peoples has held meetings on the question of indigenous health issues in an effort to support the adaptation of Article 29 of the United Nations Draft Declaration on the Rights of Indigenous Peoples.[34] This article states, "Indigenous peoples...have the right to special measures to control, develop and protect their sciences, technologies and cultural manifestations, including human and other genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs and visual and performing arts."[34] In addition, the recently created permanent forum of indigenous peoples at the United Nations, which held its first meeting in May 2002, has included health as an ongoing agenda item.

The above work has been accomplished in an era in which the ongoing advocacy of Aboriginal individuals and communities for self-determination of their heath programs and services has finally received some notice from governmental policy makers. For example, central to the recommendations of the 1996 *Report of the Royal Commission on Aboriginal Peoples*[7] is a call to respect cultural differences and recognition of the moral, historic, and legal rights of Aboriginal peoples to self-determination. Specific recommendations in the area of health include profound changes to the current systems of health and social services in Canada to better serve Aboriginal peoples, including reorganization of the existing network of services for Aboriginal peoples into a system of health and healing centres under Aboriginal control. Recommendations also included the adaptation of mainstream services "to accommodate Aboriginal people as clients and as full participants in decision making."[7] Since 2000, the newly created Institute of Aboriginal Peoples' Health, 1 of 13 Canadian Institutes of Health Research, has been supporting innovative health research using the dual criteria of scientific excellence and collaboration with Aboriginal communities.[35] The National Aboriginal Health Organization and the Aboriginal Healing Foundation have been actively promoting and facilitating ethical research with Aboriginal communities at national and international levels. In addition, over the past year, the Social Sciences and Humanities Research Council of Canada has formulated a strategic approach to research involving Aboriginal peoples.[36]

Aboriginal individuals and communities have clearly articulated a desire for self-governance and the development of community-directed, participatory health research.[2,7] Self-determination of the research agenda by Aboriginal communities will contribute to more effective and efficient research programs in this area.[37-40] Health researchers are encouraged to continually evaluate how their research is contributing to the actualization of these policies throughout the research process.

DISCUSSION

There is an urgent need for interdisciplinary research that simultaneously addresses issues of culture, biology, and physical, social, and environmental determinants. This research agenda should include an accurate and inclusive description of the health challenges facing Aboriginal communities in Canada, an exploration of health determinants of these outcomes, and culturally meaningful and community-driven evaluations of health programs and services.

The current paucity of Aboriginal health research is regrettable, not only because of its adverse impact on the public health of Aboriginal peoples in Canada, but also because the indigenous knowledge systems and approaches to health described in this paper have the potential to contribute profoundly to Canadian health research and programming more generally. The need to better interface health science research with day-to-day individual and community realities is not unique to Aboriginal

populations in Canada, as health-care professionals indeed face this challenge with every clinical encounter. At a systemic level, the Canadian Institutes for Health Research have responded to the challenge of this interface by prioritizing knowledge translation, transdisciplinarity, researcher-community partnerships, and leadership in ethics.[41,42] Aboriginal communities in Canada have the potential to help address these challenges through systems of knowledge that allow for a more holistic understanding of health and its determinants, innovative research frameworks and methodologies, community-directed processes of knowledge gathering and dissemination, and unique ethical perspectives.

The imprint of Aboriginal community work and research on this group of authors can be found in our evolving research projects. These include the design of a new approach to the provision of primary health care for persons living with chronic diseases. Although this project is not specific to Aboriginal communities, the holistic and preventative philosophy of the evolving program can be traced to the exposure of the researchers to Aboriginal contexts and paradigms. Other projects include an inventory and assessment of indigenous health indicators in Australia, Canada, and New Zealand, and the development of knowledge translation processes within the context of the Aboriginal community.

The need to link indigenous and Western scientific paradigms promotes the development of innovative transdisciplinary methodologies that could be applied to bridge gaps between the academic and Aboriginal communities in other areas. The evolving benchmarks of Aboriginal community governance and participation in research may likewise be relevant to a diversity of researcher-community partnerships. Finally, the need to contextualize research questions and approaches in local history, culture, and geography is a principle that would enhance the translation of research into effective practice in most fields of enquiry.

CONCLUSION

The challenges described in this text, like any challenges, may be viewed as opportunities or barriers. The assumption of the authors is that culturally appropriate and community-controlled collaborative research can create pathways that avoid the old pitfalls of health research in Aboriginal communities. This approach would result not only in improved health outcomes in Aboriginal communities but also contribute new insights and perspectives to the fields of public health and medicine, with the potential to improve health and health services for all Canadians.

ACKNOWLEDGEMENTS

Dr Smylie would like to acknowledge Dawn Smith, Dr Eric Wooltorton, and Irving Silver for their helpful feedback on the current text. In addition, Dr Smylie would like to acknowledge support from the National Aboriginal Health Organization and the Institute of Aboriginal Peoples Health, Canadian Institutes of Health Research, and Associated Medical Services. Dr Smylie was a research associate with the National Aboriginal Health Organization during the writing of this paper, and is currently an IAPH/CIHR/AMS senior research fellow in the history of Aboriginal health and medicine.

REFERENCES

1. Smylie J. A guide for health professionals working with Aboriginal peoples: health issues affecting Aboriginal peoples. J Soc Obstet Gynaecol Can 2000;23:54–68.
2. First Nations and Inuit Regional Health Survey National Steering Committee. First Nations and Inuit regional health survey, national report 1999. St. Regis (QC): Akwesasne Mohawk Territory; 1999.
3. MacMillan HL, MacMillan AB, Offord DR, Dingle JL. Aboriginal health. CMAJ 1996;155(11):1569–78.
4. Department of Indian and Northern Development. Basic departmental data – 2000. Department of Indian Affairs and Northern Development; March 2001.
5. Young TK. Review of research on aboriginal populations in Canada: relevance to their health needs. BMJ 2003;327:419–22.
6. Smylie J. A guide for health professionals working with Aboriginal peoples: the sociocultural context of Aboriginal peoples in Canada. J Soc Obstet Gynaecol Can 2000;22(12):1070–81.
7. Royal Commission on Aboriginal Peoples. Highlights from the report of the Royal Commission on Aboriginal Peoples. Ottawa: Ministry of Supply and Services; 1996.
8. Canadian Medical Association. Bridging the gap: promoting health and healing for Aboriginal peoples in Canada. Ottawa: Canadian Medical Association; 1994.
9. Battiste M, editor. Reclaiming indigenous voice and vision. Vancouver: UBC Press; 2000.
10. Couture J. Native studies and the academy. In: Sefa Dei GJ, Hall BL, Goldin-Rosenberg D, editors. Indigenous knowledge in global contexts: multiple readings of our world. Toronto: University of Toronto Press; 2000.
11. Brant C. Native ethics and rules of behaviour. Can J Psychiatry 1990;35:534–9.
12. Battiste M, Youngblood Henderson JS. Protecting indigenous knowledge and heritage. Saskatoon: Purich Publishing; 2000.
13. Brant-Castellano M. Updating Aboriginal traditions of knowledge. In: Sefa Dei GJ, Hall BL, Goldin-Rosenberg D, editors. Indigenous knowledge in global contexts: multiple readings of our world. Toronto: University of Toronto Press; 2000.
14. Dion Stout M, Kipling G. Establishing a leading knowledge based organization. National Aboriginal Health Organization; 2001. Available at <http://www.naho.ca>. Accessed April 15, 2003.
15. Malloch L. Indian medicine, Indian health: study between Red and White medicine. Can Womens Stud 1989;10(2,3):105–12.
16. Little Bear L. Jagged worldviews colliding. In: Battiste M, editor. Reclaiming indigenous voice and vision. Vancouver: UBC Press; 2000.
17. Shiva V. Foreword: cultural diversity and the politics of knowledge. In: Sefa Dei GJ, Hall BL, Goldin-Rosenberg D, editors. Indigenous knowledge in global contexts: multiple readings of our world. Toronto: University of Toronto Press; 2000.
18. Tuhiwai Smith L. Decolonizing methodologies: research and indigenous peoples. London: Zed Books; 2001.
19. Youngblood Henderson J. Postcolonial ghost dancing: diagnosing European colonialism. In: Battiste M, editor. Reclaiming indigenous voice and vision. Vancouver: UBC Press; 2000.
20. Duran B, Duran E. Applied postcolonial clinical and research strategies.

In: Battiste M, editor. Reclaiming indigenous voice and vision. Vancouver: UBC Press; 2000.
21. Brant Castellano M. Ethics of Aboriginal research. J Aboriginal Health 2004;1:98–114.
22. Burton-Jones A. Knowledge capitalism: business, work, and learning in the new economy. Oxford: Oxford University Press; 1999.
23. World Health Organization. Declaration of Alma-Ata. International conference on primary health care, Alma-Ata, USSR; 1978.
24. Coustan DR, Carpenter MW. Detection and treatment of gestational diabetes. Clin Obstet Gynecol 1986; 28:507–15.
25. Smylie J, Martin C, Kaplan-Myrth N, Steele L, Tait C, Hogg W. Knowledge translation and indigenous knowledge. Int J Circumpolar Health. In press 2004.
26. Canadian Diabetes Association Clinical Practice Guidelines Expert Committee. Canadian Diabetes Association 2003 clinical practice guidelines for the prevention and management of diabetes in Canada. Available at <http://www.diabetes.ca/cpg2003>. Accessed January 24, 2004.
27. Woolf SH, Battista RN, Anderson GM, Logan AG, Eel W. Canadian Task Force on the Periodic Health Examination. Ottawa: Canada Communication Group; 1994. p. xxxvii.
28. Macaulay AC, Paradis G, Potvin L, Cross EJ, Saad-Haddad C, McComber A, 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. Prevent Med 1997;26:779–90.
29. Kahnawake Schools Diabetes Prevention Project. Code of research ethics. 1996. Available at <http://www.ksdpp.org>. Accessed January 23, 2004.
30. Royal Commission on Aboriginal Peoples. Appendix B: ethical guidelines for research. Ottawa: RCAP; 1993.
31. Inuit Tapirisat of Canada. Negotiating research relationships: a guide for communities. Nunavut Research Institute, Inuit Tapirisat of Canada; 1998.
32. Masuzumi B, Quirk S. Dene tracking. A participatory research process for Dene/Metis communities: exploring community-based research concerns for Aboriginal Northerners. Yellowknife (NWT): Dene Nation; 1993.
33. Tri-Council: Medical Research Council of Canada, Natural Sciences and Engineering Council of Canada, Social Sciences and Humans Research Council of Canada. Tri-council policy statement. Ethical conduct for research involving humans. Ottawa, Canada; 1998. Available at <www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>. Accessed January 23, 2004.
34. United Nations Working Group on Indigenous Populations. 1994/45 Draft United Nations declaration on the rights of indigenous peoples. Geneva: United Nation; 1994. E/CN.4/Sub.2/1994/56.
35. Reading J, Nowgesić E. Improving the health of future generations: the Canadian Institutes of Health Research Institute of Aboriginal Peoples' Health. Am J Public Health 2000;92(9):1396–400.
36. Social Sciences and Humanities Research Council of Canada. SSHRC's dialogue on research and Aboriginal peoples: what have we heard on what should be done? Social Sciences and Humanities Research Council of Canada Summary Paper; February 2003 draft.
37. Macaulay AC, Gibson N, Freeman W, Commanda L, McCabe M, Robbins C, et al. Participatory research maximises community and lay involvement. BMJ 1999;319:774–8.
38. Macaulay AC, Delormier T, Cross EJ, Potvin L, Paradis G, McComber AM, et al. Participatory research with Native community of Kahnawake creates innovative code of research ethics. Can J Public Health 1998;89(2):105–8.
39. Fletcher C. Community-based participatory research relationships with Aboriginal communities in Canada: an overview of context and process. Pimatziwin 2003;1(1):27–61.
40. Gray D, Saggers S, Drandich M, Wallam D, Plowright P. Evaluating government health and substance abuse programs for indigenous peoples: a comparative review. Aust J Public Health 1995;19(6):567–72.
41. Canadian Institutes of Health Research. Revolution – CIHR: toward a national research agenda. Ottawa: CIHR; 2001.
42. Canadian Institutes of Health Research. Report on plans and priorities for the fiscal year 2003–2004. Ottawa: CIHR; 2003.