

Building a Health Research Relationship Between First Nations and the University in Manitoba

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ABSTRACT

This paper describes the emergence of a formal partnership between Manitoba First Nations and researchers in the Department of Community Health Sciences at the University of Manitoba. This partnership reflects two decades of a working relationship in Manitoba involving university researchers and First Nations communities, as well as new and innovative approaches to developing organizations, training initiatives and projects that strengthen First Nations principles of governance. The emerging trust that has developed between the Manitoba First Nations and the University has made it possible to extend this partnership into building further research capacity and evidence-based decision-making among First Nations. Discussions between the Assembly of Manitoba Chiefs and the Northern Health Research Unit resulted in the development of a Manitoba First Nations Centre for Aboriginal Health Research. Its mission is to initiate, coordinate and support research activities designed to assist First Nations and Aboriginal communities and organizations in their efforts to promote healing, wellness and improved health services in their communities. Much of the health research described in this journal was facilitated through this partnership, which demonstrated the value of partnerships and new funding opportunities to better address the health information needs of First Nations communities, particularly at a time when Aboriginal communities were highly skeptical of the value of academic research.

MeSH terms: Indigenous population; health policy; community participation

La traduction du résumé se trouve à la fin de l'article.

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This paper will describe the emergence of a formal partnership between First Nations in Manitoba and researchers in the Department of Community Health Sciences at the University of Manitoba.^{1,2} Extending as far back as the 1950s, faculty members of what is now the Department of Community Health Sciences have worked with northern communities.³ At the request of Aboriginal peoples in Manitoba and the Arctic and through the efforts of these Faculty members, the Northern Medical Unit (now called the J.A. Hildes Northern Medical Unit) formed in 1969 to deliver medical services to northern communities. This unit also afforded an opportunity for various northern research and education efforts. These early activities in northern health research continued to grow, thus demonstrating the need to pool efforts and resources to develop a research unit. External resources were secured, and in 1987, the Northern Health Research Unit was established with core funding from several foundations complemented by internal University resources. The mission and objectives of this Unit were as follows: to initiate and conduct research projects determined as relevant by northern communities; to ensure research projects sponsored by the Unit were sensitive and responsive to community needs and were supported by the communities; to encourage research training of northern persons; to provide consultation, coordination and assistance to the University community engaged in northern research, including researchers both in Canada and abroad; to disseminate northern health research information, and to expose northern communities to university research methods and results, increasing their awareness and assisting them in setting their own research priorities. This mandate made it possible for Unit researchers to develop new partnerships with First Nation peoples in Manitoba.

Various researchers associated with the NHRU developed and maintained research partnerships with Aboriginal communities in northern Manitoba and the eastern Arctic. However, it was not until the mid-1990s, in the aftermath of the Royal Commission on Aboriginal Peoples,⁴ that a formal research relationship was established with First Nations representatives in Manitoba.

The emergence of new approaches and mechanisms for research conduct

In 1994, Statistics Canada began two major national longitudinal surveys [National Population Health Survey (NPHS), National Longitudinal Survey of Children (NLSC)]. The general objective of each of these surveys is to assist federal and provincial governments, researchers and non-governmental organizations to develop public policy. The national sampling frames for these longitudinal surveys specifically excluded First Nations people living on reserves, and Inuit communities in the provinces.

In 1994, the NHRU was contracted to conduct a Feasibility Study for the development of a National Longitudinal Aboriginal Survey. The methodology for the Feasibility Study was to consult with Aboriginal health technicians working with Aboriginal organizations and communities across the country. "Health technicians" included Aboriginal health, social service, child development, education and socio-economic development professionals active in service delivery, research and policy development with Aboriginal communities and organizations. Workshops were held in Halifax, Montreal, Ottawa, Toronto, Winnipeg, Saskatoon, Edmonton, and Vancouver. More than 160 Aboriginal health technicians participated in these consultation workshops.

The general character of these workshops could be described as one of critical resistance. The prevailing sentiment was that "Aboriginal communities have been researched to death". Initially, virtually all Aboriginal participants were categorically opposed to any further research. However, as the workshops progressed, other views emerged. Participants indicated that they would be generally willing to consider a health survey if Aboriginal peoples controlled all aspects of the study. This would include the administration of funds, design of questions, training of Aboriginal people as research administrators, analysts and interviewers, and the interpretation and dissemination of information from the survey.

Based on these discussions, the Northern Health Research Unit recommended that a longitudinal survey should be developed along a regional (or provincial) basis.⁵ A National First Nations and Inuit Steering

Committee was established consisting of representatives from each province-based First Nation or Inuit political organization. The Health Advisor to the Assembly of Manitoba Chiefs represented First Nations communities in Manitoba. Each regional (or provincial) political organization was funded to contract with a local "technical support" organization. The Northern Health Research Unit was contracted to provide this support at both the regional and national level.

The involvement of the University of Manitoba in the regional development of the survey was entirely dependent on the invitation of the First Nations of Manitoba. Unlike most of the health research in which University community health faculty are involved, where funds are obtained for a research idea and then communities are approached for their willingness to participate, this project required the University to respond to requests for technical assistance as an independent contractor. The contract between the University and the Assembly of Manitoba Chiefs (AMC) was somewhat unique in this regard. AMC was primarily concerned that ownership of all project derivatives remain with First Nations.

In our initial discussions, AMC representatives expected full control over publication rights and copyright. The University, on the other hand, refuses to enter into contract agreements, where the contracting agency has the right to suppress publication. The University insists on its traditional responsibility to disseminate scientifically valid research results in the public domain. Contract language which delays publication on sensitive issues is sometimes agreed to, but outright suppression of information for political reasons is not permitted in University research contracts.

The first step in this process was to develop a contract that would formalize the respective concerns of both AMC and the University but would also facilitate the kind of collaborative process that we envisioned. Essentially, we agreed that for results from the regional survey, copyright would be retained by AMC who also must provide written permission before any publication. Permission to publish was dependent on a satisfactory review of the publication by the AMC Survey Steering

Committee. In the event that University authors and the Steering Committee cannot agree, papers may be submitted for publication as long as a letter accompanies them from AMC outlining their objections. It then becomes the responsibility of the journal editor (or conference organizer) to resolve this conflict.

Although the University contract was with the Assembly of Manitoba Chiefs, who controlled the funding provided by the federal government for the initiative, Manitoba First Nations communities were represented by a Regional Steering Committee (RSC) mandated by the AMC Chiefs Health Committee in a formal resolution. Considerable effort was made to ensure that the Survey was accountable to Manitoba First Nations communities through an appropriate political structure. Too often, researchers complain that it is impossible to determine who represents "the community". As a result, either inappropriate "selective" representatives, who have no legitimate accountability to the First Nations political structure, are chosen by the researcher, or researchers use this concern to avoid establishing any community-based controls over their research.

The primary health authority of First Nations in Manitoba at the time – the Chiefs Health Committee of the Assembly of Manitoba Chiefs – determined the RSC structure. The RSC consisted of the Health Directors for each of the Tribal Councils in Manitoba plus the Health Advisors from AMC and Manitoba Keewatinowi Okimakanak (MKO). MKO was established in 1983 to focus on advocacy and development for First Nations in northern Manitoba. One of the first tasks of the RSC was to develop a "Code of Ethics" for the project. The principles contained in this Code emerged as the basis for all future iterations of Codes of Ethics that govern work with First Nations in the province.

In 1998, the Assembly of Manitoba Chiefs formally recognized the RHS steering committee's contribution to developing a First Nation health infrastructure and granted it more decision-making power by way of a resolution. The resolution mandated this committee as the Assembly of Manitoba Chiefs Health Information Research Committee (AMC-HIRC) to exercise greater control over research con-

ducted for and by First Nations in Manitoba. This control included the power to oversee the long-term development and implementation of the Regional Health Survey; to review research proposals that involved First Nations health and make recommendations to improve the focus of proposals; to establish a health information system for the use and benefit of First Nations; and to ensure that health research and information development is accountable to First Nation needs and priorities.

Building capacity and strengthening relationships

The emerging trust that developed between the Manitoba First Nations and the University throughout the survey process made it possible to extend this partnership into building further research capacity and evidence-based decision-making among other First Nation health technicians. In 1997, University-based researchers applied for and received a grant from Health Canada to develop First Nation research capacity through a First Nations Applied Population Health Research "Summer Institute". This project was a joint venture formalized by the Assembly of Manitoba Chiefs' Committee on Health in a resolution passed in November 1996.

Both the NHRU and AMC-HIRC oversaw the implementation of the Institute. Members of the HIRC agreed to participate as the first wave of students. Health planners from communities that participated in the regional health survey also attended, as did a health planner from the Assembly of First Nations. First Nation protocols were integrated into the Institute, such as the opening and closing prayer by an elder, opening address and closing remarks by a representative from AMC, and a sharing circle scheduled for the last day of the training course.

The NHRU recruited faculty and tutors from several disciplinary areas such as medical anthropology, sociology, epidemiology, biostatistics, and health services research. To secure health information, partnerships were established between the NHRU, and the Manitoba Centre for Health Policy, Manitoba Health, and Health Canada Medical Services Branch (now called First Nations and Inuit Health

Branch). Overall, 46 Aboriginal health technicians registered for the course in the three years it was offered.

Since then, we have been actively involved in building research capacity in other Assembly of Manitoba Chiefs' health working groups. We have worked with the Manitoba First Nation Diabetes Strategy Working Group to develop a strategy document consistent with the principles of OCAP (Ownership, Control, Access, and Possession).^{*} Four members of this committee were former participants of the Institute. We have also worked in full partnership with the AMC disability committee in a pilot study to identify First Nation peoples with a disability, document their socio-economic conditions and job training needs, and discover other factors and barriers (health, housing, and transportation) related to their disability.

Creating new structures for research development

In terms of new institutional partnerships, further discussions between the Assembly of Manitoba Chiefs (AMC) and the Northern Health Research Unit resulted in the idea of developing a Manitoba First Nations Centre for Aboriginal Health Research (MFN-CAHR). The development of MFN-CAHR became a reality in 1999 due to a generous contribution from the AMC for capital construction and the awarding of an infrastructure grant from the Canada Foundation for Innovation and the Province of Manitoba. The new research centre opened in the spring of 2001. The MFN-CAHR continues to be a unit of the Department of Community Health Sciences in the Faculty of Medicine at the University of Manitoba.

The expanded mission of the MFN-CAHR (developed in consultation with HIRC) is to initiate, coordinate and support research activities designed to assist First Nations and Aboriginal communities

and organizations in their efforts to promote healing, wellness and improved health services in their communities. The research program also integrates scientific and Aboriginal approaches to health as illustrated in the following objectives:

- To conduct studies on the determinants of health in First Nations and Aboriginal communities.
- To support culturally appropriate studies of Aboriginal healing ways in First Nations and Aboriginal communities.
- To support and coordinate basic medical research into disease processes currently prevalent in First Nation and Aboriginal communities.
- To conduct community-based studies into innovative culture-based approaches to healing and wellness in First Nations and Aboriginal communities.
- To conduct studies into factors that influence the development of health service systems that meet the needs of First Nations and Aboriginal communities.
- To provide community- and university-based education and training in health research to First Nations and Aboriginal communities and students.
- To facilitate capacity building in First Nations and Aboriginal communities and organizations in the use of health information for policy and program development.
- To assist with the development of a quality health information system that can describe changing health conditions in First Nations and Aboriginal communities.
- To advise First Nations and Aboriginal governments and organizations on health policy issues based on the best available research evidence.
- To facilitate communication and knowledge sharing concerning Aboriginal health development nationally and internationally.

An Advisory Board provides general policy direction for the Centre, and membership on the board includes the University, Manitoba First Nations and Aboriginal communities, and other stakeholders in Aboriginal health. The HIRC, as well as an Aboriginal Health Research Group (AHRG) consisting of faculty involved in Aboriginal health research in the Faculty of Medicine, provides direction to the Advisory Board.

^{*} For a full discussion of OCAP, see Schnarch B, 2004.⁶ These principles emerged in the context of developing the two waves of the First Nations and Inuit Regional Health Survey as the fundamental rationale for insisting that federal agencies such as Statistics Canada could not be delegated responsibility for the survey. First Nations authorities argued that the statutory provisions surrounding data ownership in the Statistics Canada environment were contrary to the principle of First Nations governance over health information.

The MFN-CAHR supports meetings with the AMC-HIRC to build capacity in reviewing research proposals and assessing the ethics of a research project. The MFN-CAHR sponsors bimonthly HIRC meetings and workshops, and also assists in creating new partnerships between university investigators and the HIRC. In 1999, for instance, the MFN-CAHR coordinated the new partnership between the HIRC and the Manitoba Centre for Health Policy (MCHP). Several workshops and meetings between the HIRC and the MCHP involved building capacity in the HIRC to design a project using Manitoba Health service utilization data that is reported elsewhere in this supplement.

The MFN-CAHR also supports the Aboriginal Capacity and Developmental Research Environment (ACADRE) Training Program funded by the Institute of Aboriginal Peoples Health that is intended to expand the pool of Aboriginal researchers who can compete for national grants in the field of Aboriginal health research. MFN-CAHR also administers the Aboriginal Health Survey Support Program funded by the Institute of Aboriginal Peoples Health that will contribute in a major way to the improvement of health survey activity in First Nation, Métis, and Inuit communities.

The second wave of the First Nations and Inuit Regional Longitudinal Health Survey was initiated in 2002 and the MFN-CAHR is working in full partnership with the Assembly of Manitoba Chiefs in launching this survey. The Centre is providing technical support and training in sampling, ethical protocols, interviewing, data quality assurance, database management and dissemination.

The Centre is also discussing with the AMC-HIRC the development of a Memorandum of Understanding suitable to all partners including Manitoba First Nations, Manitoba Health, Indian Northern Affairs Canada, and First Nations Inuit Health Branch (Health Canada) that would provide for the creation of a "Master First Nations Health Registry". This Registry would be maintained by Manitoba Health under "lock and key" and would not be available to any party for any purpose without the written agreement of the signatories to the MOU.

CONCLUSIONS

This paper describes a number of initiatives jointly developed and managed by Manitoba First Nations Centre for Aboriginal Health Research and the Assembly of Manitoba Chiefs Health Information Research Committee. This partnership reflects both two decades of a working relationship in Manitoba involving university researchers and First Nations communities, as well as new and innovative approaches to developing organizations, training initiatives and projects that strengthen First Nations principles of governance. In a context where Aboriginal communities have voiced skepticism of the value of academic research, but where new funding opportunities have spawned a proliferation of similar research centres across the country, the University of Manitoba experience is illustrative. Although each region has unique dynamics in terms of First Nations relationships with university researchers, some general recommendations emerge from the Manitoba experience. First, the history of research exploitation in First Nations communities is the context in which new relationships of trust must be forged. University researchers must demonstrate that they are willing to relinquish control over the research process in order to build new relationships where shared control is possible. This approach is anathema to most scientists where research by definition must be rigorously designed and controlled. Second, federal and provincial stakeholders are potentially important partners in developing new health information infrastructure necessary

for advancing research agendas. However, university researchers must be willing to not only recognize First Nations as their principal partner, but also risk alienating government partners if OCAP negotiations around data ownership do not conform to government priorities. Finally, university researchers must recognize the intrinsic relationship between control over information and power, and understand that their activities are fundamentally about advancing self-government in the First Nations context. This understanding requires a commitment to capacity-building, knowledge translation and the use of ethical approaches consistent with First Nations values.

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RÉSUMÉ

Cet article décrit l'émergence d'une entente de partenariat officielle entre les Premières nations du Manitoba et les chercheurs du Département des sciences de la santé communautaire de l'Université du Manitoba. L'entente est l'aboutissement de deux décennies de collaboration entre le milieu universitaire et les collectivités des Premières nations au Manitoba. Elle s'articule autour de démarches nouvelles ou novatrices pour l'élaboration de structures, de projets et d'initiatives de formation qui renforcent les principes de gouvernance des Premières nations. La confiance qui s'est développée entre les Premières nations et l'Université du Manitoba a permis d'étendre ce partenariat aux activités de renforcement des capacités de recherche et des processus décisionnels fondés sur les résultats chez les Premières nations. Des discussions entre l'Assemblée of Manitoba Chiefs et la Faculté de recherche sur la santé du Nord de l'Université du Manitoba ont abouti à la création d'un centre de recherche sur la santé autochtone : le Manitoba First Nations Centre for Aboriginal Health Research. Il a pour mission de lancer, de coordonner et d'appuyer des activités de recherche pour aider les collectivités et les organismes autochtones et des Premières nations qui cherchent à promouvoir le ressourcement, le mieux-être et l'amélioration des services de santé dans leurs populations. La plupart des études sur la santé dont il est question dans le présent supplément ont bénéficié de ce partenariat. Celui-ci a prouvé qu'avec la collaboration de tous et de nouvelles formules de financement, il est possible de mieux combler les besoins d'information sanitaire des collectivités des Premières nations – un résultat non négligeable à notre époque, où les populations autochtones remettent en question la valeur de la recherche universitaire.