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# The Politics of Trust and Participation: A Case Study in Developing First Nations and University Capacity to Build Health Information Systems in a First Nations Context

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Brenda Elias, MA, University of Manitoba, Centre for Aboriginal Health Research  
John O'Neil, PhD, University of Manitoba, Centre for Aboriginal Health Research  
and Doreen Sanderson, Assembly of Manitoba Chiefs

## Abstract

Recent success of First Nations involvement in health information management is establishing the social and cultural structures necessary to build trust and participation, produce counter knowledges that decolonize the health of First Nations Peoples, develop new forms of health information systems directed at First Nations wellness, and create new institutional research partnerships that could further enhance health information development and educational opportunities. This success is illustrated through 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 and Research Committee. Alternative discourses are possible. Resistance in the form of counter discourses can produce new knowledge, speak new truths and constitute new powers such as First Nations ownership, control, access and possession of health information. In this new environment, non-Aboriginal researchers and governments will have to recognize that any work involving Aboriginal Peoples will occur in the context of resistance to colonization. However, that such resistance creates the possibilities for collaboration. For collaboration to be possible and successful, however, researchers will have to reflect on the positions represented by others, attempt to understand these positions within the context they occur, recognize that trust and participation is conditional, and accept that any sharing and production of health information will occur at the boundaries between systems of knowledge.

## Key Words

First Nations, Aboriginal, research, health information, power/knowledge, decolonization, collaboration, trust, participation

## INTRODUCTION

In Manitoba, the recent success of First Nations involvement in health information management helped establish the social and cultural structures necessary to build trust and participation, produce counter knowledges that could decolonize the health of First Nations Peoples, launch new forms of health information systems directed at First Nations wellness, and create new institutional research partnerships that could further enhance health information development and educational opportunities. This success is illustrated through 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 and Research Committee.

The First Nations and Inuit Regional Longitudinal Health Survey established the social and cultural structures necessary to develop First Nations' and universities' capacity to work collaboratively in the area of First Nations population health research. Out of this initiative, the Manitoba First Nations Population Health Research Training Institute emerged. It involved various forms of cultural resources that could demystify health information and build on the skills of First Nations health managers and providers so they could critically apply health information to First Nations health policy and service areas. The trust and

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participation developed through these initiatives created further connections and opportunities to resist the new epidemic discourses (i.e., authoritative ways of describing a population) that currently dominate First Nations health and made possible new institutional research partnerships based on principles of mutual respect, trust and participation. This respect, trust and participation occurred within the context of decolonization and at the margins between various knowledge domains and forms of sovereignty.

## ISSUES OF CONTROL OVER HEALTH INFORMATION

If researchers accept the idea that power does not exclusively operate through brute force or political repression, but also acts through systems of knowledge about how societies work, researchers should then consider scientific discourses (studies, research projects, etc.) as a medium through which power operates and that power/knowledge characterizes the way scientific knowledge acts to control members of a society by defining what is normal and expected.<sup>1</sup> What is normal and expected for one group, however, may not be the same for others.

If researchers also consider that epidemiological research studies operate as part of a broader surveillance system that regulates populations according to the values of the dominant society and that scientific discourse is rooted in the dominant value systems of ruling interests in a society, then science and state interests are interdependent. This interdependency is inevitable because government is only possible when the strength of the state is known.<sup>2</sup> Researchers should also consider that alternative discourses are possible and resistance in the form of counter discourses will produce new knowledge, speak new truths and constitute new powers.<sup>3</sup> In other words, although discourses can constrain the production of knowledge or restrict dissent and difference, they can produce new knowledges and difference(s) that can oppose the knowledges (counter-knowledges) produced by the status quo

In the context of First Nations health research, these ideas are highly applicable, particularly when applied to understanding First Nations sovereignty, resistance, capacity, and health knowledge systems.

It is not uncommon to hear First Nations Peoples say that they have been “researched to death.” For many First Nations Peoples active in community wellness development, research is viewed, at best, as irrelevant to the needs of communities, or, at worst, as a

serious encroachment on the integrity and autonomy of First Nations communities. Many First Nations communities are reluctant to participate in research projects, especially if they have no control over what information is gathered or how it is used. In many ways, these acts of resistance illustrate that First Nations Peoples are critically reflecting on the technologies, methodologies, communication strategies, etc. through which science operates. At the same time, First Nations health authorities require health information and educational opportunities that further decolonize a long history of pathologizing discourses in First Nations health research. First Nations health planners and service providers require trustworthy health information to develop appropriate health programs and target services that can meet rapidly changing needs within a limited resource environment. They also need health information to inform negotiations with federal and provincial governments to secure adequate funding for health programs, services and training. First Nations Peoples have responded to this need and are developing a self-governance strategy to make health information available to First Nations communities and to ensure that First Nations health planners and service providers receive health research training.

Consistent with their Constitutional right to self-government, First Nations governing bodies have established the OCAP principles of ownership, control, access, and possession of health information.<sup>4</sup> The main objective of these principles is to extend First Nations’ sovereignty over health information and to decolonize research relationships between First Nations organizations, universities and provincial and federal governments.

A major initiative that helped forge the OCAP principles was the First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS), which was launched in 1996-7.<sup>5</sup> At the feasibility stage of this national survey, Aboriginal organizations (First Nations, Métis, and Inuit) throughout Canada were highly sceptical as to whether they should invest their time and energy in a project that would offer little in terms of direct benefit.<sup>6</sup> These organizations were not alone in their scepticism. Resistance against research conducted by non-Aboriginal organizations and peoples is widely shared by Indigenous Peoples throughout the Americas, Australia and New Zealand.<sup>7</sup> Such research is regarded as a repressive process under the control of others.

To make research more equal participation, researchers adopted participatory action research (PAR)

approaches that can empower participants to define their own world according to their own interests. Indigenous Peoples, however, have argued that PAR still does not prevent researchers and governments from exercising intellectual arrogance or employing evangelical and paternalistic practices.<sup>8</sup>

The battle for sovereignty over the Regional Health Survey is proof of the way First Nations Peoples resisted PAR as a means to preserve a colonial relationship at the expense of First Nations sovereignty. At the initial planning stage of this survey, the FNIRLHS National Steering Committee, comprised of First Nations and Inuit representatives from nine regions across Canada, resisted the top down, paternalistic approach taken by the federal government. Medical Services Branch<sup>9</sup> employees were opting for a PAR process that maintained their administrative control of the survey. However, several members of the FNIRLHS National Steering Committee, including the representative from the Assembly of Manitoba Chiefs (Audrey Leader), resisted this act by threatening to leave the process if they did not get full control over the survey.<sup>10</sup> The federal Medical Services Branch eventually accepted this demand and transferred complete control over the survey to the FNIRLHS National Steering Committee. This victory was a major turning point. The outcome was higher levels of trust and participation at the regional level, particularly in Manitoba. This solidarity provided the base to formally establish and sanctify the OCAP principles over health information as a model for other Indigenous groups to follow.

In a code of research ethics, the FNIRLHS National Steering Committee entrenched the principles of OCAP to strengthen First Nations and Inuit self-determination over the survey process.<sup>11</sup> The committee also established a number of obligations for researchers to guarantee that Inuit and First Nations Peoples are actively involved in the research process; promote the knowledge that this process is Inuit and First Nations owned; ensure the study design, data collection and dissemination of research results is culturally relevant and in compliance with standards of competent research; undertake research that contributes to Inuit and First Nations Peoples nationally and regionally; assist in advocating and addressing health and social issues as they emerge as a result of the research; and build Inuit and First Nations research capacity in survey development, data collection, computer use, analysis, and health planning.<sup>12</sup> Today, this code of ethics stands out among other re-

search agreements<sup>13</sup> as a model that can nationally and regionally frame partnership models and that can build research capacity based on the principles of OCAP.

Entrenching the obligation to build health research capacity and information dissemination practices (e.g., meeting with communities or advisory boards, presenting at conferences, writing papers, etc.) into a research agreement was a significant departure from traditional PAR approaches. In health services research, the focus is generally on evidence-based decision-making or problem solving to address problems associated with changing the practice behaviours of health professionals.<sup>14</sup> In health promotion, most work tends to examine barriers to disseminating information, primarily designed to change health behaviours in the public domain.<sup>15</sup> However, neither of these approaches has been particularly relevant to rethinking how policy-oriented research is disseminated to health planners and program developers in a complex social, cultural and political environment. Research by N. Milio and by M. O'Neill and A.P. Pederson has revealed that effective dissemination of research results is dependent on the complexities of the relationships that must develop between the research and policy communities.<sup>16</sup> As well, decision-making is influenced by the quality of the evidence, distribution strategies and the complex environment where the decision-making and the incorporation of the evidence is actively taking place.<sup>17</sup> As well, evidence-based decision-making cannot occur if health information is not available. Its availability is often contingent on co-operation and partnerships between different research and governing bodies.<sup>18</sup>

In Canada, the need for innovative research dissemination strategies is quite widespread. There certainly are far more questions than answers as to how to achieve this objective.<sup>19</sup> The code of research ethics developed by the FNIRLHS National Steering Committee was one attempt to lay the groundwork on how to achieve this objective. The obligation to build First Nations and Inuit research capacity in survey development, data collection, analysis, and health planning established the standards to achieve this objective. This obligation opened the door for First Nations organizations and researchers to collaboratively develop new social and cultural structures and create new social connections and opportunities to build capacity among researchers and First Nations Peoples to engage evidence-based decision-making at the program, policy and funding levels.

## BUILDING RESEARCH CAPACITY IN POPULATION HEALTH RESEARCH

Extending as far back as the 1950s, faculty members of what is now the Department of Community Health Sciences have worked with northern communities.<sup>20</sup> 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 provided a vehicle 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 found, and the Northern Health Research Unit (now known as the Manitoba First Nations Centre for Aboriginal Health Research) was established in 1987. Core funding from several foundations complimented internal University of Manitoba resources. The mission and objectives of this Unit were as follows:

- to initiate and conduct research projects northern communities determined to be relevant;
- 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, co-ordination 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 Northern Health Research Unit researchers to develop new partnerships with First Nations Peoples in Manitoba. For this partnership to be successful, however, the Unit staff needed to develop a deeper understanding and respect for First Nations self-governance over health and health information. The Regional Health Survey process helped broaden and enrich the Unit researchers' understanding of self-government and decolonization. With the development of a Manitoba First Nations health information governance structure and a partnership between the Unit and the Assembly of Manitoba Chiefs, the Unit helped develop the Manitoba First Nations' capacity to assume greater control

for research conducted for and by First Nations Peoples.

In Manitoba, the primary health authority of Manitoba First Nations communities – the Chiefs Health Committee of the Assembly of Manitoba Chiefs – determined the First Nations governing structure that would oversee the Regional Health Survey. In a resolution passed in 1996, the Chiefs Health Committee created the Manitoba First Nations Regional Health Survey (MFNRHS) Steering Committee. It consisted of health directors from each of the tribal councils in Manitoba plus health advisors from the Assembly of Manitoba Chiefs and the Manitoba Keewatinowi Okimakanak (MKO), which is a political and administrative branch of the Assembly of Manitoba Chiefs for the northern half of the province. Membership also included two health directors from two independent communities that represent the northern and southern independent First Nations communities in Manitoba.

Throughout the Regional Health Survey process, the MFNRHS Steering Committee met regularly with Northern Health Research Unit staff by teleconference and in workshops. This included training and decision-making on all aspects of research methodologies. These meetings helped forge a strong and trusting relationship between the Unit staff and the MFNRHS committee members and helped build capacity among the MFNRHS committee members to assume additional responsibilities over health information. In 1998, the Assembly of Manitoba Chiefs formally recognized the MFNRHS Steering Committee's contribution to developing a First Nations health infrastructure and granted it more decision-making power through a resolution. The resolution mandated this committee as the Assembly of Manitoba Chiefs' Health Information and Research Committee (AMC-HIRC) to exercise greater control over research conducted for and by First Nations Peoples. This control included:

- overseeing the long-term development and implementation of the Regional Health Survey;
- reviewing research proposals that involved First Nations health and make recommendations to improve the focus of such proposals;
- establishing a health information system for the use and benefit of First Nations; and
- ensuring health research and information development is accountable to First Nations needs and priorities.

The high level of respect, trust and participation that developed between the Manitoba First Nations and the University of Manitoba throughout the survey

process made it possible to extend this partnership into building further research capacity and evidence-based decision-making among other First Nations health technicians. In 1996, university-based researchers received a grant from Health Canada to develop First Nations 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 Northern Health Research Unit and AMC-HIRC oversaw the implementation of the Institute. A Project Co-ordinator (Doreen Sanderson), representing AMC-HIRC, recruited First Nations health planners and service providers, secured a training facility, and supervised on-site administration at 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. The first Summer Institute was held at a college operated by the Southeast Tribal Council, which offered residential facilities for students who did not live within driving distance of Winnipeg. The co-ordinator also integrated First Nations protocols into the Institute, such as the opening and closing prayer by an Elder; opening address and closing remarks by a representative from the Assembly of Manitoba Chiefs; and a sharing circle scheduled for the last day of the training course.

The Northern Health Research Unit 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 Unit and the Manitoba Centre for Health Policy, Manitoba Health Epidemiological Unit, and Health Canada Medical Services Branch, Health Information Division.

The AMC-HIRC Committee gave permission to abstract individual level data from the Regional Health Survey to create a fictitious tribal council region. The Manitoba Centre for Health Policy, with Manitoba Health's approval, provided a data file abstracted from the provincial health-services database. This file contained health service utilization data that also imitated a fictitious tribal council region. Medical Services Branch constructed a similar database from mortality data. Together, these databases illustrated the various forms of health information that could make up a First Nations health infrastructure system.

A partnership between the Northern Health Research Unit and the University of Manitoba's Continuing Education and Department of Native Studies was also established to provide academic credit for participants and facilitate student registrations for the course. The Unit and AMC-HIRC decided to offer the course over a one-week period, which would represent, in terms of time, the equivalent of a half-term course. Students not interested in using this course towards a degree had the option to take it as a non-degree offering. Consistent with university practice, organizers developed a course evaluation form to evaluate instructors and course content.

A curriculum-working group – which included faculty, tutors and the AMC-HIRC co-ordinator – established the curriculum objectives. Each faculty member contributed course materials that were organized into a student course manual. The curriculum involved a series of lectures and tutorial sessions designed to accommodate the broad range of educational backgrounds of the students. Introductory lectures were prepared to teach students the fundamentals of epidemiology, need assessments and ethical issues in Aboriginal epidemiology. The remaining lectures covered quantitative techniques used to appraise the health of populations. Lectures covered survey, health service utilization, and mortality databases. Tutorial sessions followed each lecture to provide students with hands-on experience using health information from these data sources. By and large, the lectures and tutorial sessions exposed students to health information techniques used to shape health programs and policy.

Overall, 46 Aboriginal health technicians registered for the course in the three years it was offered. Minor changes in the curriculum were made in this period, but in general terms, the program was structured as described here. Ten faculty and four graduate students from the Department of Community Health Sciences participated in the program.

Students worked in pre-assigned topic areas, representing one of the following domains: women, Elders and children. Their assignment involved abstracting survey, health service utilization, and mortality data to justify a program to deal with health inequalities in their respective areas. Each group worked as a team. On the last day of the course, they jointly presented a project proposal to the Institute instructors who posed as a Chiefs' Committee on Health.

The evaluation of the course was highly positive. A sharing circle provided everyone with the opportunity to share in the extensive partnership work that made

the Institute a possibility. Students left the Institute with an introduction to evidence-based decision-making. The intense working group environment helped build a research network they could draw upon later.

In the second year, organizers took the Institute on the road and built research capacity in communities that participated in the first wave of the Regional Health Survey. As part of the survey dissemination plan, preliminary reports for each community were prepared. These reports provided the base for a workshop to give communities hands-on experience using data to assess health status, target resources and justify new funding. Two workshops were held – one in the north and one in the south. More than 20 First Nations community health planners attended the workshops. A few former Institute students also attended. They helped instil interest in evidence-based decision-making among the First Nations health planners who initially expressed little experience in applying health information to community health plans.

In the third year, organizers held a second Institute open to First Nations community health planners and service providers from across Canada. Another 22 Aboriginal health technicians attended and 10 faculty/tutors participated. The second Institute was similar to the first, with a few exceptions.

The college used in the first year was not available, so an alternative site was selected. The only site available was St. Andrews College, which is a Ukrainian Christian Orthodox College located on the University of Manitoba's main campus. This shift in venue triggered concern among some of the Northern Health Research Unit staff and associates. This site was adorned with Christian icons. Given the tragic history of the residential school system, staff and associates were worried that such a setting could create mistrust and limit participation among participants who attended a residential school. Staff brought their concerns to the HIRC and then to the students. Neither group perceived the presence of Christian symbols as a problem that could foster distrust or limit participation. Overall, they were comfortable with the venue and appreciated staff's concern over the potential harm such a venue could create for some attendees.

Another departure from the first Institute involved the tutorial projects. Rather than pre-assign students to groups targeting vulnerable populations, organizers assigned them to the strategic policy areas of diabetes and community healing, which recently received new federal funding. Although the curriculum remained much the same, organizers added an advanced course in survey methods. Only one student was interested in

taking this course so it was offered only as a pilot course.

The Institute generally went well. Participants positively evaluated all lectures and tutorial sessions. The exception was a presentation made by a Medical Services Branch representative regarding the roll out of the community-based First Nation Health Information System (HIS) to all First Nations across Canada. In a question-answer period that followed, several participants commented that the HIS initiative would not provide accessible data or adequate training and that its development and administration did not follow the principles of OCAP. The debate became quite heated. At the end of the presentation, several First Nations participants felt the only solution to effectively develop research capacity was through a First Nations health info-structure based on the principles of OCAP. A few weeks after the Institute, MSB sent a letter to the Department Head of the academic unit accusing organizers of creating a hostile environment at this Institute. Although the intent was not to create such an environment, organizers did accept the responsibility of playing a significant role in developing First Nations capacity to critically apply population health techniques to secure First Nations self-governance over health information. One lesson from this incident is that any advancement of the OCAP principles could potentially reveal a deep historic distrust and a lack of participation between parties. The other is that the Institute did serve its purpose. It created a new group of First Nations health planners and service providers to use population health techniques to produce counter-knowledges that can resist colonial encroachments on First Nations health.

## COUNTER-KNOWLEDGES AND NEW PARTNERSHIPS

Overall, the trust and participation built through these initiatives went beyond the Institute. They helped create new social connections and opportunities to build evidence-based decision-making in the form of counter-knowledges that could decolonize the health of First Nations Peoples, develop new institutional research partnerships that could further enhance health information development and educational opportunities, and facilitate new forms of health information systems directed at First Nations wellness.

Since then, the Northern Health Research Unit has 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. Four members of this committee were former participants of the Institute. They took a lead role in building trust and participation in committee members who were highly sceptical of the role research can play in designing the strategy. After several working meetings that mirrored the population health course, the committee produced a policy document called *The Manitoba First Nations Diabetes Strategy: A Call to Action* to contest the colonial intrusion of the federal government in developing a diabetes strategy directed at controlling what it called a First Nations diabetes epidemic. Included in this document was a health information strategy based on OCAP principles. It outlined the need for a diabetes surveillance system, research that targets the determinants of diabetes, and community-based evaluations that assess the effectiveness of diabetes intervention programs. Since then, a major diabetes study has been launched to address surveillance and health services issues in Manitoba.

The Unit has also worked in full partnership with the Assembly of Manitoba Chiefs disability committee in a pilot study to identify First Nations Peoples with a disability, document their social economic conditions and job training needs, and discover other factors and barriers (health, housing and transportation) related to their disability. The final report produced through this partnership was presented at a special Assembly of Manitoba Chiefs assembly on health. A resolution created a mandate to undertake a process that would comprehensively review and evaluate the current service delivery system as it relates to First Nations Peoples with a disability and their families. This information will be used to develop a strategy for constructive program and policy change.

In terms of new institutional partnerships, further discussions between the Assembly of Manitoba Chiefs 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 with a generous contribution from the Assembly of Manitoba Chiefs for capital construction; the awarding of an infrastructure grant from the Canada Foundation for Innovation; and partnership funding from the Health Sciences Centre Research Foundation, the University of Manitoba, and the Province of Manitoba. The new research centre opened in the spring of 2001 in 225 square metres (2500 square feet) of new research space in the Buhler

Research Centre on the Health Sciences Campus of the University of Manitoba. 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 mission of the MFN-CAHR is to initiate, co-ordinate and support research activities designed to assist 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 Aboriginal communities;
- To support culturally-appropriate studies of Aboriginal healing ways in Aboriginal communities;
- To support and co-ordinate basic medical research into disease processes currently prevalent in Aboriginal communities;
- To conduct community-based studies into innovative culture-based approaches to healing and wellness in Aboriginal communities;
- To conduct studies into factors that influence the development of health service systems that meet the needs of Aboriginal communities;
- To provide community- and university-based education and training in health research to Aboriginal communities and students;
- To facilitate capacity building in 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 Aboriginal communities;
- To advise Aboriginal governments and organizations on health policy issues based on the best available research evidence; and
- To facilitate communication and knowledge sharing concerning Aboriginal health development nationally and internationally.

An advisory board provides general policy direction for the Centre for Aboriginal Health Research. Membership on the board includes the University of Manitoba, Manitoba Aboriginal communities and other stakeholders in Aboriginal health. The AMC-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.

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 AMC-HIRC meetings and workshops and assists in creating new partnerships between university investigators and the HIRC. In 1999, for instance, the MFN-CAHR had co-ordinated a partnership between the HIRC and the Manitoba Centre for Health Policy (MCHP). Several workshops and meetings between the two groups had involved building capacity in the AMC-HIRC to design a project using Manitoba Health service utilization data that can identify and assess health status indicators of Manitoba First Nations Tribal Council areas.

The MFN-CAHR currently holds a number of significant operating grants in partnership with Manitoba First Nations that build Manitoba First Nations capacity in developing and managing health info-structures.

The Aboriginal Capacity and Developmental Research Environment (ACADRE) Training Program funded by the Institute of Aboriginal Peoples' Health will expand the pool of Aboriginal researchers who can compete for national grants in the field of Aboriginal health research. This program has the following objectives:

- To train a new cadre of Aboriginal professionals in the field of health research;
- To further the development of a research environment based on collaboration and partnership between the University of Manitoba and Aboriginal communities and organizations;
- To develop a research environment that fosters participation for scientists from all disciplines to engage in collaborative research with Aboriginal communities and organizations; and
- To ensure that research training is available for students and faculty that emphasizes the importance of appropriate communication and dissemination activities that are consistent with Aboriginal values and goals for healthy, self-governing communities.

The research program will concentrate in four areas where the University of Manitoba has already established excellence: population health, health services research, child development and health, and ethics. In addition, the ACADRE program will encourage new research initiatives and partnerships in new and emerging areas of research collaboration in the Canadian Institutes of Health Research themes of basic and clinical sciences.

The primary purpose of the program is to attract Aboriginal students into health research careers. The training initiative will be directed toward Aboriginal

health researchers at the graduate and junior faculty levels. However, in order to attract the most qualified candidates into health research, the organizers will provide opportunities for Aboriginal undergraduate and high school students to discover the opportunities that health research offers. The program will also expand the opportunity for increasing health research capacity in Aboriginal communities and organizations. Faculty and students associated with the ACADRE initiative will participate in the design and implementation of a Community Training Institute (CTI) that will be held once every two years. Participants will be drawn from the Aboriginal communities and organizations both regionally and nationally. Participants will have the opportunity to interact with academic health researchers in different fields and disciplines with the intention of nurturing new research ideas.

The Aboriginal Health Survey Support Program (AHSSP), funded by the Institute of Aboriginal Peoples' Health, will contribute to the improvement of health survey activity in First Nations, Métis, and Inuit communities. The AHSSP will facilitate university and Aboriginal governments and communities to undertake complex surveys as well as build capacity of those with limited survey research and statistical knowledge. The purpose of the program is to heighten the profile of and interest in survey research and to respond to current and potential data needs to inform health policy, health and social programs, and health service delivery. The AHSSP is committed to working in partnership with First Nations, Métis and Inuit organizations on a number of projects related to the area of survey research. It is also committed to working, in partnership with the ACADRE Training Centres to develop a research environment based on collaboration and partnerships between universities and Aboriginal communities and organizations across Canada.

The AHSSP will support the development of national expert working groups to work on existing surveys and to develop new surveys that address emerging health issues. The intent of supporting these initiatives is to strengthen a national network of faculty, practitioners, students, and Aboriginal organizations committed to research, education and services in the advancement of the health and well-being of First Nations, Inuit, and Métis Peoples. The AHSSP potentially will undertake survey research in a variety of areas, subject to agreement with the appropriate decision-making structures. The AHSSP has interest in supporting off-cycle surveys, new sur-



veys, ethical/data management protocols, and data linkage.

The AHSSP will also undertake several initiatives to facilitate statistical capacity among Aboriginal communities and universities. The AHSSP will work closely with the ACADRE training centres to ensure research training is accessible to students and junior faculty. The AHSSP program will also build on the MFN-CAHR Applied Aboriginal Population Health Research Institute and will design and implement a Summer Institute in Survey Research (SISR). As part of this activity, the AHSSP will facilitate a working group of instructors and Aboriginal organizations to develop survey research instructional materials that bridge western science and Aboriginal ways of collecting and interpreting data.

The 2002-2003 First Nations and Inuit Regional Longitudinal Health Survey has been launched by the First Nation Centre at the National Aboriginal Health Organization (FNC at NAHO) under the direction of the First Nations Information Governance Committee. The MFN-CAHR is working in full partnership with the Assembly of Manitoba Chiefs in launching this regional survey in Manitoba, developing the survey and training the regional co-ordinators. For the Manitoba regional survey, the MFN-CAHR is providing technical support and training in sampling, ethical protocols, interviewing, data quality assurance, database management, and dissemination of research results. Data from this survey will also be shaped into a tutorial database to use in the MFN-CAHR Applied Aboriginal Population Health Research Institute.

Linked to this project is the "Why are Some Communities Healthy and Others Not?" project funded by the Social Sciences and Humanities Research Council. This project helped develop and test new measures of social determinants, health and well-being to integrate into longitudinal health surveys in Aboriginal communities.

The MFN-CAHR is also working with the AMC-HIRC and communities throughout Manitoba to better understand how factors such as social cohesion, traditionality, resilience, poverty, and the social environment predict variations in the health and well-being of First Nations Peoples. An extension of this project is the Social Capital (e.g., trust and participation at the community level) as a Determinant of Health in First Nations Communities, which is funded by Canadian Institute of Health Information/Canadian Population Health Initiative. This project developed a conceptual framework for social capital as a determinant of health in First Nations communities and a social capi-

tal measurement scale. The project involved qualitative and quantitative methodologies to identify dimensions of social capital, develop culturally-appropriate items to measure social capital, conduct pilot testing of the developed instrument, and analyze the instrument and revise accordingly.

Another project under consideration is the Manitoba First Nation Health Information Data Repository System. The First Nation Health Information System (FNHIS) contains detailed health information about Status and non-Status First Nations residents of all provinces who access health services on-reserve. Information includes name, address, gender, birth date, residency, and status. It may include Band registration number, provincial health card number, and immunization status as well as data pertaining to reportable and chronic diseases, mortality, medication, medication allergy and adverse reaction, test and exams, public education, abuse, maternal/child health, and psychosocial health. The MFN-CAHR has agreed that, at some future date and at the request of the Assembly of Manitoba Chiefs, it would house the Manitoba FNHIS database in the form of a research data repository consistent with First Nations principles of OCAP.

The MFN-CAHR is also discussing with the AMC-HIRC about the development of a memorandum of understanding suitable to all partners including Manitoba First Nations, Manitoba Health, Indian and Northern Affairs Canada, and the First Nations and Inuit Health Branch (Health Canada) that would provide for the creation of a Master First Nations Health Registry. This data repository would be developed from the Indian Registry System maintained by the Department of Indian Affairs and Northern Development. It contains the name, treaty number, on- or off-reserve status, birth date, and sex of every First Nations Person in Manitoba. This file is also maintained by the First Nations and Inuit Health Branch and is known as the Status Verification System (SVS). These federal departments use these files to determine recipients of various benefits provided by both departments. Linking the SVS file/Indian Registry to the Manitoba Health database would produce a research database, updated annually, describing the health conditions and health service patterns of First Nations Peoples in Manitoba. 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 memorandum of understanding.

Altogether, these initiatives illustrate that many forms of partnerships and research can develop when

there is a high level of trust and participation. They also show that scientific discourse, when there is trust and participation, can take root in the First Nations self-government value system and coexist with First Nations self-government to ensure that the strength of First Nations Peoples are known.

## CONCLUSION

Alternative discourses are possible. Resistance in the form of counter discourses can produce new knowledge, speak new truths and constitute new powers such as First Nations' ownership, control, access and possession of health information. Several initiatives helped produce the social and cultural structures necessary to produce counter knowledges in the area of First Nations health. Research agreements helped create a First Nations research network and partnership structure that could build and maintain trust and reciprocity. In return, they could generate a system of expectations and obligations. The membership attained through various partnerships and involvement in the Manitoba research network conferred both obligations and benefits to academic researchers and to First Nations health planners and service providers.<sup>21</sup> What's more, these agreements helped secure the necessary resources that First Nations Peoples can access through these partnerships or through their membership with research working groups or policy teams. As well, OCAP, as a social control mechanism, can protect the interests of First Nations communities.

These developments also demonstrated that capacity building is not just more computer training and greater exposure to quantitative methods and databases, but also the full engagement of First Nations self-determination and governance in health services and information systems. In Manitoba, capacity building extended across knowledge systems with the intent to build the necessary social connections, opportunities and agreements for internal and external agencies, organizations, institutions, departments, and ministries. The initiatives currently underway at the MFN-CAHR clearly demonstrate that distinct knowledge domains exist and can overlap to form partnerships where information can be exchanged between various forms of sovereignty (First Nations, university, federal and provincial governments). Building First Nations capacity in applied population health, however, has resulted in new restrictions on the freedom of academics and governments to conduct or present research on First Nations Peoples, and for good reason. The literature on First Nations health is domi-

nated by pathologizing discourses. The social control function of OCAP will help undo this negative view of First Nations Peoples by uncovering the strength and resiliency of First Nations Peoples. The question for non-Aboriginal academics and governments to ponder is – are they open to agreements that respect First Nations determination, that build First Nation research capacity and that oblige them to enter the politics of trust and participation?

In this new environment, non-Aboriginal researchers and governments will have to recognize that any work involving Aboriginal Peoples will occur in the context of resistance to colonization. Such resistance, however, creates the possibilities for collaboration. The previously described experiences illustrate collaboration is possible, but much work will occur on the margins between various knowledge domains and forms of sovereignty. For collaboration to be possible and successful, researchers will have to reflect on the positions represented by others, make every attempt to understand these positions within the context they occur, recognize that trust and participation is conditional, and accept that any sharing and production of health information will occur at the boundaries between systems of knowledge.

## ACKNOWLEDGMENTS

The accomplishments reported in this paper would not have been possible without the strong will and determination of Audrey Leader who passed away in April 2002 after a lengthy illness. During her tenure as Health Director for the Assembly of Manitoba Chief, she rallied Manitoba First Nations communities and governing organizations to embrace health information as a means to advance self-determination over health service delivery and to improve the health of Manitoba First Nations Peoples through the determinants of health. Indeed, her great spirit, sense of humour, self-determination, and willingness to forge new partnerships made the Manitoba First Nations Centre for Aboriginal Health Research a reality. The authors would like to also acknowledge members of the Assembly of Manitoba Chiefs Health Information and Research Committee who were equally as important to the development of a Manitoba First Nations Health Information System and who are continuing to lead the way in advancing the principles of OCAP. The authors would further like to thank the staff of the Centre for Aboriginal Health Research, particularly Dawn Stewart, for their dedication and commitment to making all this possible. Financial support was also critical to our success. Support for the Summer Insti-

tute Program was received from the former National Health Research and Development Program of Health Canada. Funding from the Institutes of Aboriginal Peoples' Health, Canadian Institutes of Health Research and other research granting agencies is making possible the diverse and strong research and training program offered at the Centre for Aboriginal Health Research.

## ENDNOTES

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