Building Capacity in Applied Population Health Research©

BRENDA ELIAS, M.A., PH.D(C),
RESEARCH ASSOCIATE (MFN-CAHR)

JOHN O'NEIL,
PROFESSOR AND DIRECTOR (MFN-CAHR)

CENTRE *for*
Aboriginal Health
RESEARCH

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EXECUTIVE SUMMARY

First Nations health planners and service providers are requiring trustworthy health information based on the best available research. Much of this information has been housed within research and government databases, which are largely inaccessible to First Nations communities. The NHRDP project "Making Population Health Research Relevant to the Needs of First Nations Communities in Manitoba" developed an innovative research dissemination strategy involving Manitoba First Nations and population health research at the University of Manitoba. The project was a joint venture of the Assembly of Manitoba Chiefs and the University of Manitoba. The intent of this project was to create partnerships involving First Nations communities and organisations with university-based research interests and to build research capacity in First Nations communities. This report describes the dissemination strategy process and the many accomplishments associated with building capacity.

The Manitoba First Nations Summer Institute in Applied Population Health Research was part of a broader project involving various forms of cultural resources that accumulated through a network of institutionalized and cultural relationships, within the context of partnership and institutional building. The First Nations and Inuit Regional Health Survey initiated the process to develop population health that is owned, controlled and accessible (OCA) to First Nations. The survey resulted in higher levels of trust and participation at the regional level, particularly in Manitoba. A research agreement framed the partnership between the Assembly of Manitoba Chiefs Health Information and Research Committee (HIRC) and the Manitoba First Nation Centre for Aboriginal Health Research (MFN-CAHR, formerly the Northern Health Research Unit) and ensured that the HIR Committee shared leadership, power, and decision-making from design to dissemination. To build capacity further, the MFN-CAHR developed the applied population health research institute. This institute, held over the course of three years, created new social connections and opportunities to build evidence-based decision-making. Membership attained through the various partnerships and participation in the research network had conferred both obligations and benefits to academic researchers and First Nation health planners and service providers. Research agreements were clearly necessary to secure the resources to which First Nations can claim through partnerships or by virtue of their membership with research working groups or policy teams. The other benefit was the advancement of OCA as a social control mechanism to protect the interests of First Nation communities. On the downside, building First Nation capacity in applied population health research did restrict the freedom of academics and governments to conduct or present research on First Nation peoples. Nevertheless, given the over-emphasis on pathologizing discourses in Aboriginal health research, the social control function of the OCA principle is necessary to advance First Nation self-governance over health.

To date, the Manitoba First Nations Centre for Aboriginal Health Research has been successful in a number of major research initiatives that demonstrate that in order to build human capital in the area of population health research, it is also necessary to build social capital through the OCA principle. The question for non-Aboriginal academics and

governments to ponder is will they be open to agreements and institutions that respect First Nation determination, that build First Nation research capacity, and that oblige them to enter the politics of trust and participation.

INTRODUCTION

The NHRDP project "Making Population Health Research Relevant to the Needs of First Nations Communities in Manitoba" developed an innovative research dissemination strategy involving Manitoba First Nations and population health research at the University of Manitoba. The project was a joint venture of the Assembly of Manitoba Chiefs and the University of Manitoba. The intent of this project was to create partnerships involving First Nations communities and organisations with university-based research interests and to build research capacity in First Nations communities. This report describes the dissemination strategy process and the many accomplishments associated with building capacity.

A NEED FOR FIRST NATION POPULATION HEALTH INFORMATION

Confronted with the task of determining appropriate health programs and services to meet rapidly changing needs with limited resources, First Nations health planners and service providers are requiring trustworthy health information based on the best available research. Historically, much of this information has been housed within research and government databases, which are largely inaccessible to First Nations communities. Although trustworthy information is required, for many First Nations people active in community wellness development research is a dirty word. Research is perceived, at best, as irrelevant to the needs of communities, or, at worst, as an insidious threat to the integrity and autonomy of First Nations communities. At times, it is also considered "as a drain on resources" that might otherwise be used for the development of urgently needed programs. The British Columbia Royal Commission on Health Care and Costs describes this problem succinctly:

> *"Native populations, after years of being studied, are reluctant to participate in social surveys, including the Canadian Census, as they have no control over what information is gathered or how it is used. Addressing the health status of Native people in British Columbia will require treating the issue of control of data collection as a priority."*

Some of the responsibility for this unfortunate circumstance must lie with university-based researchers in the community health field. Past research practices have focused primarily on the dissemination of research results to the scientific community, with limited attention paid to community needs. Dissemination of Aboriginal health research has been largely a passive process, reliant primarily on the distribution of complex technical reports and publication in scientific journals. Rarely are study results reported in a format accessible to First Nation health planners at the community level. Most discussions to change this situation have focused on the development of alternative medium for the dissemination of research results. Use of videotape, community radio, community workshops, etc. are often recommended as appropriate vehicles to communicate risk and to make research available to First Nations communities.

Consequently, this project is not easily situated in the general field of research dissemination or dissemination research.

In the field of population health, most of the literature is focused on problems associated with changing the practice behaviour of health professionals with evidence from clinical trials and other health service evaluation research (Lomas et al 1989; Lomas 1991). In the health promotion field, most studies focus on barriers to the diffusion of information from research to the public where the emphasis is on changing public behaviours such as smoking, eating habits, etc (Parcel, Perry and Taylor 1990; Eakin and McLean 1992). Neither of these approaches, however, is particularly relevant to an interest in how policy-oriented research is disseminated in a complex cultural and political environment to health administrators and program developers. The work of Milio (1987) and O'Neill and Pederson (1992) best describes the complexities of the relationships that must develop between the research and policy communities. However, there seems to be more questions than answers as to how to develop innovative dissemination strategies related to the general public than there is to address the dissemination needs for health information systems (Stoddart and Baer 1992). This challenge, in many ways, sparked our interest in making population health research relevant to the policy and planning needs of First Nations communities.

To make population health research relevant, we opted to establish partnerships between communities and researchers to ensure that dissemination became an integral component of the research rather than a stage that begins after the research is complete. One study relevant to this interest, by Crosswaite and Curtice (1994), described the effectiveness of a project in rural Scotland where the dissemination of health promotion research was developed through a series of workshops, research partnerships, and other liaison activities. This project identified institutional barriers and ownership issues as significant barriers to effective research dissemination and recommended that research dissemination be seen as an "ongoing liaison structure" rather than as a "communication of results process". "Research interpretation skills" was another vital component identified as a successful dissemination strategy. In other words, information alone might not only be useless, but might be potentially dangerous if consumers lack the technical and analytical skills to make information relevant to community health needs and interests.

Furthermore, recent discussions related to the development of health information systems in a First Nation context underline the importance of building research capacity in First Nations communities as an integral component of developing health information systems (Chaudhry, Reading, Lamarche and Moses 1994; O'Neil 1995; Baikie and Allen 1993). Health information, when developed according to the cultural and political priorities of First Nations communities, is indeed far more valuable to First Nation health planners. Partnership models that incorporate First Nation control over the process and ongoing "capacity-building" strategies are also fundamental (Bartlett 1994), and are a significant departure from the way research has been conducted in the past. The following section describes the initiatives that had to occur to build Aboriginal capacity in applied population health research.

INITIATIVES TO BUILD RESEARCH RELATIONSHIPS

First Nations and Inuit Regional Health Survey (FNIRHS)

In 1994, Statistics Canada began three major national longitudinal surveys; National Population Health Survey (NPHS), National Longitudinal Survey of Children (NLSC), and the Survey of Labour and Income Dynamics (SLID). The NPHS and NLSC are collecting data on a two-year cycle on samples of approximately 22,000 and 25,000 Canadian households respectively. The SLID collects data annually on a sample of 15,000 households. The general objectives of each of the three surveys are to assist federal and provincial governments, researchers and non-governmental organizations to develop public policy by providing information as summarized below:

- To provide comprehensive information on the health status of the Canadian population
- To describe information on trends and changes in health status
- To examine the social determinants of health status including economic, social, demographic, occupational, and environmental correlates
- To better understand the relationship between health status and use of health services
- To determine the prevalence of various biological, social and economic characteristics and risk factors of Canadian children and youth.
- To monitor the impact of such factors, life events and protective factors on the development of these children.
- To provide information to policy and program officials for use in developing effective policies and strategies to help children live healthy, active and rewarding lives.
- To improve an understanding of links between demographics, labour market events and changes in family circumstances and income

These longitudinal studies were designed to follow a group of people over a long time-period in an attempt to understand how changes in well-being are linked to changes in their lifestyles and social environments. In the case of children, changes in growth and development can be linked to changes in home, school, and community environment. The results of these kinds of studies have more powerful policy implications than cross-sectional studies, which merely describe the presence of problems at one point in time.

The national sampling frame for these three longitudinal surveys, however, had specifically excluded First Nations people living on reserves, and Inuit communities in the provinces. Recognising the need for comparable information on the First Nations population, Health Canada, Human Resources Development Canada and the Department of Indian and Northern Affairs contracted the Northern Health Research Unit at the University of Manitoba in January 1994 to conduct a Feasibility Study into the possibility of developing a National Longitudinal Aboriginal Survey.

The design of the Feasibility Study was to consult with First Nations technical staff working with Aboriginal organisations and communities. "Technical staff" included Aboriginal health, social service, child development, education and socio-economic development professionals active in service delivery and research and policy development with Aboriginal communities and organisations. Workshops were held in Ottawa, Halifax, Montreal, Toronto, Winnipeg, Saskatoon, Edmonton and Vancouver through the fall of 1994, where approximately 150 Aboriginal health technicians participated in discussions about the possibility of developing an Aboriginal longitudinal survey of health, children and social conditions.

The Feasibility Study asked the question "What kind of national longitudinal study would be acceptable to First Nations, Inuit and Métis people at the community level, while at the same time meeting the information needs of First Nations, Inuit and Métis organisations at the community, regional and national levels, and other levels of government?" The general framework for a longitudinal Aboriginal survey proposed by the Feasibility Study is summarized below:

1. Health Canada, Human Resources Development Canada, and the Department of Indian and Northern Affairs should commit funding to develop a framework of Regional Health Surveys for First Nations and Inuit people in the ten provinces to generate information on community health, the well-being of children, and the documentation of socio-economic conditions associated with community health and the well-being of children.
2. National First Nations and Inuit organizations, and the major funding departments should be invited to appoint members to First Nations and Inuit National Steering Committees. These Committees will be responsible for the general supervision of the development of the regional cohort studies for their respective communities.
3. Regional (usually provincial) First Nation and Inuit political organizations should be invited to submit letters of intent indicating their interest in developing the longitudinal survey on behalf of all communities in their respective regions.
4. Regional organizations should be asked to propose a Research Group with whom they wish to collaborate in the development of the survey. Research groups should be approved by the National Steering Committees.
5. National Steering Committees should appoint a Core Questions Research Group who which will be responsible for the development of comparative "core questions" for the longitudinal surveys.
6. A National Aboriginal Technical committee should be established consisting of members of the "core question" Research Group and one member from all other Research Groups involved in the longitudinal surveys.
7. National Steering Committees should approve grants to each regional organization/research group to develop and implement the survey.
8. This initiative should be developed at a pace that is suitable to Aboriginal organizations and communities. It is likely that the first wave of the survey in 1996 will be restricted to several pilot projects in different parts of the country. Other regions and communities may not be ready to participate until 1998.

Of the three original participating federal departments, only Health Canada was prepared to go forward with these recommendations. With funding from the Tobacco Demand Reduction Strategy, Medical Services Branch issued a “Call for Proposals” from each of the regional First Nations political organizations and Inuit organizations in Labrador and Quebec. In response to the call for proposals, both the Assembly of Manitoba Chiefs (AMC) and the Manitoba Okimakanak Keewatiniowi (MKO) contacted the Northern Health Research Unit at the University of Manitoba to solicit interest in providing technical assistance. After discussion, AMC and MKO decided that one proposal would be submitted and that AMC and MKO would be jointly responsible for the Survey, although AMC would administer the contract for the Survey.

The contract between the University and the Assembly of Manitoba Chiefs (AMC) reflected the principle that ownership and control over the Project remains with First Nations. In our initial discussions, AMC representatives expressed concern 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.

Our task was to develop a contract, which would formalize the respective concerns of both AMC and the University but would also facilitate the kind of collaborative process that we envisioned. Although this contract contains standard language typical in university research contracts, the two clauses describing "Ownership of Project Deliverables" and "Use of Information for Publication in Learned Journals" are somewhat unique and benefit from previous work in this area by the Kahnawake Schools Diabetes Program (Quebec). Essentially, copyright is the property of AMC who also must provide written permission before any publication. Permission to publish is 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 they are accompanied by a letter from AMC outlining their objections. It then becomes the responsibility of the journal editor (or conference organiser) to resolve this conflict.

Although the University contract is with the Assembly of Manitoba Chiefs, who control the funding provided by the federal government for the initiative, direction for the Project is provided by the Manitoba First Nations Regional Steering Committee (RSC) now know as the Health Information and Research Committee, which is mandated by the AMC Chiefs Health Committee in a formal resolution. The primary health authority of First Nations in Manitoba - the Chiefs Health Committee of the Assembly of Manitoba Chiefs - determined the structure of this committee. The committee consists of the Health Directors for each of the Tribal Councils and from independent First Nation communities in Manitoba, plus the Health Advisors from AMC and MKO who represent all Bands under their respective jurisdictions. Since the project beginning, the HIRC met regularly by teleconference and in workshops. These meetings have included both "training" as well as decision-making on all aspects of research methodology.

One of the first tasks of this committee was to develop a "Code of Ethics" for the Project. This Code now emphasises both individual confidentiality and community ownership of data, as well as the responsibilities of the Northern Health Research Unit in terms of data storage and accessibility. Overall, these principles draw on the contractual language described above, but further clarify the respective rights and responsibilities of the various First Nations organizations and communities.

Implementation of FNIRHS and Capacity Building

In early summer, 1996, we hired eight First Nation university students as research assistants to conduct exploratory interviews with key stakeholders in all First Nation communities in Manitoba on health issues and concerns. Students underwent a one-week training program, which emphasized conceptual rather than technical skills. By this we mean that students were asked to develop their own interview schedules, methods for keeping notes, and approaches to soliciting interviews in their assigned communities. Our training emphasized the political context of the research, its significance for developing a First Nations controlled health information system, and general strategies for conducting community-based qualitative research. Frank Wesley, an elder who advises the Assembly of Manitoba Chiefs, also spoke to the students about their responsibility to the future of their communities.

Each student was affiliated with one of the Tribal Councils, and the second stage of training involved an orientation in the field at the Tribal Council office where appropriate contacts with community authorities were facilitated. Students developed their own approach to community consultations. In some instances, interviews were conducted mostly with health care workers and the political leadership in the community. In others, students visited schools or met with elders to discuss relevant issues. Informal meetings with a wide variety of community members in recreational and family settings supplemented these more direct consultations.

The results of this consultation phase were then summarized by each student for their respective communities, and further summarized in regional reports. Reports were then distributed widely for comment and reviewed by the HIRC. Issues raised in the reports ranged from the impact of health reform policy, to physicians' fly-in schedules, to road conditions, to family violence, to the status of elders. Together these topics describe a wide range of health and social conditions as well as the macro and micro environmental determinants of well being in communities.

One of the students, Ms. Doreen Sanderson, was subsequently hired as the Survey Coordinator and she underwent an intensive apprentice training program at the Northern Health Research Unit.

The HIRC was responsible for determining an appropriate strategy for selecting communities. Considerable discussion occurred around stratification issues. Questions were posed as to whether communities should be grouped by size, by geographic "remoteness", by political affiliation, by health service administrative features, by tribal affiliation (i.e., Cree, Ojibway, Dene, Sioux, etc.), or by whether they were regarded as healthy progressive communities or not. The HIRC was particularly concerned that whatever criteria were used, the communities must be confident that the selection was random and not biased by political interests in any way. Ultimately seventeen communities were selected for an invitation to participate in the survey according to political affiliation, tribal affiliation, geographic factors, and community size.

After the communities were identified, the HIRC extended an invitation to the Chiefs of these communities to participate in the survey. One community declined based on past involvement with other surveys. Sampling considerations next involved a discussion of how individual respondents should be identified. Use of a list of residents for each community has many problems as identified in previous research in northern communities. Resident lists are sometimes regarded as the confidential political property of the Band because they are contentious documents in negotiations for per-capita-based funding. Often lists do not accurately reflect Band members currently living in the community. Accessing respondents from a random list of names can be particularly difficult when people migrate back and forth to cities, or change residence on the reserve. The HIRC determined that a household-based approach to sampling would be more appropriate. Houses were randomly selected from a map of each community and all adults and one child or youth under eighteen years of age (by proxy) was interviewed for each house. The survey was completed in three months with an overall response rate of 81%, and a majority of communities reporting 100% completion of questionnaires.

Each participating community was asked to select up to three individuals for training as community interviewers. Communities were advised to select individuals who respected confidentiality and were considered trustworthy; research or health care experience was a secondary consideration. Three training workshops of three days duration were organized in different regions of the province for community interviewers. Training emphasized interviewing techniques, principles of random selection of respondents, and issues of confidentiality and ethics. Interviewers were encouraged to be flexible and creative in interviewer techniques, rather than expecting uniformity in approach. For example, interviewers were advised that joint interviewing of several respondents could occur if each respondent was able to complete a questionnaire independently while the interviewer acted as a guide. Interviewers were also encouraged to allow respondents to complete their own questionnaire in the interviewer's presence wherever possible in order to facilitate confidentiality.

This approach is somewhat at odds with standard survey methodology where consistency is emphasized in order to minimize interviewer bias. However, flexibility is essential in a First Nations community context to accommodate cultural differences and maximize participation rates.

Data entry and database development for the MFNRHS was undertaken by technicians at the Northern Health Research Unit. The Regional Steering Committee determined that data entry skills were not a priority at either the community or regional level. Since then, an Aboriginal assistant at the NHRU assumed all data entry responsibilities. Analysis was an iterative process with the Regional Steering Committee receiving data output at all levels. Raw frequencies on all variables were distributed as rapidly as possible and a Regional Steering Committee meeting was held to provide preliminary input into interpretation of these results. Graphic representations of key variables were next distributed to the HIRC. Community reports describing key variables in graphic form compared to regional results were then distributed to all participating communities. These reports were the property of participating communities and could not be shared or distributed without their permission. A final report was also produced which described regionally key variables from the survey. Where possible, these results were compared to national results from such surveys as the Aboriginal Peoples Survey, the National Population Health Survey, and the National Longitudinal Study of Children and Youth. The final section of the Report also provided a preliminary analysis of social determinants of health concerns including gender, age, income, and geographic location. This report was the property of the Regional Steering Committee and distributed to all First Nations communities in Manitoba, all Tribal Councils and First Nations organizations, and to other interested parties approved by the RSC. Also made available was a Summary Report of the regional health survey and this was disseminated to interested members of all First Nations communities.

In summary, the First Nations and Inuit Regional Health Survey (FNIRHS) helped forge what has become the OAC principle. “OCA”, which stands for ownership, control, and access to health information is a mechanism that extends First Nation sovereignty over health information and has helped decolonize research relationships between First Nations organisations, universities, and provincial and federal governments.

At the feasibility stage of this survey, Aboriginal organizations throughout Canada were highly skeptical as to whether they should invest their time and energy in a project that would offer little in terms of direct benefit (O’Neil et al 1995). These organizations were not alone in their skepticism, and this distrust and resistance is widely shared by indigenous peoples throughout the Americas and Australia-New Zealand (Macaulay et al 1999; Kaufert et al 1999; Tuhiwai Smith 1999; Cornwall and Jewkes 1995). A major criticism leveled against traditional research is that it is a repressive process under the control of “others”. To make research more egalitarian, researchers have adopted participatory action research (PAR) protocols. However, indigenous peoples have argued that PAR still does not prevent researchers and governments from exercising intellectual arrogance, or employing evangelical and paternalistic practices (Tuhiwai Smith 1999; Cornwall and Jewkes 1995).

For instance, at the initial planning stage, the FNIRHS National Steering Committee, comprised of First Nation and Inuit representatives from nine regions across Canada, resisted the top down, paternalistic approach taken by the Federal government. Medical Services Branch (Health Canada) employees initially opted for a PAR process that maintained their administrative control over the survey. However, several members of the FNIRHS National Steering Committee, including the representative from the Assembly of Manitoba Chiefs, resisted this act by threatening to leave the process if they did not get full-control over the survey (O’Neil et al 1995). The Federal Medical Services Branch eventually caved into this demand and transferred complete control over the survey to the FNIRHS 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, and the establishment of ownership, control, and access (OCA) over health information as a model for other indigenous groups to follow. At the regional level, a research agreement framed the partnership between the AMC-HIR Committee and the Northern Health Research Unit (NHRU) and ensured that the AMC-HIR Committee shared leadership, power, and decision-making from design to dissemination. To further build capacity, an applied population health research institute was proposed by the Northern Health Research Unit.

APPLIED POPULATION HEALTH RESEARCH INSTITUTE

The recent success of First Nation ownership, control and access over health information in Manitoba (Canada) essentially established a social and cultural structure that built trust and participation necessary for constructing new forms of health information directed at First Nation wellness. The document that helped to frame this relationship further was a code of research ethics developed at the national level to strengthen First Nation and Inuit self-determination over the survey process (FNIRHS National Steering Committee 1999).

In this code, the FNIRHS National Steering Committee set out provisions to ensure that researchers were accountable both nationally and to participating regions. It also established the obligation to build First Nation and Inuit research capacity in survey development, data collection, computer use, analysis, and health planning. Today, this code of ethics stands out among other research agreements (Macaulay et al 1999; Kaufert et al 1999) as a model that nationally and regionally frames partnership models and builds research capacity based on the OCA principle.

Entrenching the obligation to build research capacity into a research agreement is a significant departure from past approaches to disseminate research in the areas of population health and health promotion. Effective dissemination is dependent on the complexities of the relationships that must develop between the research and policy communities. Indeed, decision-making, regardless of the domain, is often influenced by the quality of the evidence, dissemination of the evidence, and the complex environment in which the decision-making and incorporation of the evidence actively takes place (Tranmer et al 1998). However, evidence-based decision-making cannot occur if health information is not available, and its availability if often contingent on co-operation and partnerships between different research and governing bodies (Black 1998).

The First Nation Applied Population Health Research Institute was our attempt to construct innovative approaches to building such research capacity. In Manitoba, the high level of trust and participation that developed between the AMC-HIR Committee and the NHRU during the survey made it possible to extend this partnership into building research capacity and evidence-based decision making in Manitoba First Nations communities and organizations. In 1996, the NHRU applied and received a grant from the National Health Research Development Program of Health Canada to develop First Nation research capacity through a First Nations Applied Population Health Research Institute. This project was a joint venture formalised by the Chiefs Committee on Health in the following resolution passed in November 1996. This resolution is what gave the AMC-HIR committee the mandate to work with the NHRU to build research capacity and to extend further First Nation control over the health care systems in their communities.

ASSEMBLY OF MANITOBA CHIEFS
SPECIAL CHIEFS ASSEMBLY
DAUPHIN, MANITOBA
NOVEMBER 19, 20, 21, 1996

CERTIFIED RESOLUTION

NOV-06.04

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Moved by: RE: FIRST NATIONS HEALTH RESEARCH TRAINING INITIATIVE

Chief Sydney Garrioch

Cross Lake FN

WHEREAS, First Nations in Manitoba are assuming control over the health care systems in their communities; and

Seconded by:

Chief Ron Evans
Norway House FN

WHEREAS, First Nations health planners need reliable an accurate health information to support community health policy and planning; and

MOTION CARRIED

WHEREAS, the interpretation and utilization of health research information requires the acquisition of relevant research skills by First Nations health planners; and

WHEREAS, the Northern Health Research Unit at the University of Manitoba has secured funding from the National Health Research and Development Program at Health Canada to work in partnership with the Assembly of Manitoba Chiefs in the development of this Training Initiative.

THEREFORE BE IT RESOLVED, that the Assembly of Manitoba Chiefs work in partnership with the Northern Health Research Unit to develop this Training Initiative; and

FURTHER BE IT RESOLVED, that the Manitoba Regional Steering Committee for the First Nations Health Survey serve as the Steering Committee for this initiative and report back to the Assembly of Manitoba Chiefs.

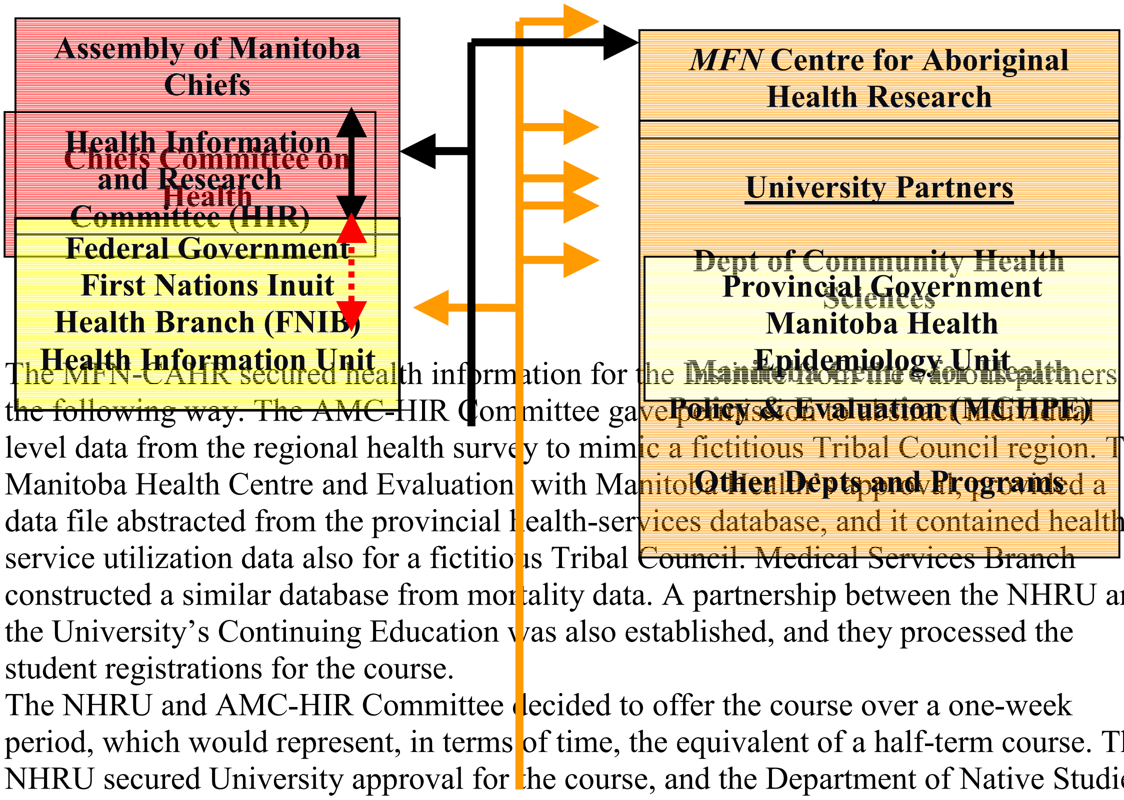
Certified copy of a Resolution Adopted on
November 21, 1996; Dauphin, Manitoba

Signed by Phil Fontaine

Phil Fontaine, Grand Chief

Both the NHRU and the AMC-HIR committee oversaw the implementation of the Institute. A Project Coordinator, representing the AMC-HIR Committee, recruited First Nation health planners and service providers, secured a training facility, and supervised on-site administration at the Institute. Members of the HIR Committee 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 Institute was held at a college operated by Southeast Tribal Council, which offered residential facilities for students who did not live within driving distance. The coordinator also integrated First Nation protocols into the Institute, such as the opening and closing prayer by an elder, opening address and closing remarks by the AMC, and a sharing circle scheduled for the last day of the course.

The NHRU recruited faculty and tutors from several disciplinary areas such as medical anthropology, sociology, epidemiology, bio-statistics, and health services research. To secure health information and content specialists, partnerships were established between the NHRU, and the Manitoba Centre for Health Policy and Evaluation, Manitoba Health Epidemiological Unit, and Health Canada – Medical Services Branch, Health Information Division. The following diagram summarizes the links between the research centre and the Assembly of Manitoba Chiefs and the HIR Committee. It also illustrates the partnerships with university departments, research centres, and government departments that the NHRU (MFN-CAHR) established to make this institute possible.



The MFN-CAHR secured health information for the Institute from the various partners in the following way. The AMC-HIR Committee gave permission to abstract individual level data from the regional health survey to mimic a fictitious Tribal Council region. The Manitoba Health Centre and Evaluation with Manitoba Health's approval, provided a data file abstracted from the provincial health-services database, and it contained health service utilization data also for a fictitious Tribal Council. Medical Services Branch constructed a similar database from mortality data. A partnership between the NHRU and the University's Continuing Education was also established, and they processed the student registrations for the course.

The NHRU and AMC-HIR Committee decided to offer the course over a one-week period, which would represent, in terms of time, the equivalent of a half-term course. The NHRU secured University approval for the course, and the Department of Native Studies agreed to offer it. 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, we developed a course evaluation form to evaluate instructors and course content.

A curriculum working-group, which included faculty, tutors, and the HIR coordinator, established the curriculum objectives, and each faculty member contributed course materials, which we 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 on the fundamentals of epidemiology, need assessments and ethical protocols of an Aboriginal epidemiology. The remaining lectures covered quantitative techniques used to assess population health. 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.

Twenty-five Aboriginal health technicians registered for the course and 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, and on the last day of the course, they jointly presented a project proposal to the principal investigators of this Institute who posed as a Chief's Committee on Health.

Overall, the lectures and tutorial session exposed students to health information techniques used to shape health programs and policy. The evaluation of the course was highly positive, and the 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, and the intense working group environment helped build a research network they could draw upon.

In the second year, we 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, and 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. We held two workshops, one in the north and one in the south. Over twenty First Nations community health planners attended the workshops, along with a few former students of the Institute. These students helped instill interest in evidence-based decision-making in the First Nation health planners who had little experience applying health information to community health plans.

In the same year, the Labrador Inuit requested a one-week training session for the Labrador Inuit Health Commission health coordinators. The workshop occurred in Goosebay, Labrador. To meet the needs of these health technicians, we modified the curriculum and used the Labrador Inuit Regional Health Survey as a database to provide hands-on training on how to apply health information to the relevant program and policy areas of the Labrador Inuit.

In the third year, we held a second Institute open to First Nation community health planners and service providers from across Canada. Twenty-two Aboriginal students attended and 10 Faculty/Tutors participated. The second Institute was similar to the first, with the following exceptions.

The educational site 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 and Residence located on the University main campus. Members of the NHRU were somewhat hesitant to use this site out of concern that a Christian residential educational environment, if associated with the First Nations' residential school experience, may foster mistrust and a lack of participation. The NHRU discussed this issue with the HIR committee and students, and they did not perceive the presence of Christian symbols at this institution as a barrier to disseminating knowledge. Another departure involved the tutorial projects. Rather than pre-assign students to groups that addressed issues unique to vulnerable populations, we assigned them to the new strategic federal policy areas of diabetes and community healing. The curriculum remained the same. However, we did add a survey course as a pilot course for the one student who wanted to take it.

The second Institute was a success, and students positively evaluated all lectures and tutorial sessions. The exception was a presentation made by a MSB 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 students 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

OCA. The exchange between the students and the federal representative, who had little exposure to First Nations organizations, was quite heated, and at the end of the presentation, several First Nation students felt that the only solution to effectively develop research capacity was through a First Nations health info structure based on the principles of OCA. A few weeks after the Institute, the Manitoba MSB program officer sent a letter to the Department Head of our academic unit criticizing the Institute for creating a hostile environment. Although our intent was not to create such an environment, we did accept the responsibility of playing a significant role in developing First Nation capacity to apply critically population health techniques in order to secure First Nation self-governance over health. Since that exchange, the Manitoba MSB (currently known as the First Nations and Inuit Health Branch) Regional Office has developed a positive working relationship with the Assembly of Manitoba Chiefs Health Information and Research Committee and together they are developing First Nation control over the health information system.

Three major lessons were learned from this project. For one, we learned that any advancement of the OCA principle could potentially reveal a deep historic distrust and lack of participation between parties. The other lesson is that the Institute did serve its purpose, and it created a cohort of First Nation health planners and service providers to use population health techniques to produce counter-knowledges that can resist colonial encroachments on First Nations health. The most important lesson of all is that counter-knowledges can transform colonial relationships into new forms of partnerships that are based on principles of mutual respect.

OUTCOMES OF TRUST AND PARTICIPATION

The trust and participation developed through these initiatives went beyond the Institute and helped create new social connections and opportunities to build evidence-based decision-making. The following discussion outlines a number of significant outcomes of this new partnership and way of conducting research and disseminating information.

Manitoba First Nation Centre for Aboriginal Health Research

The Manitoba First Nations Centre for Aboriginal Health Research (MFN-CAHR) is a collaborative research initiative of the Assembly of Manitoba Chiefs (AMC) and the Northern Health Research Unit at the University of Manitoba. The development of MFN-CAHR became a reality in 1999 inspired by a generous contribution from AMC for capital construction and 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 the spring of 2001 in 2500 sq. ft. of new research space in the Buhler Research Centre on the Health Sciences Campus of the University of Manitoba. The MFN-CAHR, which replaces the Northern Health Research Unit, 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, 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 will integrate 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 Manitoba First Nations Health Information and Research Committee (HIRC) and the Aboriginal Health Research Group (AHRG) will advise the Advisory Board. The HIRC consists of representatives from each of the Tribal Councils and Independent Bands in Manitoba and is accountable to the Chiefs Health Committee of AMC. The AHRG is a recognized Research Group in the Faculty of Medicine that consists of faculty involved in health research with Aboriginal populations and communities. Discussions are also ongoing concerning the development of an Elders Committee, which would consist of four Elders – one from the East, South, West, and North of the province of Manitoba – to advise the Advisory Board. Further development of the Advisory Board will occur in consultation with other Aboriginal groups. The objectives of the Advisory Board are as follows:

1. To develop a broad perspective on health research issues of importance to First Nations and Aboriginal communities and organizations;

2. To advise and assist the CAHR to determine an appropriate set of activities to meet its goals and objectives;

3. To assure the long-term viability of the CAHR.

4. Powers, Duties and Responsibilities:
    4.1. Promote the CAHR and its objectives.

    4.2. Assist with securing operational funding for the CAHR.

    4.3. Provide general guidance for research priorities for the CAHR.

    4.4. Ensure that First Nations and other Aboriginal leaderships are kept informed of the CAHR's operations.

    4.5. Ensure that appropriate academic and scientific standards are maintained in accord with University policy.

    4.6. Ensure that appropriate ethical and dissemination protocols are developed and maintained.

    4.7. Assist with developing and maintaining linkages and partnerships with relevant Aboriginal organizations and communities, government, and private sector.

    4.8. The Board will meet twice per year or as required at the discretion of the Director, subject to the availability of funding.

The Advisory Board shall be comprised of not less than 10 and not more than 20 members. The Director of the CAHR shall be an ex-officio member of the Advisory Board. Two members of the Board shall be appointed as Co-Chairpersons and the University of Manitoba and the Assembly of Manitoba Chiefs respectively will make this appointment. Advisory Board members shall be appointed for terms of three years and can serve consecutive terms. After each three-year period, every effort will be made to ensure that one third of the Board is replaced. Meeting per diems may be provided where the Board considers them appropriate. Per diems will be in accordance with rates currently in effect at either Assembly of Manitoba Chiefs or the University of Manitoba. Board membership includes the following and additional members may be added to represent other Aboriginal organizations at the discretion of the Board:

- One Elder.

- One member of the AMC Chief's Health Committee.

- One member of the AMC Youth Committee

- Chair of the Health Information and Research Committee (HIRC).
- One additional member of HIRC.
- Chair of the Aboriginal Health Research Group (scientists in the Faculty of Medicine).
- One member appointed by the President's Office of the University of Manitoba.
- Three members at large appointed by the Advisory Board (to ensure representation from all Aboriginal constituencies).
- One member appointed by the First Nations and Inuit Health Branch of Health Canada (ex officio).
- One member appointed by Manitoba Health (ex officio).
- Director of the CAHR (ex officio).

At this time, the CAHR is supported through external funding for research projects and other activities. The University of Manitoba may also support university faculty, where possible. The "Centre" is committed to recruiting Aboriginal people for positions at all levels in the Centre. Recruitment will be tied closely to education and training offered by the University in relevant fields. The University of Manitoba is also committed to recruiting Aboriginal faculty to support the research activities of the "Centre". Additional research and support staff will be recruited in support of specific funded projects.

Current Projects of the MFN-CAHR

The MFN-CAHR currently holds a number of significant operating grants that reflect the objectives of this centre. They are the following:

ACADRE Training Program (2001-2003 Renewable - Institute of Aboriginal Peoples Health)

This project is establishing an Aboriginal Capacity and Developmental Research Environment (ACADRE) that will result in an expansion of the pool of Aboriginal researchers who can compete for national grants in the field of Aboriginal health research. We have identified the following objectives as the focus for this ACADRE program:

- ▪ 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 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.

This research and training program will be a major component of the activity of the *Manitoba First Nations'* Centre for Aboriginal Health Research (MFN-CAHR). In the context of Aboriginal health, the research program will concentrate in four areas where the University of Manitoba has already established excellence: 1) Population Health, 2) Health Services Research, 3) Child Development and Health, and 4) Ethics. In addition, the ACADRE program will encourage new research initiatives and partnerships in new and emerging areas of research collaboration in the CIHR themes of basic and clinical sciences.

The primary purpose of the ACADRE program is to attract Aboriginal students into health research careers. The training initiative will be directed towards Aboriginal health researchers at the graduate and junior faculty levels. However, in order to attract the most qualified candidates into health research, we will provide opportunities at the undergraduate and high school level for Aboriginal students to discover the opportunities that health research offers.

The ACADRE program will also expand the opportunity for increasing health research capacity in First Nations and 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 First Nations, Inuit and 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 "incubating" new research ideas.

Aboriginal Health Survey Support Program (2001-2004 Renewable - Institute of Aboriginal Peoples Health)

The purpose of the national 'Aboriginal Health Survey Support Program' *(AHSSP)* is to contribute in a major way to the improvement of health survey activity in First Nation, 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 AHSSP 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 Nation, Metis 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 Aboriginal Capacity and Development Research Environment Training Centres funded by the Institute of Aboriginal Peoples Health (CHIR), to develop a research environment based on collaboration and partnerships between Universities and with 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 Nation, Inuit, and Métis peoples. The AHSSP in partnership with various Aboriginal advisory groups/organizations will undertake survey research activities in the following areas: 1) First Nation and Inuit Regional Longitudinal Health Survey (FNIRLHS), 2) FNIRLHS Off-cycle surveys, 3) New Surveys, 4) Ethical/Data Management Protocols, and 5) 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 Aboriginal Capacity and Development Research Environment training centres to ensure that 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 also 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.

First Nations and Inuit Regional Longitudinal Health Survey (FNIRLHS)

First Wave (1996-1998 - Funded by Health Canada; 2001 FNIRLHS Second Wave Survey Development Phase - Funded by the Assembly of First Nations, Assembly of Manitoba Chiefs and Health Canada.

As noted, the first cycle of data collection occurred in 1997 with nine regions participating, and continues every five years thereafter producing both cross-sectional and longitudinal estimates. At the regional level, the MFN-CAHR has worked in full partnership with the Assembly of Manitoba Chiefs *(AMC)* and the Labrador Inuit to develop comparative and regionally specific questions. In Manitoba, the MFN-CAHR also provided technical support and training in sampling, ethical protocols, interviewing, data quality assurance, and database management. It also produced a final regional report, 17 community reports, and developed a tutorial database to use in the MFN-CAHR Applied Aboriginal Population Health Research Institute. Nationally, the MFN-CAHR helped implement this survey in nine regions and developed a national database comprised of data from all nine regions. In terms of dissemination, the MFN-CAHR produced four chapters of the First Nations and Inuit Regional Health Survey Final Report and co-presented data from this survey at numerous conferences. The MFN-CAHR currently houses the 1997 national and Manitoba regional database. It is also assisting the First Nations Information Governance Committee and the AMC Health Information Research Committee in the second wave of the survey.

Manitoba First Nations Longitudinal Health Survey (1999: Medical Research Council)

This project will develop new methodology for a longitudinal study of the social determinants of health in First Nations communities. Based on the experience with the first wave of the First Nations and Inuit Regional Health Survey, the MFN-CAHR has been developing new questionnaires, sampling strategies, ethical and dissemination protocols for culturally appropriate surveys. It has also linked data from the first wave of the regional health survey to the Manitoba Health Utilization Database to understand the determinants of First Nation peoples' use of hospital and physician services.

Why are Some Communities Healthy and Others Not? (1999-02:Social Sciences and Humanities Research Council)

This project is developing and testing new measures of social determinants, health and well being for integration into longitudinal health surveys in Aboriginal communities. The MFN-CAHR is working with communities throughout Manitoba to better understand how such factors as social cohesion, traditionality, resilience, poverty, and the social environment predict variations in the health and well being of First Nations peoples.

Social Capital as a determinant of health in First Nations communities (2001-2002: Canadian Institute of Health Information/Canadian Population Health Initiative).

This project is developing a conceptual framework for social capital as a determinant of health in First Nations communities and a social capital measurement scale. The project involves qualitative and quantitative methodologies and the objectives are to identify dimensions of social capital, to develop culturally appropriate items to measure social capital, to conduct pilot testing of the developed instrument, and to conduct psychometric analyses of the instrument and revise accordingly.

Expanding Data Partnerships: The Manitoba First Nation Health Information Data Repository System (2001/Ongoing – Assembly of Manitoba Chiefs)

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, date of birth, residency, status, and may include Band registration number, provincial health card number, 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, and psychosocial health. At the request of the Assembly of Manitoba Chiefs, the MFN-CAHR has agreed to house the Manitoba FNHIS database in the form of a research data repository. At this time, the National Aboriginal Health Organization is engaged in discussions with Health Canada *(FNIHB)* and the First Nations Information Governance Committee *(FNIGC)* to become the data stewards of the national FNHIS database. The National Aboriginal Health Organization and the CAHR will initiate a process for a national working group to consider the feasibility of data stewardship and evaluate the intellectual, hardware, and software capital necessary to create, manage, protect, and analyze this repository database, particularly in relation to the First Nations and Inuit Regional Longitudinal Health Survey.

Projects recently undertaken by the MFN-CAHR

Manitoba First Nations Disability Survey (2000-2001 – Assembly of Manitoba Chiefs and Human Resources Development Canada).

The MFN-CAHR in full partnership with the Assembly of Manitoba Chiefs Disability working group developed a survey to identify the prevalence of First Nation people aged 15 years and older who have a disability and to create a registry database for future research initiatives. The survey included questions on the socioeconomic, health, and social service needs of First Peoples with a disability. Fifty-one out of 63 Manitoba First Nation communities participated in the survey, and community interviewers screened 7,161 households and completed 1,618 in-depth surveys with First Nations peoples aged 15 year and older identified with a disability, and 102 children with a disability. The MFN-CAHR currently is the data steward of this database.

Canupawkpa Community Health Survey (1998 – Canupawkpa First Nation).

The MFN-CAHR developed an off-cycle survey of the Manitoba First Nations Regional Health Survey to assess community health needs of the Canupawkpa First Nation. Data produced from this survey was comparable to the data produced from the first wave of the Manitoba First Nations Regional Health Survey. The community used the data from this survey to support the transfer of health services from Health Canada - Medical Services Branch *(MSB)* to the Canupawkpa First Nation.

Evaluation of Transferred Services in the Shibogama First Nations Council Communities of Kingfisher Lake, Wapekeka, and Wunnumin Lake (1998-1999 - Shibogama First Nations).

The MFN-CAHR, at the request of the Shibogama Health Authority (Northwestern Ontario), conducted a 5-year evaluation of the transfer of health services from Medical Services Branch of Health Canada to the First Nations of Wunnumin Lake, Kingfisher Lake and Wapekeka. The evaluation involved a community-based survey and qualitative interviews. A survey team, comprised of members from the MFN-CAHR, Tribal Council and communities, developed an 80-item questionnaire and administered it.

Concept Paper on Aboriginal Health Research (1999 - Social Sciences and Humanities Research Council).

The MFN-CAHR recently developed a "Concepts" paper with funding from SSHRC/CHSRF for the development of a strategic program in Aboriginal health research for the Canadian Institute of Health Research.

Ongoing and New Advisory Relationships of the MFN-CAHR

AMC and the HIR Committee

The research centre (both as the MFN-CAHR and as the NHRU) supports meetings with the AMC Health Information and Research Committee (AMC/HIR) to build capacity in reviewing research proposals and assessing the ethics of a research project. The MFN-CAHR sponsors bimonthly meetings/workshops and assists creating new partnerships between university investigators and the AMC HIRC. For instance, the MFN-CAHR coordinated the new partnership between AMC - HIR committee and the Manitoba Centre for Health Policy and Evaluation (MCPHE). Several workshop and meetings between the HIR Committee and the MCHPE (Principal Investigators) involved building capacity in the HIR Committee to design a project that identifies and assesses health status indicators of Manitoba First Nations Tribal Council areas.

First Nation Information Governance Committee

The MFN-CAHR is working in partnership with the national First Nations Information Governance Committee *(FNIGC)* on a number of projects related to the development and implementation of a health infostructure in First Nations communities. The FNIGC manages and governs the development of national surveys and administrative databases, creates opportunities for statistical and institutional developments, implements recommendations from the Ministerial Advisory Committee on the Canadian Health Info way on the Aboriginal Health Infostructure, advances regional priorities, and builds research capacity to extend First Nation control over health research. Since 1997, the MFN-CAHR has supported this committee technically through a contractual relationship on a range of First Nation health information initiatives (First Nations and Inuit Regional Longitudinal Health Survey, First Nation Health Information System, and other health surveillance initiatives).

National Aboriginal Health Organization

The MFN-CAHR is currently working with the National Aboriginal Health Organization *(NAHO)* and its three centres of excellence for First Nations, Inuit and Métis in facilitating research partnerships with Academic and Aboriginal communities in the area of survey research and capacity building. Together, the MFN-CAHR and NAHO will facilitate partnerships in survey design, sampling, data collection, data management, data sharing and ethical protocols, training, statistical analysis, and interpretation of data and to develop methodologies consistent with both cultural and scientific standards, including cultural and scientific ways of transmitting traditional knowledge and with the NAHO standards of knowledge management principles.

CONCLUSION: CAPACITY BUILDING AND SOCIAL CAPITAL

In summary, these initiatives in many ways demonstrate how to build that ambiguous phenomenon called social capital (Elias et al 2000; Elias 2001). The research agreements facilitated the development of a First Nation research network and partnership structure that could build and maintain trust and reciprocity, and in turn, generate a system of expectations and obligations. Membership attained through the various partnerships and participation in the research network had conferred both obligations and benefits to academic researchers and First Nation health planners and service providers (Hawe and Shiell 2000; Portes 1998). These agreements also secured the necessary resources to which First Nations can claim through partnerships or by virtue of their membership with research working groups or policy teams. The other benefit was the advancement of OCA as a social control mechanism to protect the interests of First Nation communities. On the downside, building First Nation capacity in applied population health did restrict the freedom of academics and governments to conduct or present research on First Nation peoples. Nevertheless, given the over-emphasis on pathologizing discourses in Aboriginal health research, the social control function of the OCA principle is necessary to advance First Nation self-governance over health. The question for non-Aboriginal academics and governments to ponder is will they be open to agreements that respect First Nation determination, that build First Nation research capacity, and that oblige them to enter the politics of trust and participation.

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APPENDIX

Presentations

THE POLITICS OF “TRUST” AND “PARTICIPATION”: A CASE STUDY OF DEVELOPING FIRST NATION CAPACITY TO APPLY HEALTH INFORMATION

ELIAS, Brenda[1], O’NEIL, John D.[1], READING, Jeffery[2] and LEADER, Audrey[3]

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1. University of Manitoba, Northern Health Research Unit, Department of Community Health Sciences, Winnipeg, Manitoba Canada
2. University of Toronto, Department of Epidemiology and Public Health, Toronto, Ontario Canada
3. Assembly of Manitoba Chiefs, Winnipeg, Manitoba Canada

In Canada, First Nation health authorities require health information and educational opportunities to decolonize a long history of pathologizing discourses in First Nation health research. The recent success of First Nation ownership, control and access over health information in Manitoba (Canada) established a social and cultural structure that built trust and participation necessary for constructing new forms of health information directed at First Nation wellness. This paper will first provide some background on the recent success of First Nation ownership, control, and access over health information. It will then describe the Manitoba First Nations Population Health Research Institute, which involved various forms of cultural resources that accumulated through a network of institutionalized and cultural relationships. It will then describe how the institute demystified health information and created trust and participation in applying health information to critical policy areas in First Nation Health. Finally, it will describe how this trust and participation extended beyond the Institute and created new social connections and opportunities to resist the new epidemic pathologies dominating First Nations health. It will describe how participants of this institute mobilized a network of First Nation women and men to contest the colonial intrusion of the federal government in developing a diabetes strategy directed at controlling a First Nations "diabetes epidemic."

To begin this presentation, it is important to revisit the familiar. Today, it is not uncommon at meetings today to hear First Nation people say that they have been "researched to death." For many First Nation people active in community wellness development, research is viewed, at best, as irrelevant to the needs of communities, or, at worst, a serious encroachment on the integrity and autonomy of First Nations communities. It is therefore not uncommon to find that many 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 the meantime, First Nation health planners and service providers require trustworthy health information to develop appropriate health programs and to target services that can meet rapidly changing needs within a limited resource environment. They also need health data to inform negotiations with federal and provincial governments for the purpose of securing adequate levels of funding for health programs, services, and training.

In Canada, First Nations have developed a self-governance strategy to make health information available to First Nations and to ensure that First Nation health planners and service providers receive training in health research. Consistent with their constituted right to self-government, First Nations governing bodies have established the OCA principle, which stands for ownership, control, and access to health information. The main objective of this principle is to extend First Nation sovereignty over health information and to decolonize research relationships between First Nations organisations, universities, and provincial and federal governments.

A major initiative that helped forge the OAC principle is the First Nations and Inuit Regional Health Survey (FNIRHS), which was undertaken in 1996-7 (FNIRHS National Steering Committee 1999). At the feasibility stage of this survey, Aboriginal organizations throughout Canada were highly skeptical as to whether they should invest their time and energy in a project that would offer little in terms of direct benefit (O'Neil et al 1995). These organizations were not alone in their skepticism, and this distrust and resistance is widely shared by indigenous peoples throughout the Americans and Australia-New Zealand (Macaulay et al 1999; Kaufert et al 1999; Tuhiwai Smith 1999; Cornwall and Jewkes 1995). A major criticism leveled against traditional research is that it is a repressive process under the control of "others". To make research more egalitarian, researchers have adopted participatory action research (PAR) protocols. However, indigenous peoples have argued that PAR still does not prevent researchers and governments from exercising intellectual arrogance, or employing evangelical and paternalistic practices (Tuhiwai Smith 1999; Cornwall and Jewkes 1995).

The First Nation and Inuit Regional Health Survey is a case in point. At the initial planning stage, the FNIRHS National Steering Committee, comprised of First Nation and Inuit representatives from nine regions across Canada, resisted the top down, paternalistic approach taken by the Federal government. Medical Services Branch employees were opting for a PAR process that maintained their administrative control of the survey. However, several members of the FNIRHS National Steering Committee, including the representative from the Assembly of Manitoba Chiefs, resisted this act by threatening to leave the process if they did not get full-control over the survey (O'Neil et al 1995). The Federal Medical Services Branch eventually caved into this demand and transferred complete control over the survey to the FNIRHS 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, and the establishment of ownership, control, and access (OCA) over health information as a model for other indigenous groups to follow. At the regional level, a research agreement framed the partnership between the AMC-HIR Committee and the Northern Health Research Unit and ensured that the AMC-HIR Committee shared leadership, power, and decision-making from design to dissemination.

A critical document that framed this relationship was a code of research ethics developed at the national level to strengthen First Nation and Inuit self-determination over the survey process (FNIRHS National Steering Committee 1999). In this code, the FNIRHS National Steering Committee set out provisions to ensure that researchers were accountable both nationally and to participating regions. It also established the obligation to build First Nation and Inuit research capacity in survey development, data collection, computer use, analysis, and health planning. Today, this code of ethics stands out among other research agreements (Macaulay et al 1999; Kaufert et al 1999) as a model that can nationally and regionally frame partnership models and build research capacity based on the OCA principle.

Entrenching the obligation to build research capacity into a research agreement is a significant departure from past approaches to disseminate research in the areas of population health and health promotion. In population health, the focus is generally on evidence-based decision-making or problem solving to address problems associated with changing the practice behaviours of health professionals (Lomas et al 1989; Lomas 1991; Kuker and Kenrick 1995. In health promotion, most work tends to examine barriers to disseminating information, primarily designed to change health behaviours in the public domain (Parcel, Perry and Taylor 1990; Eakin and McLean 1992). 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 Milio (1987) and by O'Neill and Pederson (1992) has certainly revealed that effective dissemination is dependent on the complexities of the relationships that must develop between the research and policy communities. Indeed, decision-making, regardless of the domain, is often influenced by the quality of the evidence, dissemination of the evidence, and the complex environment in which the decision making and incorporation of the evidence actively takes place (Tranmer et al

1998). However, evidence-based decision-making can not occur if health information is not available, and its availability if often contingent on co-operation and partnerships between different research and governing bodies (Black 1998). The overall conclusion is that there is a need for innovative dissemination strategies, but there seems to be more questions than answers as to how to achieve this objective (Stoddart and Baer 1992).

The First Nation Population Health Research Institute was our attempt to construct innovative approaches to building research capacity. In Manitoba, the high level of trust and participation that developed between the AMC-HIR Committee and the NHRU during the survey made it possible to extend this partnership into building research capacity and evidence-based decision making in Manitoba First Nations. In 1996, the NHRU applied and received a grant from the National Health Research Development Program of Health Canada to develop First Nation research capacity through a First Nations Applied Population Health Research Institute. This project was a joint venture formalised by the Chiefs Committee on Health in a resolution passed in November 1996. This resolution gave the AMC-HIR committee the mandate to work with the NHRU to build research capacity to extend further First Nation control over the health care systems in their communities.

Both the NHRU and the AMC-HIR committee oversaw the implementation of the Institute. A Project Coordinator, representing the AMC-HIR Committee, recruited First Nation health planners and service providers, secured a training facility, and supervised on-site administration at the Institute. Members of the HIR Committee 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 Institute was held at a college operated by Southeast Tribal Council, which offered residential facilities for students who did not live within driving distance. The coordinator also integrated First Nation protocols into the Institute, such as the opening and closing prayer by an elder, opening address and closing remarks by the AMC, and a sharing circle scheduled for the last day of the course.

The NHRU recruited faculty and tutors from several disciplinary areas such as medical anthropology, sociology, epidemiology, bio-statistics, and health services research. To secure health information, partnerships were established between the NHRU, and the Manitoba Centre for Health Policy and Evaluation, Manitoba Health Epidemiological Unit, and Health Canada – Medical Services Branch, Health Information Division. The AMC-HIR Committee gave permission to abstract individual level data from the regional health survey to mimic a fictitious Tribal Council region. The Manitoba Health Centre and Evaluation, with Manitoba Health's approval, provided a data file abstracted from the provincial health-services database, and it contained health service utilization data for a fictitious Tribal Council. Medical Services Branch constructed a similar database from mortality data. A partnership between the NHRU and the University's Continuing Education was also established, and they processed the student registrations for the course.

The NHRU and AMC-HIR Committee decided to offer the course over a one-week period, which would represent, in terms of time, the equivalent of a half-term course. The NHRU secured University approval for the course, and the Department of Native Studies agreed to offer it. 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, we developed a course evaluation form to evaluate instructors and course content.

A curriculum working-group, which included faculty, tutors, and the HIR coordinator, established the curriculum objectives, and each faculty member contributed course materials, which we 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 on the fundamentals of epidemiology, need assessments, and ethical issues in Aboriginal epidemiology. The remaining lectures covered quantitative techniques used to assess population health. Lectures covered survey, health service utilization, and mortality databases, and tutorial sessions followed each lecture to provide students with hands-on experience using health information from these data sources.

Overall, twenty-five Aboriginal health technicians registered for the course. 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, and on the last day of the course, they jointly presented a project proposal to the principal investigators of this Institute who posed as a Chief's Committee on Health.

Overall, the lectures and tutorial session exposed students to health information techniques used to shape health programs and policy. The evaluation of the course was highly positive, and the 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, and the intense working group environment helped build a research network they could draw upon.

In the second year, we 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, and 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. We held two workshops, one in the north and one in the south. Over twenty First Nation community health planners attended the workshops. A few former students of Institute also attended, and they helped instill interest in evidence-based decision-making in the First Nation health planners who had little experience applying health information to community health plans.

In the third year, we held a second Institute open to First Nation community health planners and service providers from across Canada. Twenty-two Aboriginal students attended and 10 Faculty/Tutors participated. The second Institute was similar to the first, with the following 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 main campus. Although there was some concern over using this site by members of NHRU, the HIR committee and the students did not perceive the presence of Christian symbols as a problem that could foster distrust or limit participation.

Another departure involved the tutorial projects. Rather than pre-assign students to groups targeting vulnerable populations, we assigned them to the strategic policy areas of diabetes and community healing which recently received new funding from the Federal government. The curriculum remained the same, and we added a survey course. Only one student wanted to take it, so we offered it as a pilot course. The Institute generally went well, and students positively evaluated all lectures and tutorial sessions. The exception was a presentation made by a MSB 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 students 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 OCA. The debate became quite heated. At the end of the presentation, several First Nation students felt that the only solution to effectively develop research capacity was through a First Nations health info structure based on the principles of OCA. A few weeks after the Institute, MSB sent a letter to the Department Head of our academic unit accusing us of creating a hostile environment at this Institute. Although our intent was not to create such an environment, we did accept the responsibility of playing a significant role in developing First Nation capacity to apply critically population health techniques to secure First Nation self-governance over health. One lesson we learned from this incident is that any advancement of the OCA principle could potentially reveal a deep historic distrust and lack of participation between parties'. The other is that the Institute did serve its purpose, and it created a cohort of First Nation health planners and service providers to use population health techniques to produce counter-knowledges that can resist colonial encroachments on First Nations health.

In addition, the trust and participation built through these initiatives went beyond the Institute and helped create new social connections and opportunities to build evidence-based decision-making. Since then, we have been involved in building research capacity in AMC health working groups, such as the Manitoba First Nation Diabetes Strategy Working Group. Four members of this committee were former students of Institute and they took a lead role in building trust and participation in committee members who were highly skeptical of the role of 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 a First Nations "diabetes epidemic."

In summary, these initiatives in some ways demonstrate how to build that ambiguous phenomena called social capital. The research agreements facilitated the development of a First Nation research network and partnership structure that could build and maintain trust and reciprocity, and in turn, generate a system of expectations and obligations. Membership attained through the various partnerships and participation in the research network had conferred both obligations and benefits to academic researchers and First Nation health planners and service providers (Hawe and Shiell 2000; Portes 1998). These agreements also secured the necessary resources to which First Nations can claim through partnerships or by virtue of their membership with research working groups or policy teams. The other benefit was the advancement of OCA as a social control mechanism to protect the interests of First Nation communities. On the downside, building First Nation capacity in applied population health did restrict the freedom of academics and governments to conduct or present research on First Nation peoples. Nevertheless, given the over-emphasis on pathologizing discourses in Aboriginal health research, the social control function of the OCA principle is necessary to advance First Nation self-governance over health. The question for non-Aboriginal academics and governments to ponder is will they be open to agreements that respect First Nation determination, that build First Nation research capacity, and that oblige them to enter the politics of trust and participation.