
Integrating A Focus on Aboriginal Health Research in the Development of the Canadian Institutes of Health Research: A Concept Paper

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Summary of Recommendations

- 1) That the CIHR provide one seat of the Governing Council to a representative from the Aboriginal Health Institute.
- 2) That the CIHR establish an Aboriginal Health Research Council and an "Office/Institute of Aboriginal Health Research". The Council will provide oversight and direction to the "Office/Institute" which should have the same administrative status as other CIHR "Institutes" and should have the mandate to ensure Aboriginal health research is developed appropriately across the various CIHR divisions and Institutes. It should also have direct responsibility for a research and capacity-building program as outlined in this proposal.
- 3) That the development of a national cadre of Aboriginal academic health researchers be designated as a CIHR priority and appropriate investments be made to support Aboriginal students and researchers at all levels of career progression.
- 4) That the CIHR ensure that peer review mechanisms for research funding within the proposed Institute structure be adaptable to ensure that the research process issues identified in this proposal are taken into account. Peer review in the context of Aboriginal health research must include community perspectives, policy applications, interdisciplinarity, and methodological diversity.

Executive Summary

Central Issue:

Consideration of how Aboriginal Health should be integrated into the design of the CIHR is an important priority for several reasons:

Aboriginal people suffer the worst health conditions of all Canadians and a better understanding of the determinants, experience, and promotion of health and wellness, and response to illness, in Aboriginal communities is essential.

Aboriginal people have a unique historical and political relationship with the Canadian State that justifies consideration of their unique entitlement, which is distinct from other stakeholder communities.

Determination of Research Need

Aboriginal people bear a disproportionate burden of illness in Canada. Some of these health problems have been highlighted in the Royal Commission on Aboriginal Peoples Report (1997):

- Life expectancy at birth is about seven to eight years less for Aboriginal people than for Canadians generally.
- For infants, the death rate is about twice as high as the national average. There are also high rates of injury and accidental death among Aboriginal children and adolescents.
- Infectious diseases of all kinds are more common among Aboriginal people than others.
- The incidence of life-threatening degenerative conditions such as diabetes, cancer, and heart, liver and lung disease – previously uncommon in the Aboriginal population – is rising.
- Overall rates of injury, violence and self-destructive behaviour are disturbingly high.
- Rates of overcrowding, low educational attainment, unemployment, welfare dependency, conflict with the law and incarceration all point to major inequalities in the social conditions that shape the well-being of Aboriginal people.

Identification of the Issues

- 1) *Research Relationships:* The Royal Commission on Aboriginal People identified past practices in Aboriginal health research as inconsistent with the production of valid and useful knowledge about the nature and resolution of health problems in Aboriginal communities. While Aboriginal communities have often been the objects of scientific investigation, Aboriginal people feel that this activity has contributed very little to improvements in the health of their communities. As a result, Aboriginal communities are increasingly unwilling to participate in research initiatives that derive from mainstream scientific agendas.

As an alternative, researchers and communities have begun to develop a health research agenda that provides for the full articulation of Aboriginal interests in the research process. This “partnership” process includes the full range of research activities including the definition of what constitutes a research problem, the management of the data collection, the process of interpreting results, and the dissemination of research results in scientific, policy, and community-based environments. This development has important implications in many related areas discussed below.

- 2) *Epistemological Considerations:* Mainstream academic interest in Aboriginal health research is grounded in the paradigm of Western science, with its cultural origins in the rationalist developments of the European Enlightenment. While this paradigm has had a productive history, it is not always consistent with Aboriginal cultural ideas about health and its causality. Understanding the “determinants of health” from diverse Aboriginal epistemological perspectives can lead a researcher to ask very different questions and employ different methods than might otherwise be the case. Developing a health research agenda that accords equal respect to all paradigms is a challenging task.
- 3) *Disciplinarity:* Consistent with the epistemological consideration is recognition that Aboriginal health research benefits distinctly from multi- or inter- disciplinary approaches. Not only does Aboriginal health research require collaboration across the basic, clinical, social, and applied policy sciences, but collaboration across disciplines within these fields is critical. For example, to better understand what works to prevent further increases in the prevalence of diabetes in Aboriginal communities, research expertise from fields as diverse as psychoneuroimmunology, genetics, epidemiology, nutrition, anthropology, political science, and Aboriginal cultural studies is required.
- 4) *Methodological Considerations:* Consideration of methodological issues ranges from requirements that the research process be “participatory” and “policy-oriented” to more fundamental considerations of scientific method. For example, sampling theory in Western science assumes “communities” are aggregates of individuals; sampling in an Aboriginal community requires consideration of kinship, culture history, and politics. Interpreting research results from an Aboriginal perspective may require innovative merging of qualitative and quantitative methodologies.
- 5) *Capacity and Infrastructural Development:* Developing a research agenda that reflects a true partnership between academic research and the Aboriginal community requires a significant investment in both the human and institutional capacity of the Aboriginal community to conduct health research. This investment must include both the development of an Aboriginal academic research community, as well as institutional research structures with accountability to the Aboriginal governments.
- 6) *Existing Research Resources:* Aboriginal health research in Canada has relied largely on either individuals or small groups of researchers developing partnerships with Aboriginal communities, and functioning largely in isolation from one another. Rarely has there been any substantial institutional investment in these resources, and collaboration across research groups is rare. This situation is unlike either the United States or Australia where a similar research focus has resulted in a significant institutional investment in a network of research centres and institutes. However, despite few resources and little institutional support, the Aboriginal health research community in Canada has achieved remarkable distinction and is considered the international leader in this field.

- 7) *Dissemination Activities:* For health research to be relevant to the policy needs of Aboriginal communities and governments, dissemination activities must target these audiences in unique ways. Researchers have a responsibility to ensure that research results are validated by both scientific and community review. Integration of research results into policy considerations requires ongoing and long-term relationships between the researcher and policy makers.
- 8) *Ethical Considerations:* Aboriginal communities have invested significant effort in the development of ethical protocols that reflect their concern that health research be of direct benefit to their communities. These protocols require a high level of researcher accountability to Aboriginal organizations and communities, and often stipulate community ownership of research results.

Recent Developments:

In the last several years, national Aboriginal organisations have undertaken the development of an *Aboriginal Health Infostructure (ref Report)*. Central to this *Infostructure* is the development of the Aboriginal Health Institute (AHI), with funding from Health Canada. This Institute will support the health information and policy needs of Aboriginal governments and organisations, and will be fully accountable to Aboriginal authorities. Together with this proposal to CIHR, discussions are also underway with Statistics Canada, Laboratory Centres for Disease Control, Canadian Institutes for Health Information, and other federal departments, to develop other partnerships and initiatives designed to complement the AHI in elaborating the health infostructure needed to address health issues in the Aboriginal community.

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Introduction:

In order to evaluate the content of this proposal, it is important to understand the source of the ideas and recommendations outlined herein. This is particularly important in the field of Aboriginal health research because, as described in the Executive Summary, the primary issue in this field is one of Aboriginal community participation in all aspects of the research process. Research initiatives that are undertaken without Aboriginal partnership are not only unlikely to succeed, but may misrepresent the needs and interests of the Aboriginal community.

At the same time, the academic community with interests in Aboriginal health has not had the opportunity to develop strong inter-regional or national networks to the same extent as other research communities. Aboriginal health research has been significantly underfunded historically, and research infrastructural development in the academic community has been meagre. Academic researchers working in this area may have developed strong local partnerships with Aboriginal communities and organisations, but rarely have these partnerships acquired a more national character.

As a result, undertaking an appropriate consultation process in support of this application, in the very limited time available (August 1 – September 15, 1999), has been exceedingly difficult. Unlike other research networks involved in the CIHR design process which can be relatively easily mobilised through e-mail distributions to university-based collaborators, this consultation has required a more politically and culturally sensitive process.

However, despite our best efforts, we cannot claim to have conducted a full consultation on the CIHR design issue. In particular, we have not consulted with all Aboriginal organisations and communities as fully as is expected. For example, the consultation process undertaken by the various national Aboriginal organisations related to the development of the Aboriginal Health Institute has required more than one year and \$500,000 to complete. As a result, we cannot claim that all the representative Aboriginal authorities have in any way ratified this proposal.

At the outset of this project, we recognised that this would be a severe limitation. Indeed, in the absence of a real opportunity for consultation, we hesitated to initiate this proposal. However, several factors convinced us of the importance of proceeding. First, we recognised that the design of the Canadian Institutes for Health Research was proceeding very rapidly and we felt it was critically important that an Aboriginal Health research agenda be included from the beginning. Second, we feared that the CIHR development team might assume that the Aboriginal Health Institute would assume all responsibility in the general area of health research and that CIHR should have minimal responsibility in this area. Not only would such an assumption severely limit the potential resources that might be available to tackle the huge and pressing health issues in the Aboriginal community, but it would misrepresent both the intent and stage of development of the AHI, as we will demonstrate later in this document. Finally, we understood that the benchmark for CIHR funding will be scientific excellence, which requires significant input from the academic community.

With these considerations in mind, we proceeded to do “the best we could” under the circumstances. This proposal was developed primarily by academic researchers at the Northern Health Research Unit at the University of Manitoba. Two of the five members of this research group are Aboriginal (Reading, Bartlett). Dr. Reading is a First Nations community member with a formal advisory position with the Assembly of First Nations. Dr. Bartlett is Metis and is an advisor to the Aboriginal Council of Winnipeg. Drs. O’Neil,

Kaufert and Young have well-established research relationships with many Aboriginal communities and organisations, and have worked collaboratively with other academics in this research area throughout Canada and the world.

Our approach to consultation was to begin to build a national network of Aboriginal and non-Aboriginal researchers who could assist us in developing a concept paper on how an Aboriginal health research agenda should be integrated into the design of CIHR. Current participants in this network are listed in an appendix. More than half of the participants are Aboriginal health researchers, some of whom hold academic appointments, some of whom work for government or Aboriginal organisations, and some of whom are community-based. Non-Aboriginal participants in the network are generally senior academics at Canadian universities who have responsibilities for the development or direction of research centres and programs focused on Aboriginal health issues.

Although we did not have the time to organise formal consultations with all national Aboriginal organisations, we were fortunate to have the opportunity to meet with research colleagues from the Assembly of First Nations (AFN) at a Workshop held in Ottawa on September 12. This meeting was organised through Dr. Reading who holds an appointment as research advisor to AFN. This Workshop provided the network with an opportunity to receive feedback on the ideas and recommendations outlined in this Report. Although AFN representatives indicated general support for the direction we were taking, this support should not be construed as a ratification of the recommendations described here. Further consultation with both AFN and the other Aboriginal organisations is required prior to any implementation of an Aboriginal health research agenda by CIHR.

Despite these qualifications, the recommendations in this Report reflect the input of ideas from members of the research network, many of whom have indicated enthusiastic support for the initiative, as indicated in letters appended. In general, this report argues that CIHR needs to develop an Aboriginal health research strategy that will complement the activities of the Aboriginal Health Institute. This strategy needs to be both accountable to the Aboriginal community as well as consistent with the CIHR vision of promoting research of the highest scientific standard. In order to meet these complementary goals, the Report has focused on capacity-building as a core objective. Increasing the number of well-trained Aboriginal health researchers in appropriate academic environments is a fundamental goal that will pay huge dividends for the health of Aboriginal communities in the future. In support of this objective, this Report also recommends that both local and national research “milieus” or networks need to be strengthened in order to provide productive and accountable research environments for a new cadre of Aboriginal health researchers.

The Report is organised in two sections. The first section provides a background and rationale for why an Aboriginal health research agenda should be given high priority by the CIHR. This section is a revised and abridged version of sections of two papers that were originally developed in conjunction with a project undertaken by the Assembly of First Nations on contract to the Ministerial Advisory Council on Health Infrastructure. Under the direction of Dr. Reading as a member of the Advisory Council, these papers were written by Gail Macdonald from AFN, Dr. O’Neil and Yvon Allard from the University of Manitoba, Laurel Lemchuk-Favel of FAVCOM Consultants, and Carman Maracle of Strategic Design and Production, Tyendenaga First Nation.

The second section will describe in detail a plan for implementing an Aboriginal health research agenda in the Canadian Institutes for Health research.

Background and Rational

Aboriginal People in Canada.

According to the Royal Commission for Aboriginal People (1996), there are 720,600 Aboriginal people in Canada, or 2.4% of the Canadian population. Of this total, 35 % are registered First Nations people living on reserves, 25% are First Nations people living off-reserve, 44% are urban Aboriginal, 36% live in the north, 19% are Metis, and 5% are Inuit.¹ Each of these populations has distinct needs related to the development of a health research agenda.

These needs will be identified in detail in subsequent portions of this report and are introduced generally here. Of particular significance is that the vast majority of health information available to assess health status and health care describes the situation of First Nations people living on-reserve, and Inuit in Quebec, Labrador, Nunavut, and the Northwest Territories. Urban Aboriginal identity and Metis identity is rarely included in health databases at either the provincial or federal levels. Health research as well has focused almost exclusively on the health conditions and health care needs of First Nations people living on reserve, and the Inuit.

Also, although the Aboriginal population makes up a relatively small proportion of the total Canadian population, in some northern regions, the Aboriginal population approaches or is the majority. For example, Inuit constitute 84% of the new Nunavut Territory; and Aboriginal people constitute 94% of the total population (26,735) of northern Saskatchewan, 45% of the total population (64,165) in northern Manitoba, and 41% of the total population (36,310) of northern Quebec.² In these and other areas, general governance issues related to health research and health information infrastructure development will be directly affected by Aboriginal concerns.

Health and Well Being: Aboriginal Perspectives

The Aboriginal view of health and well-being, seen through the Medicine Wheel or Circle of Life, is focused on holistic healing which encompasses physical, mental, emotional and spiritual domains. Only in the last twenty years, has the mainstream health system adopted a similar perspective, one that acknowledges that health and well-being stem from a variety of factors and influences, classified as 'broad health determinants.' These determinants include social and economic forces, psychological influences, physical and genetic factors and cultural elements. The importance of health determinants has been validated in numerous studies which have shown the connection between health status and a number of factors including income, position in society, employment, lifestyle factors, and control over one's personal situation. As well, international comparisons of per capita spending, life expectancy, and morbidity rates have illustrated that countries, which spend high amounts of money on health expenditures, do not have the best health indicators. Beyond a certain level, investments in illness care services do not equate to the same magnitude in improved health status, which suggest that other factors are important in improving population health. Certainly the situation in Aboriginal communities provides a real life example of the impact of health determinants, such as poverty, nutrition, living conditions and unemployment on individual and community health and well being.

¹ Percentages do not add to 100 since urban and north includes members of most other groups.

² "Northern" refers to roughly the northern half of the geographic area of these provinces.

Despite the importance of health determinants in individual and population well-being, the Canadian health system has retained a primarily clinical (and with respect to insured services, a medical) focus with respect to Aboriginal people. The health system available to most Aboriginal people is mainly a reactive, illness care service which has not yet fully embraced in a practical sense, the concept of health determinants.

For Aboriginal people, holistic healing which interrelates physical, mental, emotional and spiritual elements, will restore not only wellness to individuals, but also renew their capacity to exercise collective responsibility and build caring, inclusive communities. RCAP identified several areas where Aboriginal health and healing concepts are congruent with the health determinants model:

- True health comes from the connectedness of human systems not their separate dynamics. The four components of the healing circle reinforce the results of research on health determinants. "Health is the total effect of vitality in and balance between all life support systems."
- Economic factors are particularly important in determining the level of health of a population.
- Responsibility for health is both individual and collective. Personal choices on lifestyle (smoking, diet, exercise etc.) combined with an individual responsibility for well being are complementary to Aboriginal perspectives on collective responsibility for community well-being as well as individual self-care.
- Aboriginal beliefs regarding good health are based on balance and harmony within one's self and within the social and natural environment. This is echoed in research that has proven causal links between stress and ill health.
- A healthy and happy childhood is the foundation for life. Many factors influencing health status throughout life are to be found in childhood and before birth, such as poverty, accidents and injury, and smoking and alcohol consumption during pregnancy.

For Aboriginal people, an integral component to restoring balance and well being to communities, involves community empowerment as well as individual well-being. To this end, health and social services delivery must be under Aboriginal control, and services delivered by trained Aboriginal people. The ultimate expression of an Aboriginal health system that embodies both individual and community empowerment is self-government; however in reality, most communities are using the Health Transfer initiative as the practical first step on this journey to assuming control over their health system.

Traditional medicine which is based on holistic healing operates outside of government imposed regulations, as it is inherent to Aboriginal culture. Traditional healing services are now being revived, as Aboriginal people have realised the limitations of the western medical model and looked to their own culture for answers. Generally, although these two systems may exist in the same community, little integration of these two systems occurs. An exception is addiction services where traditional approaches to healing may co-exist with western medical services in the same treatment facility. As well, some hospitals allow traditional healers to treat Aboriginal patients upon request and transportation costs of traditional healers visiting Aboriginal persons are also a reimbursable expenditures under the Non-insured Health Benefits program.

Recently the Aboriginal Healing Foundation was created by federal funds with a mandate to allocate \$350 million towards addressing the legacy of physical and sexual abuse of Aboriginal students in residential schools. A central part of its mandate is to fund healing services, provided through healing centres and community activities. These services may utilise traditional or western approaches to treatment. All funded projects must involve a

holistic approach, encompassing the four domains of the Medicine Wheel. The program themes which are being considered by the Foundation as funding areas are: community-based healing and healing centres; restoring balance in the community through early detection and prevention of abuse; developing and enhancing Aboriginal capacities to provide healing activities; and disclosures of abuse through a historical record. Traditional healers will be self-regulating in this system, through a central advisory council, which will ensure the credibility of healers operating as a result of funds from the Foundation.

Health Conditions

Aboriginal people bear a disproportionate burden of illness in Canada. Some of these health problems have been highlighted in the Royal Commission on Aboriginal Peoples Report (1997):

- Life expectancy at birth is about seven to eight years less for Aboriginal people than for Canadians generally.
- For infants, the death rate is about twice as high as the national average. There are also high rates of injury and accidental death among Aboriginal children and adolescents.
- Infectious diseases of all kinds are more common among Aboriginal people than others.
- The incidence of life-threatening degenerative conditions such as diabetes, cancer, and heart, liver and lung disease – previously uncommon in the Aboriginal population – is rising.
- Overall rates of injury, violence and self-destructive behaviour are disturbingly high.
- Rates of overcrowding, low educational attainment, unemployment, welfare dependency, conflict with the law and incarceration all point to major inequalities in the social conditions that shape the well-being of Aboriginal people.

Despite a substantial decline in the infant mortality rate in the aboriginal population of Canada during the past two decades, the infant death rate is still approximately twice the rate for all Canadians. In 1993, the infant mortality rate for First Nations infants was 10.9 deaths per 1000 live births (compared to the Canadian rate of 6.3 deaths per 1000 live births). The mortality rate among aboriginal neonates (newborns), 6 per 1000 live births for First Nations, and 8.4 per 1000 for Inuit neonates, is higher than that in the Canadian population (4.7 per 1000). (Lemchuk-Favel, 1996).

Aboriginal children also have much higher rates of death from injuries than all children in Canada. A comparison of First Nations children with the total Canadian population of children in 1993 showed that, for infants, the rate of deaths from injuries is almost four times greater among First Nations children (63 versus 17 per 100,000 population); among preschoolers, the rate is more than five times greater (83 versus 15 per 100,000); and among teenagers 15 to 19 years of age, the rate is more than three times greater (176 versus 48 per 100,000). (Canadian Institute of Child Health, 1994).

Although the mortality rate among aboriginal people declined during the 1980s, it remains higher than the rate for Canada as a whole. The female age-standardized mortality rate (ASMR) from all causes was 10.0 deaths per 1,000 population for 1993, whereas the rate among all Canadian women was 6.3 deaths per 1000 population. The male ASMR was 11.5 deaths per 1000 population in 1993, compared with 7.4 deaths per 1000 population among all Canadian males. These data further show that although mortality rates for both male and female First Nations persons fell over the past decade, the gap between First Nations and Canadian rates remains (Young, 1997).

Inuit continue to have the lowest life expectancy of all Aboriginal people, among both women and men, followed by First Nations people living on-reserve. First Nation people in urban settings, whether registered or not, have the highest life expectancy of Aboriginal people, exceeding that of urban Metis people by about one year for both women and men (Ibid).

Canada's aboriginal peoples have been reported to be at an increased risk of infectious diseases, including tuberculosis, hepatitis A and B, gastro-enteritis, meningitis, and sexually transmitted diseases (Postl and Moffatt, 1998). HIV infection and AIDS are of major concern to Aboriginal peoples, especially in Northern and remote communities where HIV testing and AIDS treatment is limited or unavailable. Both children and adults in the aboriginal population suffer an increased frequency of acute respiratory infections compared with non-aboriginal people. Although the reasons why aboriginal people are at an increased risk of some infectious diseases are unknown, suggested risk factors include nutritional problems, genetic factors, poverty and crowding, and environmental pollutants such as tobacco smoke and wood smoke (Young, 1994).

Of the aboriginal population 15 years of age and older, the 1991 Aboriginal Peoples Survey found that 31% had been informed by health care professionals that they had a chronic health problem (Statistics Canada, 1991). Chronic conditions are sometimes called the diseases of modernisation, or western diseases, because they attend the lifestyles typical of western industrial nations: reduced physical exercise; diets overloaded with fat and sugar; high levels of stress; and increased exposure to a wide range of pollutants in the air, water and food supply. As well, there is excess use of caffeine, alcohol, non-traditional use of tobacco and recreational drug usage. Cardiovascular disease, cancer, metabolic disorders (particularly diabetes), respiratory and digestive disorders are significant factors in Aboriginal illness and death.

Diabetes mellitus is a major health and wellness issue among aboriginal peoples in Canada. In 1991, 6% of Canadian aboriginal people 15 years of age and older reported that they had diabetes mellitus, whereas 2% of the Canadian population reported having the disease. The First Nations and Inuit Regional Health Survey (FNIRHS) reported a crude prevalence rate of 10.9 % for diabetes in 1997, almost a twofold increase over six years (NAIRCP, 1998; MFNRHS, 1998).

Aboriginal people suffer more end-stage renal disease (ESRD) than other Canadians; the age-standardised incidence rate of newly registered chronic renal failure among aboriginal people is 2.5 to 4.0 times higher than the national rate. The total (crude) rate for all Canadians is 5.66 cases per 100,000 population each year (Young et al, 1989).

Cardiovascular disease is a leading cause of illness and death in the Canadian population as a whole, and recent studies in Canada and the United States have shown that cardiovascular disease is a new and increasing health problem in aboriginal peoples in North America. Hypertension is of particular concern to aboriginal peoples in Canada (Young, Moffatt and O'Neil, 1993).

Lung cancer is an emerging health concern of aboriginal people, due to the non-traditional usage of tobacco products. FNIRHS data indicate that 62% of aboriginal people in Canada report smoking regularly (NAIRCP, 1998). Smoking cessation programs need to be culturally based for use in aboriginal communities.

Health and wellness involves much more than physical health, i.e. the absence of infectious and chronic disease. Good health is a state of balance and harmony involving body, mind, emotions and spirit. It links each person to family, community and the earth in a circle of dependence and interdependence, described by some in the language of the

Medicine Wheel. Many of the social issues reported as problems by aboriginal people are closely linked with mental health and social problems.

Suicide rates among Aboriginal Canadians are two to three times higher than those among non-aboriginal Canadians (DNHW, 1991). From 1986 to 1990, the mean annual suicide rate among Canadian First Nation youth was 37 per 100,000, five times greater than the rate in the total Canadian youth population (Statistics Canada, 1991). Substance abuse, including drug and alcohol abuse, is a common problem and a major issue of concern to Canada's aboriginal people (Adrian, Layne and Williams, 1990). Studies have shown that improvement in socio-economic conditions reduced alcohol consumption. A major concern in Aboriginal communities is Fetal Alcohol Syndrome (FAS), since children with FAS have major learning and socialising problems (Bray and Anderson, 1989).

These federal statistics however, do not provide a complete picture of Aboriginal health status. First, they do not describe the health conditions of Metis and off-reserve/urban Indians. (Waldram, 1989). Second, they do not provide a clear picture of mental health conditions and social problems in Aboriginal communities where family violence, child abuse, and fetal alcohol syndrome have been identified as priority areas of concern, particularly by Aboriginal women's organisations (Canadian Council on Social Development, 1989). Third, these data have been collected by agencies (government and universities) external to Aboriginal Nations and have been interpreted without Aboriginal input (O'Neil, Reading and Leader, 1998). And finally, despite these limitations, the picture of health conditions that emerges indicates that solutions to these problems lie not in improved medical services but in improvements in the fundamental conditions of Aboriginal life including local economies, access to country foods, housing, sanitation systems, and community-based healing programs (including traditional medicine). (Young, 1988; McIntyre and Heinke, 1987).

Research on Aboriginal Health: Knowledge and Power

Research

Perhaps one of the most surprising consequences of the multi-jurisdictions involved in service provision to Aboriginal people, is the range of knowledge that exists on the health status of different Aboriginal groups. For First Nations and Inuit, as will be described below, a large amount of data and research analysis is available, which may be of questionable value depending on the perspective of the researcher, the user and the Aboriginal community itself. By contrast, Metis and other off reserve Aboriginal people have had very little documentation of health concerns, although there is little dispute that their problems are comparable to First Nations and Inuit communities. Research has evolved significantly since MSB started collecting the first statistics on First Nations communities. The sections below present perspectives of the past and present, and show two polarities of research; that which was initially "on and about" Aboriginal peoples; and that which is "for and by" Aboriginal peoples and which is strongly tied to the Aboriginal self-determination and self-government movement.

The Past: Research on Aboriginal People

First Nations and Inuit people, particularly since the reserve system was created and federal health services established in these reserve communities, have been literally captive specimens for all manner of researchers, investigators, government officials, consultants, academics, and the like. This has happened for many reasons, which encompass the spectrum from altruistic to selfish. Certainly documentation has been and is needed to determine required levels of health and other services, whether programs are

effective accomplishing their goals, to assist communities in accessing resources available in government programs, and for planning purposes. However, the feeling among many Aboriginal people has been that research has been one-sided; that researchers enter communities for motives of personal career enhancement, academic publishing, and/or financial incentives, in addition to the more laudable goals of improving health and well being. Research on Aboriginal peoples, particularly in a First Nations community which is serviced by MSB, in some respects represents a close to ideal situation. The data obtained is comprehensive, it is complete, and it is supported by federal systems geared to provide ongoing statistics.

Perhaps the suspicion and distrust of research conducted by non-Aboriginal outsiders might have been less severe, had Aboriginal communities in the past participated in the research and received concrete, positive benefits. In an analysis of research ethics in an Aboriginal environment, past research activities are characterised as a colonising process that has negatively contributed to First Nations' oppression, First Nations' science, and First Nations development. The author goes on to provide a stinging description of a typical research process:

- The research is short term in nature
- The researcher enters into a community
- The researcher extracts information and/or biological samples
- The researcher leaves the community (without clearing the results)
- The researcher later publishes his/her own conclusions without the community's consent, knowledge or any verification."

Research activities in this model had many limitations, most if not all of which were negative to communities. There was no cultural context on which to base conclusions and researchers likely did not use culturally sensitive methods to collect data or recognised the importance of oral traditions. They may have indiscriminately published information with no regard to the effects on the community it came from, and left the community without helping to develop capacity in communities through training community members in research protocols or analysis. The resulting reports may have published erroneous conclusions that did not have the benefit of a community's analysis or input. Just as important, there was no consultation with the community before the research process was initiated to determine if the research addressed a health priority, an activity which by itself could generate important present and future partnerships between the community and the researcher.

Due to the realities of the situation facing First Nations communities, the vast majority of publicly disseminated research has projected a negative image of Aboriginal people in the media, as unhealthy mentally and physically, unemployed, poorly educated, marginalized and vulnerable. The harm that this has done to the esteem and pride of a people is difficult to conceptualise both in community and individual terms. The lack of hope which was implicit in many descriptions chronicling ongoing high rates of mortality and morbidity despite a public perception of adequate health and social funding, may well be a contributing factor to the perpetuation of a stereotype rather than to offer valuable information for positive health change.

Epidemiological research on Aboriginal health can function as a powerful social instrument for the construction of Aboriginal identity. International research has shown that public health surveillance systems perform disciplinary and regulatory functions in society independent of their overt purpose of tracking health conditions (Armstrong 1983). This analysis points out the ways in which knowledge is constructed about sectors of society which reinforces unequal power relationships; in other words an image of sick disorganised communities can be used to justify paternalism and dependency (O'Neil et al 1998).

External analysis of epidemiological data often constructs an image of Aboriginal communities as desperate, disorganised and depressed. This image is usually created with the intent to provide evidence for greater need for health care resources in the Aboriginal community. However, this image is often reflected through the Canadian media to the general public with quite different results. This image can re-inforce racist and other stereotypic images held by Canadians generally of Aboriginal people. This image is also sometimes internalised by Aboriginal communities and individuals, reinforcing dependency relationships.

The Present: Knowledge is Power

Resistance to the oppressive effects of external research is emerging in Aboriginal communities who are increasingly asking that health research be under Aboriginal control. In general, Aboriginal communities require research proposals to be vetted through appropriate Aboriginal authorities, and that all health research provides significant opportunities for research capacity-building. Aboriginal involvement in directing all phases of the research including design, implementation, analysis and interpretation is becoming routine. The formality of these requirements ranges considerably and several examples are provided.

Indeed, one of the areas where Aboriginal people are now enjoying their greatest success in the path to self determination is in the area of relevant and appropriate, community controlled research. Aboriginal people no longer tolerate externally driven research agendas, the lack of community needs and perspective, and research protocols which are alien to traditional methods of knowledge acquisition. As more Aboriginal people have become health professionals or entered the professions of epidemiology, policy development, public health and the world of academia, a culturally sensitive perspective is appearing in research results. Research protocols are assuming a holistic perspective, as the physical, emotional, mental and spiritual domains are incorporated into their design. Importantly, data and other results of research remain firmly in the hands of the Aboriginal communities from where they originated.

Aboriginal control of research has a number of benefits:

- There is an expanded interest in health as opposed to simple descriptions of illness;
- A strict control over its dissemination and use ensures that rather than a piece meal approach to analysis and usage, a holistic community perspective is retained;
- It is a positive contribution to the broad self-determination and healing activities of communities, and may be a catalyst to community empowerment;
- It allows a participatory approach to research, which means that people are involved in research, not just as subjects but as collaborative partners throughout the entire research process;
- The research has a higher probability of being useful for community policy making as it has been developed and driven by community priorities;
- It allows training and development of Aboriginal people and contributes to economic development in a global sense; and
- It ensures that non-Aboriginal values and beliefs, which may be unconsciously held by external researchers, do not bias the analysis.

Codes of ethics are now being developed in Aboriginal research activities to guide the process, analysis, use and dissemination of information. The largest Canadian data gathering exercise in Aboriginal issues was the Royal Commission on Aboriginal Peoples, which overcame serious barriers and mistrust by Aboriginal peoples in its five year history. It did so, in part, through an integrated research plan that clearly spelled out the ethical

guidelines for all sponsored research. More recently, the First Nations and Inuit Regional Health Survey has provided a successful example of a national-level Aboriginal designed and led survey of health status, practices and perceptions of health.

Another example of community control over research is the research license required in the Northwest Territories. In the NWT, a research license has been required to work in Inuit or First Nations communities since the 1970's. This licence is usually granted if a researcher has the permission of the local community council. Lately however, researchers are required to demonstrate a more rigorous adherence to an evolving set of ethical conditions describing an ongoing relationship between a researcher and the community under study. Researchers' ethical responsibilities extend beyond the basics of ensuring that data collection does not harm research subjects. Researchers are now expected to describe dissemination strategies designed to ensure that the community benefits more directly, and is not harmed by inconsiderate or out-of-context interpretations of the research data. This requirement has been rigorously applied in the area of environmental health research where research, which generates unnecessary fears of contaminated food supplies, has been shown to have direct negative effects on community health.

While some might argue that free and democratic access to scientific information precludes interpretive control over research, the fact is that most health scientists and information managers are members of an elite and dominant sector of society that generally does not include representatives of Aboriginal communities. Although scientific work is ostensibly value-neutral, science workers cannot help but reflect the normative assumptions of their social reference group in their scientific work. Until Aboriginal communities have proportional representation in the institutions which structure public interpretations of health information (i.e., universities, health professions, scientific journals, media, etc.), their only recourse is to attempt to control the dissemination of information which reflects their everyday lives.

Towards an Aboriginal Health Info-Structure: Providing the Context for the Application of Health Research

Aboriginal people are involved or affected by a range of strategic initiatives, in which each, to varying degrees, influence the effort of communities to achieve self-determination and control of health programs. These ongoing initiatives contribute to the body of Aboriginal health data that Aboriginal communities need, individually and collectively, in order to exercise control and undertake informed health management and planning. This data will also constitute much of the relevant Aboriginal information that will flow over the health information highway to Aboriginal communities. The current initiatives represent a significant investment in human and financial resources that, from an Aboriginal perspective, will show returns when processes and outcomes are under Aboriginal control and directed by Aboriginal institutions to enhancing the capacity of communities to improve the health of their citizens. This represents another vital step toward self-determination.

The development of an **Aboriginal Health Info-Structure** could serve to strengthen these efforts if it is developed in full co-operation with Aboriginal communities, and if it provides resources for the continued development of both individual and institutional capacity in the Aboriginal community.

A national initiative, which supports an Aboriginal Health Info-Structure, can play a significant role in improving Aboriginal Health in a number of ways including:

- To provide the tools and technologies for Aboriginal Peoples to effectively be informed, to monitor and evaluate the programs and service delivery structures and to determine their appropriateness and effectiveness in impacting wellness.
- To provide networking opportunities among Aboriginal Peoples to share information on resources, strategic directions and program and service innovations that have been culturally designed to meet the needs of the Aboriginal Peoples.
- To link Aboriginal Peoples to other health care providers and sources of information to enhance the knowledge and understanding of health and the determinants to health which affect the day to day lives of each individual, family and community.
- To link and share Aboriginal specific information and data bases which would facilitate a more informed, evidence-based decision making structure within Aboriginal communities in health planning and establishing health priorities.
- To support an Aboriginal controlled longitudinal health survey infrastructure that would continue providing an on-going picture of Aboriginal Health status. This project would also provide insight into the causal relationships to health as well as provide needed research and evidence based data which would support community health planning, program evaluation and setting health priorities and determining cost effective programs and services.
- To provide education and training capabilities to Aboriginal Peoples in various sectors of the health care spectrum especially for those in more remote and isolated areas where education and training opportunities are difficult to obtain without leaving their communities.
- To facilitate the connectivity and operability of telecommunications in northern and remote areas so that Aboriginal peoples can be equal participants on the "Health Information Highway" rather than passive, uninformed bystanders.
- To provide a forum for Aboriginal Peoples to share their experiences and knowledge with the Canadian population in respect to Aboriginal healing and wellness.
- To facilitate Aboriginal Peoples capacity to effectively plan, organise and manage the health and social care issues in the community without having to compromise the use of insufficient health care resources toward investment in technology and information management infrastructure.

Although there are many issues which would impact the development of an Aboriginal Health Info Structure, we will attempt to address a number of the most obvious and currently relevant for consideration.

First Nations Health Information System

The First Nations Health Information System (HIS) is a community-based computerised system that was adopted by the Medical Services Branch as its standard health information and surveillance system. The HIS currently consists of 13 subsystems: Client Information, Immunization, Reportable Diseases, Maternal Health, Environmental Health, Abuse Profile, Test/Exam, Medication, Medication Allergy/Adverse Reactions, Public Health Education and Client Mortality Information. Data for all subsystems are collected according to standard clinical and public health practice. The HIS is the joint property of Ontario First Nations and Medical Services Branch of Health Canada.

The HIS was created in response to a 1988 assessment of health-related data for the First Nations population in Ontario Region, which revealed many inconsistencies in data collection practices. This assessment highlighted the need to develop a comprehensive Health Information System that would standardise data collection practices and improve the reliability of the data available for case management, program planning and evaluation and surveillance.

Currently 45 First Nations are using the HIS. Medical Services Branch intends to make the HIS available to all First Nations, primarily through WEB-based technologies. Implementation activities are expected to conclude by March 2000.

The Chiefs of Ontario and MSB equally and jointly own the intellectual property embedded in HIS;

- The Chiefs of Ontario and MSB will equally share in revenue received from HIS.
- MSB will have access to aggregate, non-descriptive data on terms agreed by the national HIS Management Committee
- Regional data will be controlled by the First Nations of each region.
- Any transfer of HIS to First Nations and Inuit communities or to federal departments will require an agreement acceptable to both founding partners.

Capacity building, in terms of human resource and infrastructure development and the principle of Aboriginal control over Aboriginal data developed in consultation with First Nations, must be an integral component of the HIS national roll-out.

First Nation and Inuit Regional Longitudinal Health Survey

First Nations people living on reserve and Inuit communities in the provinces were (and continue to be) excluded from three national population longitudinal surveys – Survey of Labour and Income Dynamics, National Population Health Survey and the National Longitudinal Study on Children and Youth. In response to this situation, First Nations representatives from across the country and the Labrador Inuit developed and implemented the FNIRHS in 1996.

This Survey was conducted under the total control and authority of First Nations and Inuit peoples. The Survey was conducted in 183 First Nations and 5 Inuit of Labrador communities with a sampling size of 9,870 adults representing 199,782 adults and a child proxy interview component with a sample of 4,138 representing 112,592 children.

The First Nation and Inuit Regional Health Survey Project consisted of nine (9) participating regions, who each developed and conducted their own survey process within the framework of the national survey. Each regional survey incorporated a set of national core questions developed and approved by the mandated First Nation and Inuit National Steering Committee established to oversee the process

This initiative was undertaken to facilitate a First Nations and Inuit owned and controlled process of community, participatory research and health surveillance on the health status and the determinants to health and to facilitate the evaluation and efficacy of health care delivery within a longitudinal survey process.

The First Nation and Inuit Regional Health Survey Project has produced a National Report which provides a detailed analysis and discussion in the areas of Children's Health, Chronic Diseases, Tobacco and Environmental Smoke, Health Services and Dental Health, Wellness, Physical Disabilities, Elder Health and Residential Schools.

The National Steering Committee has received a renewed mandate from the Assembly of First Nations to proceed with a survey with a specialised longitudinal health survey to include an off-reserve First Nations sample and to include the NWT, Yukon and Newfoundland as regional surveys. Also, the mandate includes the development of specialised survey on sensitive health and social issues and determinants and to expand and enhance the national core content. The longitudinal survey will be conducted in 4-year survey cycles, which will commence in the year 2001 and every four years thereafter.

The First Nation and Inuit Regional Health Survey Project represents a continued opportunity for First Nation and Inuit peoples to own, control, manage, validate and determine a national research process. This opportunity will provide important health and social data and community information which will aid in the identification of health and social priorities, evaluate programs and effectiveness of program interventions, and provide information for political advocacy. It enables the regions and communities themselves to analyse and interpret their own data and validate it's findings.

Aboriginal Health Institute

The Aboriginal Health Institute concept was introduced within the Liberal Government's "Red Book II – Securing Our Future Together" commitment which stated that it would work with Aboriginal Groups to establish an Aboriginal Health Institute as recommended in the National Forum on Health. This institute would provide a vehicle for the development of capacities and expertise in the field of Aboriginal Health.

Both the National Forum on Health and the Report of the Royal Commission on Aboriginal Peoples supported the establishment of an Aboriginal Health Institute that would specifically address issues that affect the health of all Aboriginal peoples. They recommended that it would:

- Support the development of health research consistent with the needs of Aboriginal peoples and communities
- Gather and disseminate information on the practice and efficacy of culturally appropriate medicines and treatments.
- Support basic and advanced training of Aboriginal health workers
- Serve as a support system for health workers in Aboriginal communities and
- Build on existing capacity.

The Federal Government has committed \$20 million dollars over four (4) years to establish an Aboriginal Health Institute. The goal is to establish the Aboriginal Health Institute by late 1999. Once created, the Institute will have an on going operating budget of five (5) million dollars per year.

In September, 1998, Health Canada provided funding to each of the five (5) national Aboriginal organisations to begin consulting with their constituencies: the Assembly of First Nations, Inuit Tapirisat of Canada, Metis National Council, Native Women's Association of Canada and the Congress of Aboriginal People.

In discussions with the five (5) national Aboriginal organisations, the federal government has indicated that it would like the Aboriginal Health Institute to be:

- Aboriginal controlled
- One Health institute, not separate Institutes for First Nations, Inuit and Metis peoples (although issue-specific satellite centres will be considered).
- At arm's length from the government
- Linked with existing organisations, not duplicating existing programs or deliver health services
- Respecting diversity among Aboriginal peoples; and
- Ensuring that gender and age issues are an integral part of the work of the Aboriginal Health Institute.

Once fully realised, the Aboriginal Health Institute will be a critical element in the development of an Aboriginal Health Info-Structure as it could serve as a single window of available, validated Aboriginal health information and data to aid in research, community

program planning and evaluation, sharing of knowledge, training and educational endeavours. The Institute could also facilitate training, capacity development, reference and serve as a virtual information clearinghouse which could link Aboriginal and non-aboriginal health information sources, and oversee research under the principles of Aboriginal ownership, control and access.

Aboriginal Peoples Survey II

The 1991 Aboriginal Peoples Survey (APS) was conducted by Statistics Canada to provide information to support the planning and development of programs and services for Aboriginal People. It also provided a demographic profile of all Aboriginal groups and gathered data on a wide variety of characteristics.

In order to establish the population to be surveyed, the APS was conducted following completion of the 1991 Census. Information gathered from responses to two census questions, pertaining to original and registered Indian/Band membership were used to identify the Aboriginal population. As a result, a sample of approximately 92,000 persons living in Aboriginal communities and 44,000 living in other areas participated in the 1991 APS. The sample includes people from all Aboriginal groups; Metis, Inuit and First Nations, both on and off reserve, children and adults. Data was collected on income, housing, employment, education, mobility, disability, lifestyle and social issues, health and language. However, a total of 273 First Nations communities did not participate in the 1991 APS largely due to the perception that they had limited control over the research process.

In its response to the RCAP final report, the federal government through its Aboriginal Action Plan "Gathering Strength", has mandated Statistics Canada to carry out a second APS (APS-2) following the 2001 Census. Statistics Canada is working in co-operation with the Aboriginal Community to build upon the 1991 APS process and experience and approach APS-2 with flexibility and innovation and strengthen the partnerships with all the stakeholders involved by dialogue and consultation.

Statistics Canada states that in order for APS-2 to reach its full potential, three essential building blocks must be implemented which will not only enhance the success of APS but also provide a number of benefits to Aboriginal organisations in the long and short term:

- Involvement of Aboriginal Peoples –
- at every aspect of the survey from beginning to end in a comprehensive manner that will allow direct input in regard to all aspects of the process.
- Capacity Building – opportunities to build statistical capacity. Knowledge and resources must be development that will allow for data and information to be used in an effective and timely manner.
- Aboriginal Statistical Program – Statistics Canada will offer its expertise to assist in the development of a more co-ordinated approach by various partners in collecting and analysing Aboriginal data and information.

Statistics Canada is currently in the process of consultation with Aboriginal Organisations and various stakeholder including the federal and provincial governmental departments on their information needs and the management process for the APS-2.

General Principles

Data Ownership:

The issue of data ownership and control by Aboriginal Peoples is a critical element that will play an important role in the involvement and commitment to an initiative. The experience of Aboriginal People in the ownership of various research and program developments has generated a greater level of awareness of the potential practical use of research results. Hence, potential for real, positive change and improvement in the health status based on evidence generated from research is a significant outcome from this process.

Aboriginal Peoples are slowly gaining a level of respect and value in the collection of data and the subsequent analysis and interpretation of that data when there has been involvement and active participation in the data collection process. When Aboriginal People are outside the process, the outcomes are not as meaningful. As was described in the example of the First Nation and Inuit Regional Health Survey Project and the Ontario First Nations Health Information System, ownership played a key role in the success of the initiatives.

Data Ownership has several key elements that must be taken into consideration:

- To have control and ownership in the data collection process within an agreed upon, principled and ethical research framework.
- Consent of the individual and community to access the data and the degree or level of that access.
- Approvals of the community to interpret, respond and approve the analysis of the data findings prior to public release.
- To recognise the rights of the community to determine how the information will address the needs of the community.
- To ensure that the publication of the data will do no harm to the community.
- To ensure the confidentiality of the data and controlled safeguarding of the data.
- Copyright, Intellectual Property rights and stipulated access to the data is determined by the community.

Self Government Framework:

A health info-structure must be complementary to and facilitate the self-determination and self-government initiatives of Aboriginal people.

Its requirements in this context include:

- respect for the special relationship of the federal government with Aboriginal people,
- replacement of functions which were previously provided under federal programs, such as data collection and analysis,
- accommodation of the changing needs of communities which are progressing from Health Transfer initiatives to more autonomous methods of governance,
- flexibility to accommodate both traditional and western models of care and treatment,
- ensuring that data ownership resides with the self-governing body,
- significant improvement of the provision of health services to remote areas, and creation alternatives, such as telehealth, to reduce travel of community members to distant health institutions,
- monitoring of health expenditures (such as dental and pharmacy benefits now federally administered) to ensure an appropriate and effective use of limited resources,

- provision of management information systems for policy formulation, program evaluation and accountability reporting,
- safeguarding of privacy and incorporation of confidentiality procedures,
- a focus on the client, and the empowerment of community members to participate in decisions affecting their health services, both individually and collectively, and
- a holistic integration of all health and social services.

The current initiatives represent a significant investment in human and financial resources that, from an Aboriginal perspective, will show returns when outcomes are under Aboriginal control and directed to enhancing the capacity of Aboriginal communities to improve the health of their citizens, thereby taking another vital step toward self-determination.

The following are general principles under which development of a Aboriginal health infostructure and a health research agenda should proceed:

- **Self-Determination:** Wherever Aboriginal people and communities have achieved success in developmental initiatives, these successes have occurred in the context of an emerging context of self-determination. In many communities, particularly on-reserve First Nation and Inuit, this context may be best characterized as a move towards self-government.
- **Unique Constitutional Status:** Aboriginal people are not an “interest group” in the sense that other sectors of the Canadian population might be considered. For historical and judicial reasons, Aboriginal people have fundamental rights to autonomous institutional development that cannot be met without a commitment to independent institutional development.
- **Knowledge is Power:** A primary requirement of self-government is the institutional capacity to direct and control the assembling of information necessary to determine policy and implement and evaluate programs. Control over databases, research, and the analytical process of linking health information to policy and program outcomes is essential for Aboriginal communities if development in this area is to be supported.
- **Inequities in human resource capacity and institutional development:** Tremendous strides are being made by Aboriginal people and communities to create new educational resources and structures. Capacity-building in the area of health research is still urgently required if the health infostructure is to be meaningful to Aboriginal communities. The obvious analogy of the health infostructure to the development of the national railroad can be extended to Aboriginal people. Without the institutional and human resource capacity to participate as equals in the development of the health infostructure, the effect on Aboriginal communities could be as destructive as the historical impact of the railroad.

Section Two: Proposal to Create an Interim Aboriginal Health Research Strategic Program within CIHR

This proposal is focused on creating an interim strategy for bringing CIHR resources to bear on the Aboriginal health issues outlined above. The proposal is interim because it is difficult at this time to ascertain the precise role that the Aboriginal Health Institute may play in the eventual activities of the CIHR, given the early developmental stage of the AHI. Our recommendation is that at the end of three years, a general review of this research

program be undertaken by the Aboriginal Health Institute to determine whether the strategy remains consistent with the objectives of the AHI and the Aboriginal community.

The Canadian Institutes of Health Research should recognise that a research agenda in this field must be developed in full partnership with the Aboriginal community. This partnership should include a relationship with the Aboriginal Health Institute, as well as the creation of an administrative unit within the CIHR. This unit should have responsibility for both ensuring that Aboriginal health issues are addressed by other administrative units such as Divisions, Institutes, and Programs, and for managing a strategic research program designed to build the capacity of Aboriginal people to undertake health research of the highest scientific standard in their communities. Recommendations to achieve this objective are:

- 1)** The Aboriginal Health Institute (AHI) should have one seat on the CIHR Governing Council. It would be the responsibility of the Board of the AHI to recommend the appropriate person for this appointment. This seat should be held open until such time as the AHI is prepared to make the appointment.
- 2)** The CIHR should create an Aboriginal Health Research Council (AHRC). This Council should have the responsibilities and authority of a Board of Directors and will provide general direction and oversight for the activities of an "Office/Institute of Aboriginal Health Research". This Council may be considered interim until such time as the Aboriginal Health Institute is fully developed and may assume this role. (Estimated administrative cost - \$200,000 per year)

The implementation of an Aboriginal Health Research Strategy will require collaboration among Aboriginal organisations and Universities across the country, who will be responsible for developing training initiatives and academic opportunities for Aboriginal health researchers. In order to ensure both accountability to all Aboriginal communities and to encourage broad participation of academic partners, we recommend that the Council have ten voting members to be structured as follows:

- The five National Aboriginal Organisations (Assembly of First Nations, Inuit Tapirisat, Metis National Council, Aboriginal Congress of Canada, and the National Aboriginal Women's Association) should be invited to appoint one member each. These representatives may be drawn from the political or administrative levels of organisations or may be identified from the broader Aboriginal community, but should include some degree of regional representation.
 - Five University representatives should be appointed by the CIHR Governing Council. These representatives should be Aboriginal or have strong evidence of effective research relationships with Aboriginal people, should hold relatively senior academic appointments to facilitate input into University affairs, and should be drawn from Universities representing all regions of Canada. Recommendations for these appointments should be reviewed by the five national Aboriginal organisations.
 - Subject to review by the voting members of the Council, Government should appoint ex-officio representatives from various government departments and programs. These members would help to assure that federal and provincial programs and resources are linked effectively to the Strategic research program.
 - The Council should develop other terms and responsibilities of the Council.
- 3)** The Council for Aboriginal Health Research should create an "Office/Institute of Aboriginal Health Research" within CIHR. We are using "Office/Institute" in this

proposal because it is unclear at this point how CIHR plans to develop Institutes. If CIHR determines that a relatively few Institutes will be created around major health issues such as “Population Health” or “Cancer”, then this recommendation is for an Office to be established that is independent of any Institute but which has the same decision-making authority as Institutes within the overall CIHR administrative structure. By this we mean that an Office Director should have the same status as Institute Directors in the governance structures of the CIHR, even though an Office may not be responsible for managing resources on the same scale as an Institute. If, on the other hand, the CIHR decides to create many Institutes of differing sizes, then an Institute for Aboriginal Health Research should be created with the same administrative status and responsibilities as other Institutes. The “Office/Institute” should have responsibilities for the co-ordination of an Aboriginal health research agenda in the operating plans of other CIHR Institutes and Offices, and for the operational implementation of the strategic research plan outlined below. (Estimated Administrative Cost - \$200,000 per year)

The AHRC should appoint a Director and establish the “Office/Institute” in an appropriate University environment that meets the following criteria and conditions:

- The Director has an established reputation in conducting high quality health research in collaboration with Aboriginal communities.
- The University provides an appropriate collaborative environment where Aboriginal people and issues are considered a priority for program development.
- The University environment provides the appropriate opportunity for the development of post-graduate training of Aboriginal health researchers.
- The University provides the appropriate environment for facilitating interdisciplinary research across the major CIHR themes of Basic Biomedical, Applied Clinical, Population Health, and Health Services Research.

4) The AHRC should appoint an Aboriginal Research Review Committee. This Committee should be charged with the responsibility of providing an appropriate peer review process (science, cultural and policy relevance, and ethics) for all research initiatives undertaken by CIHR that involve Aboriginal people or communities. This peer review process should complement other CIHR peer review mechanisms. If peer review of research proposals is centralised within the CIHR administrative structure, the input of the Aboriginal Research Review Committee should be sought for all relevant proposals. Centralised peer review rating systems should be adapted to ensure that input from the Aboriginal Research Review Committee is accorded appropriate value. Composition of the Aboriginal Research Review Committee should be determined by the AHRC. (Estimate administrative costs - \$200,000 per year)

5) The CIHR in co-operation with the Office/Institute of Aboriginal Health Research should establish an Aboriginal Health Research Strategic Program. This program will consist of the following initiatives:

- A) Develop an Aboriginal Health Community-University Research Alliance (AHCURA) Program jointly with SSHRC (\$1million)
- Modify and expand existing CURA program that is currently administered by SSHRC.

- This program would be specifically responsible for facilitating a partnership development process for Universities and Aboriginal communities according to the guidelines already developed by SSHRC.
- Community and University capacity-building to undertake collaborative research is a primary objective.
- Fund up to ten Aboriginal Health CURA's to be distributed regionally over a three-year period.
- Primary focus of this initiative is to provide regionally based resources for Aboriginal communities and organisations to work with University technical expertise to develop research questions and proposals for CIHR consideration.

B) Implement Aboriginal Health Research CONSORTIA Initiative (\$1million)

- Objective is to build capacity for teams of researchers ("Consortia") to develop research initiatives of national significance.
- Consortia should include both academic and non-academic research partners from more than one region of the country. Research partners should include Aboriginal and non-Aboriginal scientists, health planners and policy analysts.
- RFP for proposals for Consortium around specific high priority research questions such as Diabetes, child health, health services evaluation, environmental health, etc.
- Consortia could also support existing national level research partnerships where ongoing research activities have documented success (e.g., First Nations and Inuit Longitudinal Health Survey)
- Consortia to include expertise from both Aboriginal health and "mainstream" research communities. For example, a Diabetes Consortia should include basic science expertise in diabetes.
- Criteria for consortia must include partnerships with Aboriginal organisations and communities, should be regional or national in scope and membership, and should include multidisciplinary perspectives including "Aboriginal health science".
- Consortia should be provided with resources to facilitate capacity development to enable them to develop competitive CIHR research grants and disseminate research results.
- Consortia support grants should be on a 3 yr renewable term in order to facilitate long-term capacity-building. However, consortia should be required to change, re-focus research questions, and include new members in order for renewal of support.

C) Implement Aboriginal Career Development Initiative (\$1million)

- The purpose of this initiative is to support the career development of a cadre of Aboriginal health researchers
- This program must provide incentives to attract the "best and brightest" Aboriginal students into health research careers in an environment where highly paid government and health service careers are readily available.
- Recipients of these awards should be attached to Research Consortia and Aboriginal Health CURA's as described above.
- In addition to stipend for awardees, each award should include a support grant to the academic units where these awards will be taken up in order to ensure research and mentorship support and cross-centre training (i.e., training at different research centres).

- 3 Career Awards at the rank of Assistant to Full Professor (5 yr renewable) - (\$300g - \$100g each)
- 3 Post-doctoral fellowships to facilitate retraining of Aboriginal scholars from other disciplines such as social sciences, humanities, social work and education – (\$180g - \$60g each)
- 12 studentships for Aboriginal students enrolled in Master's and Doctoral programs in health research related fields (\$480g - \$40g each)
- Summer Studentships – for undergraduate and senior high school student internships to create interest in health research careers.(\$160g - \$5g each)

6) Total Initiative - \$3.6 million in first year rising to \$5.6million in 3rd year

- \$1 million new funding in each subsequent year but renewal required in fourth year
 - SSHRC co-funding on AHCURA
 - NHRDP co-funding on Consortia for HIV/AIDS
 - CHRSEF co-funding on Consortia for health services and policy research
 - Potential for Provincial co-funding of 20% of approved projects
 - CIHR commitment: approximately \$3 million per year plus grants (potentially unlimited if capacity building is successful)
-