

Under Four Flags:
**Development of an International Research
Consortium for Inuit Health**

1. Goals and Objectives

Our goal in applying for a program development grant under the *Global Health Research Initiative* (GHRI) is to create an international research partnership devoted to planning, implementing, and disseminating a long-term program of research to seek ways to improve the health status of the Inuit people and strengthen the health information capacity of the health systems in the circumpolar regions.

During the course of the one-year funding period, the applicants will:

- Continue and consolidate existing links between academic research centres, Inuit political organizations, regional health authorities, scientific/professional associations, and government agencies;
- Conduct community consultations and convene technical working groups through regional workshops and planning meetings during 2003;
- Produce a memorandum of agreement outlining the terms of partnership and collaboration signed by lead officers of the various institutions and organizations at the 12th International Congress of Circumpolar Health in September, 2003 in Nuuk, Greenland [to be known as the Nuuk Declaration];
- Prepare one or more project proposals ready for submission to research funding agencies for operating and/or infrastructure grants in the fall of 2003.

The GHRI program development grant will thus provide the seed money to create the *International Research Consortium for Inuit Health* [IRCIH], which will then be sustained by research grants and other fundraising activities.

2. Proposed Program of Research

The IRCIH's program of research addresses the following broad questions:

- What is the current pattern of health and disease of the Inuit and what factors are responsible for its development?
- Why do Inuit communities differ in their level of health and well-being and in the distribution of various health determinants?
- Why do Inuit populations fare poorly compared to the general population of the larger nation-states with which they are associated?
- What can be done to reduce the burden and impact of prevalent and emerging health problems affecting the Inuit people?
- What can other societies in developing countries learn from the Inuit experience?

These questions will be researched through the following specific projects, in the order of their implementation:

1. Creating a *Circumpolar Inuit Health Data Repository*: This is a web-based virtual library of datasets, data dictionaries, questionnaires, protocols, and research reports from all previous regional health surveys, censuses and studies involving the Inuit population. A compendium of health indicators, continuously updated, which will be aggregated at the community, regional, or national level where appropriate, will be created. An additional resource will be the preparation of an Arctic food table to assist nutrient analyses. The Repository will be freely accessible to researchers, planners, health care providers and members of the public. It will help researchers plan future studies by avoiding duplication and focusing the research question; facilitate regional health authorities' evidence-based planning by generating custom tabulations on request; and assist front-line health care workers in solving clinical/community health problems in a timely fashion. A beginning has been made in this direction over the past 2 years by the merging of the core datasets of health surveys in Greenland, the Nunavik and Kivalliq regions of Canada, and Alaska conducted during the 1990s.
2. Launching the *Inuit Health in Transition Study*: This is a long-term prospective cohort study of over 12,000 Inuit adults across the circumpolar North, investigating the impact of social, cultural and economic factors, the physical environment (including contaminants) and health behaviours (including diet, physical activity, and smoking), and their interactions with genetic susceptibility, on health outcomes, with special (but not exclusive) focus on the chronic diseases. The baseline survey will consist of interviews, clinical examinations, and laboratory tests. The follow-up period is anticipated to be at least 10 years, with periodic repeat examinations and also tracking of major health events through electronic linkage to health care databases and vital statistics. The longitudinal design, multi-level analyses, data linkage, and banking of biological specimens offer opportunities for methodologic innovations. Results, initially of cross-sectional analyses, will be immediately relevant to policy development and program planning. Sub-cohorts of children born to mothers in the Study will enable investigations into the perinatal/early infancy origins of adult diseases; nested case-control studies can pursue associations with novel risk factors.

Planning of this study has begun, with two preliminary meetings of interested scientists to explore its feasibility in Québec City (May 2001) and Montréal (February 2002). A meeting of potential stakeholders, including representatives of Inuit organizations and government agencies, was convened in Montréal in May, 2002, at the invitation of the Presidents of the Inuit Circumpolar Conference and the International Union for Circumpolar Health, funded by a meeting grant of the CIHR Institute of Aboriginal People's Health. The consensus of the meeting was to proceed with the planning, conduct community consultations, and seek financial support.

3. Establishing an *Inuit Mortality and Morbidity Surveillance System*: Currently existing, regionally limited mortality (eg. Greenland) and disease registries (eg. cancer and diabetes in Alaska) will be extended across all Inuit jurisdictions, using standardized, consistent and comparable procedures. Where appropriate, the most cost-efficient method of identifying and extracting Inuit cases from ethnically non-

differentiated national/regional health databases will be investigated. The international collaboration involved in the circumpolar Inuit cancer surveillance project (covering the period 1969-1988) will be used as a model for the creation of registries of diseases of special interest – cancer, diabetes, ischemic heart disease, stroke, tuberculosis, and suicide. While our focus is on the Inuit, by making the surveillance ethno-specific, it will also benefit health planning of regional health authorities serving multi-ethnic populations.

4. Designing *Community-Based Intervention Trials*: A variety of projects with different target conditions and different intervention strategies will be tried in selected sites with different cultural traditions and community dynamics. These will generally be directed at behavioural and environmental changes related to smoking, physical activity, and nutrition. The staged implementation will allow appropriate communities to serve as controls, but they will also benefit from the interventions at a later time. All communities will have participated in baseline surveys (as part of Project 2). This project will be driven by Inuit organizations and regional health authorities, with the scientists serving as technical advisors in study design and evaluation. The planning will likely occur in the medium term (3-5 years) of the Consortium's workplan.

3. Background and Rationale

The health of the Inuit has been extensively reviewed (Bjerregaard and Young 1998). A select bibliography of key documents and studies relevant to the present proposal is provided in Appendix A.

- *Who are the Inuit?*

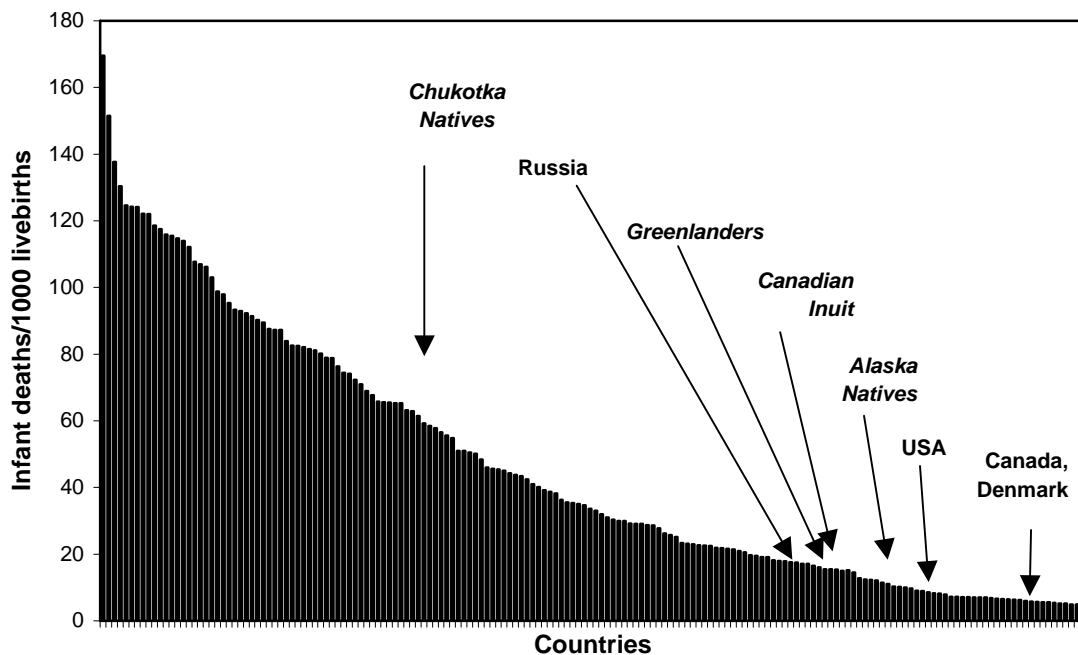
The Inuit homeland stretches from the easternmost tip of Russia in the west, to Greenland in the east, and today they live under four flags. World wide there are around 167,000 Inuit distributed in Greenland (50,000), Denmark (8,000), Alaska (44,000), other parts of USA (13,000), Canada (50,000), and Russia (1,700). There are two main linguistic branches: The *Inuit/Inupiat* which extends from northern Alaska, across Canada, to Greenland; and the *Yup'ik* who inhabit central and southwestern Alaska and the Chukotka peninsula in Russia. In Canada, Inuit are sometimes grouped with First Nations and Métis people and referred to as *Aboriginal people*. In Alaska, the term *Alaska Native* encompasses Eskimos (a term still widely used and not considered to be pejorative), Aleut, and American Indians. Greenland Inuit refer to themselves as *Kallaallit*. The term *Eskimoski* exists in Russian, and Inuit are a very small minority within a non-Slavic minority collectively known as *malochislennye narody Severa*, or “numerically small peoples of the North”. While no one single term covers the Inuit/Inupiat/Yupik/Kallaallit entirely satisfactorily, we use the term “Inuit” collectively, since it is also used in the official name of the multinational Inuit Circumpolar Conference

- *What are the chief characteristics of the health of the Inuit?*

The health of the Inuit and other indigenous peoples of the circumpolar north has undergone substantial changes over the past 5 centuries, as a result of the changes brought about by interactions with Europeans. This process was accelerated considerably in the second half of the 20th century, with important consequences for their health. The absolute burden of mortality and morbidity has decreased substantially, measurable in terms of overall indices such as life expectancy at birth and infant mortality rate.

Significant changes in the health of the Inuit include:

- (1) the decline but persistence of infectious diseases such as tuberculosis, stabilizing at a level still higher than that of the non-indigenous, national population;
- (2) the emergence of chronic diseases such as heart disease;
- (3) the overwhelming importance of the social pathologies, including injuries, violence, suicide and substance abuse.



The figure shows clearly the disparities that exist between the health status of the indigenous populations and the general population of the nation-states with which they are associated. It should also be noted that considerable variation exists across regions and between communities.

The Inuit population has made substantial contributions to public health research over the years, with an impact that extends beyond the Arctic. Examples include the field trial of isoniazid prophylaxis for tuberculosis and hepatitis B vaccination in Alaska, and studies on the role of marine-based polyunsaturated fatty acids in atherosclerosis in Greenland.

- *What factors are responsible for the observed pattern of health?*

The health transition among the Inuit reflects the interaction of genetic and environmental factors. Human biology in the Arctic has been concerned with the genetic contributions to

disease and physiological adaptations to the cold climate. Until recently, the Inuit could be considered both geographically and genetically isolated. Their long habitation in the Arctic has also resulted in the evolution of many genetic (and cultural) adaptations which allowed them to survive and thrive successfully in one of the coldest and most inhospitable environments on earth. Moreover it is the recent introduction of new stressors and their compression into a short time period which has the most significant impact on health.

Traditionally, the Inuit appeared to have been protected from atherosclerotic diseases and diabetes, the result of a particular genetic endowment and/or their high dietary intake of marine mammals and fish, and vigorous physical activity. The apparent “protection” from these diseases is disappearing, primarily because of the rapid change in lifestyles. Existing data are discouraging in that the Inuit have acquired an unfavourable health risk profile compared to other contemporary populations and to Inuit in the past, especially the high prevalence of smoking. Traditional food system use is declining rapidly, though not uniformly across the Arctic. In some areas, dietary fat from market foods now exceed that from traditional, marine-mammal-based sources.

While the Arctic is often assumed to be a pristine, unpolluted area, many man-made chemicals such as PCBs, dioxins, toxaphenes, and other pesticides are now transported to the Arctic by ocean and atmospheric currents, and then are biomagnified in the marine food web, ultimately ending up in humans. This is superimposed on “old” environmental health problems related to crowded housing and inadequate water supply and sanitation.

In terms of the broader socio-economic environment, by almost any indicator – educational attainments, individual and family income, housing quality, employment and occupation – and any composite index combining some or all of these, the Inuit also fare poorly. Health also becomes adversely affected when there is discrepancy between modern and traditional values. Individuals and communities may develop coping strategies which build on their cultural repertoire, but these stresses may be so strong and unfamiliar that the protection provided by traditional culture may be dissipated.

- *What are the weaknesses of existing Inuit health information systems*

Given the diversity of their political and national health care systems, it can hardly be expected that there is uniformity in the collection and presentation of Inuit health information in the four countries. Within each jurisdiction, there are operational problems in performing even basic functions such as providing Inuit-specific numerator (health events) and denominator (population), making describing and tracking the health of the Inuit population difficult.

The Census is the chief source of information (not just for population, but also for key socio-economic data) for Canada (conducted every 5 years in years ending in “1” and “6”), and the USA (conducted once every 10 years in a year ending in “0”). The last Soviet census was in 1989. The last census in Greenland was held in 1976 but demographic data are continuously updated through the Central Population Registry.

Tracking population growth of ethnic groups through the census is complicated by the fact that ethnic origin is based on self-asciption and is therefore subject to changing perception of group identity, ethnic pride and also entitlement to special rights and benefits such as those resulting from land claims settlements. Enumeration practices also changed over time, (eg. in question design, operational definitions, and allowing multiple origins).

The membership lists of Canadian regional Inuit organizations and Alaska Native regional corporations established for land claims registration purposes provide an alternate source of population data. Under Canada's system of universal health insurance, each province/territory maintains a registry of beneficiaries, which can serve as a de facto population registry. Inuit ethnicity, however, is only identifiable in the Territorial Health Insurance System (THIS) for NWT and Nunavut. The degree of concordance among this multiplicity of Inuit population sources vary according to the region.

It is also difficult to identify with certainty many health events as occurring among Inuit. Often it is only possible to attribute an event as occurring in a geographical region where the Inuit predominate. The lack of Inuit-specific data is less of a problem in Nunavut or Nunavik, as almost all "Aboriginal" are Inuit, and in fact the majority of population are Inuit (85% in Nunavut and 90% in Nunavik). In Alaska there are six census areas where Eskimos constitute over 90% of the Native population and between 70% and 90% of the total all-race population. Various proxies are often used. Reports from Greenland, including the annual health report of the Chief Medical Officer (*Embedslægeinstitutionen for Grønland*), tend to compare residents "born in Greenland" with those "born in Denmark". The former is often used to represent Greenland Inuit.

Even where the capability to produce Inuit-specific data exists, such data are not always made available to the public in published form, or readily accessible without extra efforts and costs in computer programming. Two key annual publications of the US Indian Health Service (of which the Alaska Area Native Health Service is an administrative region), *Trends in Indian Health* and *Regional Differences in Indian Health*, tend to group all Alaska Natives together and it is not possible to distinguish Eskimos from Aleuts and Indians. In Canada, the *Health Conditions of the Northwest Territories*, published annually until the late 1980s, used to provide detailed compilation of health data broken down into Inuit, Indians and Other categories. This practice is no longer followed by its successor. Of the 27 types of indicators provided in the *NWT Health Status Report 1999*, a breakdown into the Aboriginal and non-Aboriginal populations is provided for only three indicators (life expectancy, smoking prevalence, and home language), with no distinction at all between Inuit and First Nations people.

A few examples will show how combining Inuit and First Nations data is detrimental to assessing the health needs of both groups. Data from the NWT Suicide Database shows that Inuit suicide rate from 1986-96 was almost 3 times that of First Nations and 5 times that of Métis and non-Aboriginal residents. On the other hand, the prevalence of diabetes is lowest among Inuit, which is only about 1/4th that of the First Nations rate. Smoking data from the 1999 NWT Labour Force Survey showed that, while smoking is a prevalent problem among Aboriginal peoples, it is worst among Inuit (65%), compared to 56% in

First Nations. When all sites of cancer are combined, Inuit during the period 1979-1988 are at increased risk (1.3 times) relative to all Canadians, whereas First Nations in the NWT have a reduced risk (0.65). Not only is the overall risk of cancer higher among Inuit, but the pattern of individual cancer sites also differs.

Regional Inuit populations can be considered “small areas” in the statistical sense, with infrequent health events and highly unstable rates. Even small changes of the numerator and/or denominator can affect the resulting rates and proportions substantially. Aggregating data for 5 or 10 years is often necessary. For some regional or national surveys, the sampling strategy does not allow for the disaggregation of data to the community level. Communities often express the desire to see health data specific to their community but may not recognize their limitations.

The many deficiencies of the existing system are highlighted in an inventory of available health indicators for the various Inuit regions conducted by the Inuit Tapirisat of Canada and published in the 2000 report *Evaluation of Models of Health Care Delivery in Inuit Regions*. The tabulation is notable in the number of blanks that are found throughout. The availability of Inuit-specific health data was identified as a priority health issue in the 2000 Inuit Health Policy Forum.

Much new work can be done to monitor the health of the Inuit beyond the traditional list of readily available indicators. With the availability of a variety of Inuit health surveys and mortality/morbidity databases, it is now possible to construct health expectancy measures that combine both quantity and quality of life indicators, as well as various composite indices of health needs and disparities.

- *Are there precedents for international collaboration in Inuit health research?*

There has been a long history of cooperation among the circumpolar countries in health research. The first International Symposium on Circumpolar Health was held in 1967 in Fairbanks, Alaska. Subsequent symposia and congresses were held in Oulu, Finland (1971); Yellowknife, NWT (1974); Novosibirsk, USSR (1978); Copenhagen, Denmark (1981); Anchorage, Alaska (1984); Umeå, Sweden (1987); Whitehorse, Yukon (1990); Reykjavík, Iceland (1993); Anchorage, Alaska (1996); and Harstad, Norway (2000). The next congress will be held in 2003 in Nuuk, Greenland. Each conference has brought together researchers, administrators, practitioners, and community representatives from all the circumpolar countries. The congress proceedings serve an invaluable function as a permanent record of the type of research that has been conducted over the years, which has also evolved from a preoccupation with physiological adaptation to cold climates in the early years to increased attention to community-based participatory research on health care delivery issues in more recent years. Beginning with the Whitehorse congress, there has been an indigenous health program separately planned and administered by indigenous (eg. Inuit, First Nations, Sami) organizations.

The International Union for Circumpolar Health (IUCH) has existed since 1981 as a federation of national organizations based in Canada, Alaska, Russia, Greenland and the

Nordic countries. The IUCH sponsors the circumpolar health congresses as well as publishes the *International Journal of Circumpolar Health*. In 1995 it organized in Inuvik an international workshop on the ethics of health research among indigenous peoples.

Two of the co-applicants (Dewailly and Bjerregaard) are involved in the multinational Arctic Monitoring and Assessment Program (AMAP) concerned with the health impact of pollution in the Arctic, and they co-authored the chapter on human health in the *State of the Arctic Environment Report*.

Extensive collaborative research in Chukotka occurred throughout the late 1980s and early 1990s under bilateral agreements between the Russian Academy of Medical Sciences and the Universities of Alaska and Manitoba.

4. Research Partners

The consortium will consist of members of research centres/institutes, Inuit organizations at the international, national and regional levels, health services and related government agencies, and individuals from the private sector. Letters of support/collaboration which have been received to-date can be found in Appendix B. A smaller Planning and Priorities Committee consisting of about 10-15 partners will be constituted [marked by *] from this larger group. Five select publications from members of the consortium can be found in Appendix C. Technical working groups dealing with specific issues will also be formed.

International

- International Union for Circumpolar Health*
- Inuit Circumpolar Conference*

Canada

- Unité de recherché en santé publique, Université Laval, Beauport, Québec*
- Centre for Indigenous People's Nutrition and Environment, Macdonald Campus of McGill University, Ste-Anne-de-Bellevue, Québec*
- Department of Public Health Sciences, University of Toronto, Toronto, Ontario*
- Centre for Aboriginal Health Research, University of Manitoba, Winnipeg, Manitoba*
- Blackburn Cardiovascular Genetics Laboratory, Robarts Research Institute, London, Ontario
- Inuit Tapiriit Kanatami, Ottawa*
- Inuit Centre, National Aboriginal Health Organization, Ottawa*
- Nunavik Regional Board of Health, Kuujuaq, Québec*
- Labrador Inuit Health Commission, Nain, Newfoundland and Labrador
- Northwest Territories Department of Health and Social Services, Yellowknife, NWT
- Nunavut Department of Health and Social Services, Iqaluit, Nunavut
- First Nations and Inuit Health Branch, Health Canada [Northern Secretariat; Québec Region, and Atlantic Region]
- Northern Contaminants Program, Department of Indian and Northern Affairs, Ottawa

- Circumpolar Liaison Directorate, Department of Indian and Northern Affairs, Ottawa
- Other national Inuit bodies: Pauktuutit (Inuit Women's Association), National Inuit Youth Council, Inuit Elders Council
- Regional Inuit organizations/development corporations: Makivik Corporation, Kuujuuaq, Québec; Inuvialuit Development Corporation, Inuvik, Northwest Territories; Nunavut Tunngavik Inc, Iqaluit, Nunavut; Kivalliq Inuit Association, Qikiqtani Inuit Association, Kitikmeot Inuit Association
- Northern-based research organizations: Nunavut Research Institute, Iqaluit, Nunavut; Aurora Research Institute, Inuvik, NWT; Igloodik Research Centre, Igloodik, Nunavut; Nunavik Research Centre, Kuujuuaq, Québec

Alaska/USA

- Centre for Alaska Native Health Research, University of Alaska, Fairbanks, Alaska *
- University of Virginia School of Medicine, Charlottesville, Virginia*
- Alaska Native Tribal Health Consortium, Anchorage, Alaska*
- Alaska Native Health Board, Anchorage, Alaska*
- Yukon Kuskokwim Health Corporation, Bethel, Alaska*
- Norton Sound Health Corporation, Nome, Alaska
- Cooper Institute, Dallas, Texas
- MedStar Research Institute, Washington, DC
- Washington Hospital Centre Information Systems, Washington, DC
- EDN Nutrition Consulting, Anchorage, Alaska

Greenland/Denmark

- Division of Research in Greenland, National Institute of Public Health, Copenhagen, Denmark*
- Ministry of Health, Greenland Home Rule Government, Nuuk, Greenland*
- Centre for Primary Health Care, Nuuk, Greenland
- State Serum Institute, Copenhagen, Denmark
- Centre for Arctic Environmental Health, Århus, Denmark

Chukotka/Russia

- Siberian Branch, Russian Academy of Medical Sciences, Novosibirsk, Russia
- Department of Health, Chukotka Autonomous Region Administration, Anadyr, Russia
- Russian Association of Indigenous Peoples of the North, Moscow

5. Relevance to GHRI Funding Partners

- *Institute of Population and Public Health* –As a population of genetically closely affined peoples living in 4 countries with different historical experiences and subjected to different types and rates of sociocultural transition, the Inuit provide a unique opportunity to conduct “research into complex interactions (biological, social, cultural, environmental), which determine health, and the application of that

knowledge to improve the health of populations”, one of the stated objectives of IPPH in the RFA.

- *Institute of Aboriginal People’s Health* – Circumpolar indigenous health is specifically mentioned in the RFA, as an example of “indigenous populations in post-colonial developed countries” in which the IAPH has a specific interest.
- *Institute of Circulatory and Respiratory Health* – Our research is highly relevant to ICRH’s interest in “gene-environment interactions in determining susceptibility to circulatory diseases”. We intend to build on previous collaboration with Robert Hegele [Robarts Research Institute, London, ON] who have investigated a variety of genetic markers among the Inuit of Kivalliq region in Canada.
- *Institute of Gender and Health* – In any analyses of our data, we will be cognizant of IGH’s mandate to generate “evidence of the impact of sex/gender on health status” and its interactions with other health determinants. For example, the association between SES and obesity indices is reversed for Inuit men and women, a result likely of their different social roles in a transitional economy. It is also notable that Inuit women traditionally have played a major role in national/international political organizations and have a special interest in health. In Canada, for many years the Inuit Tapiriit Kanatami has delegated its health portfolio to Pauktuutit (Inuit Women’s Association).
- *Institute of Infection and Immunity* – As a population undergoing the epidemiologic transition, the Inuit have experienced the decline (but persistence) of infectious diseases. Both “old” (eg. TB) and “new” (eg. HIV) infectious agents pose significant threats. Historically the Inuit have made unique contributions to research on the epidemiology and control of infectious disease, eg. TB, hepatitis A and B, meningitis.
- *Institute of Neurosciences, Mental Health and Addiction* – The Inuit suffer from high rate of youth suicide, substance abuse and mental health problems related to the stress of rapid social change. Our research in this area should be of interest to INMHA. Mental health was identified as the no.1 priority health issue in the 2000 Inuit Health Policy Forum.
- *Institute of Nutrition, Metabolism and Diabetes* – We are delighted that INMD has explicitly identified obesity as its strategic research focus. There are important issues which remain unresolved, eg. do conventional measures and criteria for obesity have the same metabolic significance among the Inuit? Is obesity a protective trait in cold regions which has become maladaptive in the modern era?
- *Canadian International Development Agency* – Although the Inuit live in some of the world’s most highly developed and industrialized countries and thus fall outside the purview of Canada’s official development assistance mandate, lessons learned from our program of participatory research broadly aimed at sustainable human development can be useful to indigenous populations in developing countries. On the other hand, post-Soviet Russia is CIDA’s sixth largest recipient country. The inclusion of the health and environmental impact of the transition to a market economy in Chukotka would fit one of CIDA’s three priorities and its strategy for the Russian North. The ICC has been funded by CIDA to assist the Russian Association of Indigenous Peoples of the North in training and development.
- *Health Canada* – The First Nations and Inuit Health Branch established a Northern Secretariat in 1998 to coordinate federal health programs and services in the

Territories in partnership with the territorial governments, including health promotion and disease prevention. The Atlantic and Québec Regions serve Inuit communities in Labrador and Nunavik, respectively. FNIHN is thus a key partner in the dissemination and translation of research results emerging from our research program.

- *International Development Research Centre* – IDRC has substantial interests in indigenous knowledge (especially relating to the environment) in developing countries. Interestingly it has actually funded projects within Canada (eg. water testing training program in a Cree First Nation in northern Manitoba). It is a potential source of funding for projects under its Ecosystem Approaches to Human Health, Research for International Tobacco Control (Inuit have one of the highest prevalence among Canadians, at 65%), and perhaps an Essential Health Interventions Project targeted at the Circumpolar North based on the Tanzania model.

6. Opportunities for Research Training

The variety of research projects in our proposed program will provide ample opportunities for hands-on training of all levels of graduate students, post-doctoral fellows, and young scientists early in their career. Training will also occur in the regional health authorities and Inuit organizations, which can serve as short term placement (or internship) sites offering trainees the opportunity to solve practical problems with research tools that they have learned, under the joint supervision of their academic advisors and local “decision-maker”. The data analysis capacity of these organizations will also be enhanced. Training of research assistants also occurs in the communities. The skills acquired by such individuals (survey interviewing, data entry, project coordination, etc) are readily transferable to other programs/projects to the community’s benefit.

Among the special initiatives announced in 2001 by CIHR-IAPH, two are of particular relevance to training and capacity development. One is the establishment of a survey centre for Aboriginal health at the University of Manitoba’s Centre for Aboriginal Health Research, one of the co-applicants of this proposal and consortium partner. The objective is to create a research centre which will develop, implement and analyze health surveys.

The other CIHR-IAPH initiative is funding a network of Aboriginal Capacity and Developmental Research Environment or ACADRE centres to facilitate the expansion of Aboriginal capacity in health research. The University of Manitoba also received an ACADRE award. Two of the co-applicants have also submitted proposals to establish ACADRE centres in Québec City and Toronto. Thus ample opportunities exist for research training among consortium partners. These centres have different regional and research focus and are complementary to one another. The centre at Laval is named *Centre Avativut/Ilusivut* [“our environment, our health”].

7. Research Dissemination and Translation

The partnership involving research scientists, Inuit organizations, regional health authorities, professional societies and government agencies (in health, social services, environment) will shorten the distance between research and policy. By making health

research data accessible to practitioners and administrators, the data repository will provide timely information to assist clinical and public health practice, ultimately benefitting Inuit clients.

The applicants are aware of the special requirements for research dissemination involving indigenous peoples. At the June 2001 meeting of the Inuit Health Information Initiative in Inuvik, recommendations were made regarding the role of communities in reviewing research results before publication or release to the media. The communication of research results requires that they not only be in plain, easily understood language, but also in an appropriate Inuit dialect. The newly created Inuit Centre of the National Aboriginal Health Organization has its central focus the dissemination of scientific information to Inuit communities. The consortium offers an opportunity partner with NAHO to develop the necessary health research terminology in Inuit dialects, and also the training of translators and interpreters. Inuit communities and regions can take full advantage of the phenomenal explosion in information technology, as distance no longer poses any logistical problem in the delivery of information to the remote North. Investment and training are needed, a role that the consortium can facilitate.

The traditional mode of scientific communication via the publication of papers in scientific journals and presentation at conferences is still an important mechanism to ensure that the research that has been completed is valid and acceptable to peers. Unsound research, no matter how culturally sensitive, will ultimately harm the interests and indeed well-being of communities. It is also important that research results be archived in the public domain and easily accessible by the public, such that they can still be retrievable years after the research has been completed.

8. Ethical Considerations

The applicants are sensitive to the need for ethnic-specific data collection (especially of “negative” phenomena such as disease and poverty) to balance between the risk of stigmatisation and the importance of specific targeting of interventions.

The collection of data, whether on special occasions in the course of a research study, or routinely as part of the health information system, may involve direct contact with individuals, as in health surveys, with varying degree of invasiveness in terms of pain, discomfort, and inconvenience. Other methods do not involve any direct contact, as in medical records review or electronic data linkage of large databases, but nevertheless raise concerns of threats to individual confidentiality and privacy. Issues of data ownership, confidentiality, access and disclosure have become extremely complex. New legislations have emerged in many jurisdictions which affect the conduct of much public health research. For Inuit, there is the additional demand that they should control the different steps in the flow of data including data collection, analysis and dissemination. Access to government-controlled data to serve Inuit planning needs must also be negotiated. We do not underestimate the complexity and difficulty of these issues but believe that the partnership model offers the best approach to resolving them.

Research in Canadian universities is now guided by the Tri-Council Policy Statement. Although it contains a section discussing research among Aboriginal peoples, the Councils decided not to establish policies due to insufficient consultations with the various constituencies. For years research in the NWT requires a license from the NWT Science Institute. This function has now been taken over by the Aurora Research Institute based in Inuvik and more recently, also the Nunavut Research Institute at Iqaluit. In addition to ethical safeguards, the licensing process also intends to promote communication between researchers and the communities and ensure that research is relevant to the needs and of value to northern residents.

Our university-based consortium partners have acquired considerable experience in developing innovative research governance structures and partnership models. For example, McGill's CINE has a governing board with representation from key national and regional Inuit/First Nations organizations. Manitoba's CAHR was created jointly by the Assembly of Manitoba Chiefs, the university and hospital research foundation. The Yukon-Kuskokwim Health Corporation is a partner of the University of Alaska CANHR.

The Alaska Native Health Board has produced *Guidelines for Partnering with Native and Tribal Organizations on Research Projects and Studies* [www.anhb.org/sub/epi/publications.html]. This can serve as a model for other areas, adapted to local needs.

9. Relevance and Importance

The establishment of an international research consortium on Inuit health and the implementation of its research program addresses important scientific questions relating to the health of the Inuit population, its determinants and strategies for improvement. It also strengthens an Inuit-specific health information system. The partnership model promotes Inuit participation in the design and implementation of a system which is informed by community values, views and opinions.

One of the key recommendations from the June 2001 meeting on the Inuit Health Information Initiative at Inuvik proposed the establishment of a partnership framework in the management and control of health information involving Inuit organizations at the national and regional levels, Health Canada and health ministries of relevant provincial and territorial governments. Our consortium proposal extends this concept internationally to four circumpolar countries.

Traditionally, the substantial amount of health research has been conducted *on* Inuit, with the people serving in a passive capacity as human subjects. Increasingly there is a trend towards research *for* Inuit, with Inuit organizations and communities deciding on priorities and seeking external experts and partners to help them achieve their research objectives. Ultimately, with training and capacity development, the goal of research *by* Inuit can be attained. Our international consortium proposal will make this transformation a reality.