

**Health Research Needs North of 60:
Northern Town Hall Meetings, September 2001**

**Canadian Institutes of Health Research
Institute of Aboriginal Peoples' Health and the
Institute of Nutrition, Metabolism and Diabetes**

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Executive Summary

The Canadian Institutes of Health Research (CIHR) Institute of Aboriginal Peoples' Health (IAPH), and Institute of Nutrition, Metabolism and Diabetes (INMD) undertook a series of Northern Town Hall meetings in the last week of September 2001, in order to listen to the health research concerns of the northern Aboriginal community, northern researchers, and health care professionals. The meetings, which were held in Whitehorse, Yukon; Yellowknife, Northwest Territories; and, Iqaluit, Nunavut, were hosted by local Aboriginal organizations. A number of common themes presented themselves in each of the territories. The seven expressed research needs that were voiced at each of the meetings include Aboriginal involvement in the research process; inclusion and respect of Aboriginal knowledge; training and capacity building; environmental health research; research into the effectiveness of traditional practices; resiliency and wellness research; and access to health services via health outcomes research.

Need # 1: Aboriginal involvement

The primary concern voiced by northern Aboriginal people deals with the principles of Aboriginal ownership, control, access and possession (OCAP). Aboriginal peoples are concerned that their knowledge is being appropriated, and they have no way to protect it. It is important that researchers realize that the knowledge they gain from research in Aboriginal communities belongs to the people and appropriate recognition of that should be given. Aboriginal people also seek to have more control over the research process. Researchers can no longer treat community members as subjects or informants; people want to be active participants in the research process. This requires a paradigm shift for many researchers to a participatory research process. Aboriginal people want to be involved in project design and implementation, as well as interpretation of research results, in order to ensure community relevance of research projects involving their communities. Aboriginal people also desire greater access to research results, data and interpretation so they may be able to use this information for their own purposes. Data possession is another principal, and legal issue that concerns the Aboriginal community. Aboriginal communities want possession of research data and results, because by holding the data they have power over the research processes.

Need # 2: Inclusion and respect for Aboriginal knowledge

Other concerns that were voiced at the CIHR Northern Town Hall meetings include the request that researchers respect traditional/elder knowledge. Elders are the "community's scientists" because they possess extensive knowledge of the environment, weather, medicines etc. It is imperative to the Aboriginal communities that researchers respect the knowledge of elders as much as knowledge obtained from publications. It is also important that research is inclusive of traditional Aboriginal values and beliefs. Traditional Aboriginal beliefs regarding health include the concepts of balance and harmony. Ill health cannot be treated solely through physical means. Treatments must include a social, emotional and spiritual component.

Need # 3: Training and capacity building

Capacity building among northerners to undertake scientific research was also a pervasive topic of discussion. Northerners have a better understanding of the social, economic, political and environmental contexts that affect the health of northern Aboriginal people. The ideal situation would be for Aboriginal researchers to have the capacity to undertake scientifically excellent research in their own communities. The concern, however, is not only that Aboriginal youth be encouraged to pursue academic careers in the sciences, but that they be trained in the North. The people feel that they are losing their youth to the South when they leave home to receive their formal post-secondary

education. Therefore, there is a need for northern university health research education programs situated in the territories.

Need # 4: Environmental health research

Environmental degradation is a major concern among Aboriginal northerners. The environment affects almost every facet of life in the North. Environmental toxins affect their country food sources, and now people are wary about eating country foods, as they do not know if they are safe and healthy to eat. People have changed their diet to include a number of processed foods; this dietary shift has had negative impacts on the health status of Aboriginal communities. Another environmental health concern deals with the changing migration patterns of animals important in their diets. It was mentioned that caribou have changed their migration routes, that gophers have disappeared etc. Retreating icebergs is also a concern because it interrupts their ability to hunt for sea mammals. The northern environment is of paramount importance to the people, because it is there that they find medicines for healing and better health. A changing northern environment not only affects the health of northerners, but also has ramifications that carry into southern environments.

Need # 5: Research into the effectiveness of traditional practices

Traditional medicine is an additional strategic area of health research that interests people in all three territories. The interest lies not in testing the validity of traditional medicines, but in the comparison of traditional Aboriginal medicines and healing practices to those of western medicine. The question is whether or not herbs are better than chemicals for the people who use them.

Need # 6: Resiliency and wellness research

Research into the people's resiliency and into wellness is also an important shift of focus that northern Aboriginal communities request that the research community undergo. People are tired of hearing that they are at the highest risks for various diseases. Such statistics are demoralizing and may in fact perpetuate ill health. Instead the community is interested in research that investigates how they overcome obstacles to wellness, and in projects that look at what makes and keeps the people healthy.

Need # 7: Access to health services via health outcomes research

A final and persistent topic that was raised in each of the meetings deals with the need for greater access to health services. While the issue of health services and health care delivery falls under the jurisdiction of the federal and territorial governments, it also has research ramifications. Research could focus on ways to make health services more accessible to people in remote areas. This may include investigations into the benefits and restrictions of implementing telehealth in community settings.

In addition to the shared research concerns raised at each of the IAPH and INMD Town Hall meetings, each community raised research concerns and priorities specific to their region.

Part A: Document Review and Background

The Land

With over nine million square kilometers (sq km), Canada is the second largest country on the globe, behind only Russia. It stretches through six time zones and has the largest coastline of any country as the Pacific, Arctic and Atlantic Oceans border it on three sides. Approximately 40% of Canada's landmass and freshwater is north of 60° of latitude north, and approximately 27% of Canada is north of the tree lineⁱ. This makes Canada one of eight circumpolar nations, including the USA, Russia, Finland, Sweden, Norway, Iceland, and Greenland (Denmark). [See Appendix 1 for circumpolar map]. However, while almost half of Canada's landmass is north of the southern limit of discontinuous permafrost the North is home to only one percent of Canada's population of 30 million.

The area north of 60° is divided into three territories including the Yukon, Northwest and Nunavut territories. Part of the northern area of the province of Quebec also extends north of 60°, however it will not be considered for the purposes of this paper, since it is a province and is therefore subject to different social, political and jurisdictional realities.

The People

Canada's North is home to numerous Aboriginal people who have deep seeded roots there. The ethnic breakdown, and percent of Aboriginal peoples inhabiting the northern territories differs from one territory to the other. Each Aboriginal group has a distinct heritage and affinity to the land.

Alaska to the West, the Northwest Territories to the East, British Columbia to the South and the Beaufort Sea/Arctic Ocean to the North border the Yukon Territory. The Territory is 536,327 sq km, and is home to approximately 31 000 people. According to the 2000 Yukon Fact Sheet only twenty-one percent of 31 000 people in the Territory identified themselves as Aboriginal, most of which are First Nations with a small percentage of Inuit and Metisⁱⁱ.

Yukon became a territory in 1898 and its capital city Whitehorse is also its most populated. The Klondike gold rush in the late 1800's led to a population boom with the influx of gold rushers. To this day Yukon's leading industry by far is mining; lead, zinc, silver, gold, and copper are the principal minerals.ⁱⁱⁱ The Yukon experiences extreme climates. Above the Arctic Circle (latitude 66° north), the Yukon is known as "the land of the midnight sun" because for three months in summer, sunlight is almost continuous. In winter, however, darkness sets in, and the light of day is not seen for a quarter of the year.^{iv}

The Northwest Territories lies between the Yukon and Nunavut territories. It is north of Alberta and Saskatchewan and it borders on the Beaufort Sea. With approximately 42 000 people, it is slightly more populated than the Yukon. According to the Minister of Public Works and Government Services the Dene, Inuvialuit and Metis people make up 48% of the population in the Northwest Territories, while non-Aboriginal people make up the remaining 52%. There are eleven official languages in the Northwest Territories. Yellowknife, the Northwest Territories capital city is home to over 40% of the population and is a day's drive from the closest major city. The main industries in the Northwest Territories are mining, oil and gas, however traditional Aboriginal subsistence such as hunting; trapping and fishing have also made a contribution to its economy.^v The Northwest Territories has two climate zones, the arctic and sub-arctic. Like the Yukon it also experiences long days in the summer with an average of 18-24 hours of sunlight.

Nunavut, which means “Our Land” in Inuktitut, was created on April 1, 1999, when the Northwest Territories was divided into two territories. Nunavut differs from the other two territories, as 85% of its population is Inuit. Nunavut encompasses one fifth of Canada’s landmass, yet its population is only 27 700. Nunavut’s creation enabled the Inuit to gain greater control of their affairs. Government employment and mining are important to the economy. Nunavut is a vast territory that expands over four time zones; as a result it has a varied climate. Summers are short and some of the northern areas experience 24-hour sunlight during parts of the summer, and some areas in the Arctic Circle may experience less than 5 hours of sunlight a day during the long winters.

The Research

Given that almost half of Canada’s land mass is north of the southern limit of discontinuous permafrost, it is a natural assumption that Canada should be a leading expert on northern research. However a recent survey undertaken by the National Science and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC) indicates that Canada has fallen behind other nations in the area of northern research. In their 2000 report *From Crisis to Opportunity: Rebuilding Canada’s Role in Northern Research* they illustrate numerous shortcomings in Canada’s northern research strategy. The following paragraphs offer a brief summary of their findings.

Due to the relative inaccessibility of the North, research costs are high. Thus researchers at Canadian universities have been heavily reliant upon partnerships with the Federal Government in order to subsidize the costs of research. With government cutbacks and downsizing these partnerships have substantially dwindled, and as a result researchers are unable to pursue their northern research interests. The decrease in resources available to researchers interested in the North has further affected the research community, as there has been a decrease in recruitment of faculty and graduate students interested in pursuing northern research. In fact faculty are less inclined to encourage students to pursue research in the North because funds are fleeting. A decrease in research activity in the North has led to a decreased research capacity in Canada. As an unfortunate consequence Canada is unable to contribute much to the international pool of knowledge in the North. Canada’s northern research activity is further affected due to Canada’s lack of a formal Northern Science and Technology Policy. In comparison to other circumpolar nations Canada’s northern research activity, and funding in that area is minor.

The United States Arctic Research and Policy Act (amended in 1991) “positions the United States as an Arctic nation with strong strategic, economic, social, scientific and international interests.” The United States invests over US\$300 million annually for funding of Arctic research whereas Canada’s granting councils spend only \$2 million annually on northern research. Other nations with interests in the North, such as Finland, Sweden, Norway, Denmark, Greenland and Russia are also exceeding Canada in funding and northern research policies. Many nations have prestigious Arctic research institutes that have no comparable counterpart in Canada. Many of these nations also support research in the Antarctic, however Canada does not. Considering the vastness of Canada’s North in comparison to other circumpolar nations, it is really unacceptable that funding for research in the North is so poor.

Canada’s participation in international programs and northern research activities has also decreased. Canadian researchers may be approached to participate on scientific projects that have been conceptualized and designed elsewhere. Canada has lost the capacity to become international leaders in this area; instead Canada’s position is relegated to that of a follower of international trends in northern research.

The importance of a strong northern research component to Canada's research agenda cannot be understated. Canada has in its jurisdiction much of the world's Arctic marine and terrestrial environment, thus it is important for Canada to re-build its northern research capacity, in order to make a substantial contribution to the existing pool of knowledge. Canada must re-assert itself as a leader in northern research in order to assert its sovereignty in the North, and in order to honor its national and international research obligations.

The NSERC and SSHRC Taskforce on Northern Research put forth five recommendations that are aimed at stimulating high-quality northern research in Canada. First is the creation of a Northern Research Chair program. Secondly, the taskforce recommends graduate scholarships and post-doctoral fellowships aimed at building capacity among students to undertake quality research. Thirdly the taskforce recommends the support of innovative, multi-disciplinary northern research projects. Fourth is the development of northern Community-University Research Alliances (CURA-North), which are aimed at building strong alliances between community groups and university researchers. The Taskforce's final recommendation is that we must increase equipment, infrastructure and logistical support.

The Ethics

In addition to the concerns raised by NSERC and SSHRC regarding Canada's need to develop a strong research agenda and a cadre of excellent researchers who are trained in the area of northern research, Aboriginal people living in the North have voiced concern regarding research conducted on their lands and involving Aboriginal people. As an unfortunate consequence of the lack of research capacity among northerners, research in the North tends to be initiated by southerners, who have their own agenda. There is a feeling among northern Aboriginal peoples of resentment towards southern researchers who pursue their own agendas, and do not treat the Aboriginal people as active participants in the research process but as subjects. It has been repeatedly indicated that researchers conduct their research and then fail to disseminate the findings back to the community in a meaningful manner. As a result northerners have begun to develop strict research protocols that would-be researchers must adhere to, in order to get a license to engage in research in the territory.

While it is important to promote research in the North, efforts must proceed with caution. Ethics in research involving Aboriginal people is a critical issue, which must be addressed, especially since Aboriginal people make up a large proportion of the population north of 60, and they have historical and contemporary interest in much of Canada's North. "Research as currently perceived by Aboriginal northerners, is a phenomenon of the last 25 years or so. It appeared in the context of colonial intrusion and of sharp contrast between employment, income, and living conditions of Aboriginal northerners on the one hand, and southern visitors on the other."^{vi} It is therefore understandable that Aboriginal northerners are wary of research.

In order to lessen the negative image that research has acquired among the Aboriginal community, research ethics and protocols need to be developed and adhered to so that the community's interests are addressed. The Canadian Institutes of Health Research (formerly the Medical Research Council of Canada) along with SSHRC and NSERC vaguely touch upon the issue of ethics in research involving Aboriginal peoples, in their 1998 Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans. Section six in the document titled *Research Involving Aboriginal Peoples* outlines a number of suggested good practices for ethical conduct of research involving Aboriginal community groups. While this document is a starting point to get researchers to think of the interests of the community, there is an urgent need for the document to be reviewed and further developed. The language in the document is too far removed from the people and perpetuates traditional power

relations. Aboriginal people should be partners in research that involves them, not simply informants or subjects of study. This partnership should be reflected in the research procedure and ethical guidelines.

Participatory research is the preferred research paradigm for Aboriginal peoples. Traditional research limits the role of Aboriginal peoples to that of an informant rather than an active participant. Full participatory research gives Aboriginal people the opportunity to design and conduct the research project themselves. The community is then responsible for deciding how funds will be allocated and responsibilities divided. The key difference between traditional research and participatory research is the level of ownership and access to the research results and findings. Ownership, control, access and possession (OCAP) are pervasive principles that recur in Aboriginal dialogue on research. Aboriginal people have the right to protect their intellectual property. It is important that researchers understand that the knowledge they gain from conducting research with Aboriginal people belongs to the people. It has been said that the “Inuit have authored many theses” and yet they are not given the credit for their contribution and knowledge. Aboriginal people are also starting to assert their right to have greater control over the conduct of research and the interpretation of research results. Access to research findings is also an important issue that needs to be negotiated with researchers. Aboriginal people would like more access to the data so they can use it for their own purposes. Possession of research findings and data is an additional matter that concerns Aboriginal people. Data possession is a legal issue that affects the power relationships between the researchers and the community.

Aboriginal people have voiced several concerns regarding the conduct of research in their communities and on their land. A list of comprehensive research ethics concerns frequently voiced by the Aboriginal community include:

- 1) Informed consent should be obtained by the community and any individuals involved in the research
- 2) Researchers need to explain the purpose of the research; sponsor of the research; the person in charge; potential benefits and problems associated with the research for both people and the environment; research methodology; participation of/or contact with residents of the community
- 3) Anonymity and confidentiality must be guaranteed except where it is legally excluded or denied by individuals
- 4) Ongoing communication of research objectives, methods, findings and interpretations is required
- 5) Research should be suspended if at any time during the research the community deems it to be unacceptable
- 6) Efforts should include local and traditional knowledge in all stages of research including problem identification
- 7) Research design should include capacity building among the Aboriginal community
- 8) Research must avoid social disruption
- 9) Research must respect the privacy, dignity, cultures, traditions and rights of Aboriginal people
- 10) Written information should be available in the appropriate languages
- 11) The peer review process must be communicated to the communities and their advice/participation sought in that process
- 12) Aboriginal people should have access to research data, not just the summary reports. The extent of data accessibility should be agreed upon as part of any approval process

(From: Negotiating Research Relationships in the North: A background paper for a workshop on Guidelines for responsible research- Yellowknife 22-3 September 1993 Prepared by Inuit Tapirisat of Canada [ITC].)

These concerns stem from historical abuses that researchers have perpetrated against Aboriginal communities. If research is to continue to involve Aboriginal people it is imperative that the concerns of the Aboriginal communities are addressed. Aboriginal people are not obliged to participate in research that takes place in their communities, so if researchers want the privilege to engage in research with Aboriginal people they must establish meaningful partnerships and relationships with communities and engage in high quality ethical research. At the same time research has the potential to be very beneficial to Aboriginal people, so it is important that issues of ethics are addressed to the satisfaction of all parties engaged in the research process.

In the North there are already some strict guidelines established by the Aboriginal people, in concert with the research agencies that are based there. All researchers must obtain research permits in order to conduct any research in the North. Each territory has a permit application and has stipulated the rules for engaging in research within the territory. In order to obtain a permit in the Yukon researchers should contact the Northern Research Institute or the Heritage Branch of the Government of Yukon; in the Northwest Territories research applications are available through the Aurora Research Institute; and in Nunavut through the Nunavut Research Institute.

Part B: CIHR Northern Town Hall Meetings

The Role of CIHR

CIHR can play an important role in the stimulation of top quality ethical northern research. CIHR is in a position to engage in tripartite discussions with NSERC and SSHRC regarding the further development of section six in the tri-council document on Ethical Conduct for Research Involving Humans. As well, each of the thirteen Institutes that comprise CIHR can make northern research a strategic priority. In particular the IAPH can emerge as a natural leader in guiding the process.

IAPH and INMD Northern Initiatives

The IAPH is one of the thirteen inaugural institutes of the CIHR. The goal of the IAPH is to lead a national advanced research agenda in the area of Aboriginal health, and to promote innovative research in this field that improves the health of Aboriginal peoples living in Canada. The goal of the IAPH is to balance scientific excellence and community relevance in its strategic priorities.

The IAPH was created to address the unique health research needs of the Aboriginal community. There are three groups that are recognized in the Canadian constitution as Aboriginal, they are the First Nations, Metis and Inuit. Therefore the IAPH strives to be inclusive of all Aboriginal peoples in Canada, and at the same time to participate in international research activities that are relevant to the health of the international indigenous community, including those in the circumpolar nations.

The mandate of the INMD is to support research to enhance health in relation to diet, digestion, excretion, and metabolism; and to address causes, prevention, screening, diagnosis, treatment, support systems, and palliation for a wide range of conditions and problems associated with hormones, digestive system, kidney and liver function. The vision of the INMD is to be recognized as an institute that serves investigators, practitioners, policy makers, and the Canadian public through strategies that build capacity and foster excellence in health research. Through strategies that increase inter- and multi-disciplinary research and that integrate basic and applied approaches, it is the goal of the INMD to improve strategies for health promotion, disease prevention and care.

The INMD was especially interested in participating in the Northern Town Hall meetings because many health issues that affect northerners fall under the INMD mandate. Obesity, diabetes, and access to healthy foods are some of the major concerns for a significant proportion of Aboriginal communities.

The northern Aboriginal community, especially the Inuit, has expressed concern regarding the lack of their involvement in research initiatives. In order to get an understanding of the research concerns of the northern Aboriginal peoples, the IAPH and the INMD engaged the Aboriginal and research communities in the territories in preliminary town hall meetings. These meetings were held in the capital of each territory, in the last week of September 2001.

CIHR Northern Town Hall Meetings

The IAPH organized three Northern Town Hall meetings that took place in Whitehorse, Yukon; Yellowknife, Northwest Territories; and Iqaluit, Nunavut on September 25, 27, and 29, 2001 respectively. [See Appendix 2 for list of meeting participants] The IAPH Scientific Director, Dr. Jeff Reading (Ph.D.) and INMD Scientific Director, Dr. Diane Finegood (Ph.D.) were accompanied at the meetings by the IAPH Institute Liaison, Ms. Ginette Thomas; and CIHR Director of Partnerships, Dr. David Phipps (Ph.D.).

The aim of the meetings was two-fold. The first goal was to hold an information sharing session in order to clarify the roles of CIHR, IAPH and INMD in health research. The second aim was to hear the various stakeholder concerns with regards to northern research.

The meeting in Whitehorse was hosted by the Kwanlin Dun First Nations, and was held in the Potlatch House. There were twenty-one people in attendance representing community groups, research agencies and the federal government.

The Denendeh National Office was contracted to host the Yellowknife meeting that was held in the Smokehouse Restaurant. Although this meeting was smaller than the one held in the Yukon (nine people) there was representation of the Aboriginal and research communities and the government.

The last meeting was held at the Frobisher Inn located in Iqaluit and was hosted by Polynya Adventures & Coordination Ltd. Although the meeting was held on a Saturday there were still nineteen people in attendance, again representative of the diversity of northern stakeholders.

There were a number of common themes that were voiced in each meeting, as well as some unique to each area.

Northern Research Issues

Some major issues that were raised at each meeting include: ethical research; community driven research; need for dissemination of research results and knowledge translation; respect for traditional and elder knowledge; the need to build research capacity among northerners; research on the effectiveness of traditional practices; research that includes Aboriginal concepts of health; research into wellness and resiliency; environmental health research; and access to health services via health outcomes research.

There was concern in each of the regions regarding the ethical protocols and guidelines that are in place in order to protect the best interests of the community. The community is not only concerned

with issues of confidentiality and informed consent but also they are concerned with protecting their knowledge. Currently there is no legal way to protect traditional/community knowledge from appropriation. Aboriginal peoples, not only in the North but also throughout the world are concerned with the protection of their intellectual property rights. There is apprehension that their knowledge will be taken away from them and they will get nothing in return by way of benefits to their health. For example pharmaceutical companies may harvest Aboriginal knowledge on the healing powers of certain herbs and roots, and then take that knowledge, re-package it and sell it back to the people. There is a northern emphasis on the principles of ownership, control, access and possession (OCAP). In order to protect their knowledge Aboriginal people assert that the knowledge that researchers gain from the research conducted with Aboriginal peoples belongs to the community. As such Aboriginal people want more control over the uses of the knowledge and the interpretation of research findings. If the research is going to be transformative then the community also needs greater access to research results for their own purposes. Aboriginal communities want to possess the research data and results, because doing so positively affects their power position in research relationships.

As already stated each of the territories has developed research permits that require researchers to indicate the benefit of their research to the community. Researchers must meet not only the standards outlined in the tri-council document: *On the Conduct of Ethical Research Involving Humans*, but they must also meet the ethical protocols specific to each territory. These ethical protocols or rules of engagement are not intended to discourage research. On the contrary they are in place to ensure that the research is conducted in an ethical fashion with the interests of the community in mind. Aboriginal people need accountability for the research that is conducted in their communities and on their lands.

Another important theme identified at each of the meetings is the need for the community to drive the research agenda. Historically, southerners who have their own research agenda, which may or may not coincide with the priorities of the Aboriginal community, have conducted northern research. Research involving the community must come from the community. Unless communities are engaged on their own terms they will quickly lose interest in the research project and process. Many people already feel that they have been surveyed to death and are reluctant to participate in projects that are not directly relevant to the health of the community. It is, therefore important that researchers undertake a consultation with the community in order to ascertain the relevance of the proposed research, and to investigate more pressing issues if the community so desires. Research methods must shift in order to be more inclusive of Aboriginal people. Participatory research is the key; Aboriginal people should be actively engaged in the research project including project design and implementation, as well as analysis, interpretation and dissemination of results.

Another concern that northern Aboriginal people have with respect to the conduct of research in their community is lack of dissemination of results. In order for the research to be transformative and effect positive changes in people's health, the community needs to be provided the research results. Dissemination needs to go beyond traditional journal writing and scientific seminars. Northern Aboriginal peoples want research findings to be translated into Aboriginal languages and expressed in lay terms. They also want research results to be distributed through a number of media including: TV, radio, and announcements in papers. There was also an expressed interest in knowledge sharing throughout the territories. Since Aboriginal northerners share similar environments they would like information gained through research projects in other territories to be made available for their own use. This could be done through a database of northern research. Health professionals also expressed a desire to know what research was being conducted elsewhere in the North. Northern Aboriginal peoples want to keep an ongoing dialogue on health research. Another concern closely related to dissemination and knowledge transfer is knowledge translation. People expressed that they were tired of participating in research that does not lead to meaningful

programs that positively affects their health. Information is needed on healthy practices and the nutritional value of country foods. People do not want any more statistics on suicide, rather they want effective suicide prevention programs.

There is a need for researchers engaging in research in the North to respect traditional Aboriginal knowledge and the roles that elders play in Aboriginal knowledge systems. Elders in Aboriginal communities are respected and consulted for their wisdom and intelligence. Elders have attained knowledge through life experience. They are the “community’s scientists” because they possess extensive knowledge of the environment, weather, country foods and medicines. It is important to the Aboriginal communities that researchers respect the knowledge of elders as much as knowledge obtained from publications. It is also important that research is inclusive of traditional Aboriginal values and beliefs. For example approaches to health research should integrate the spiritual, emotional and social aspects of health in addition to the physical. This model is named the Medicine Wheel concept in First Nation communities. The underlying concept is that ill health results from an imbalance in one or more of the above listed domains. It is, therefore important that research addresses more than just the physical. Respect for Aboriginal knowledge also means that it should be recognized in any report that uses that knowledge so that this knowledge is not appropriated.

The Aboriginal people feel it is important that researchers engage in qualitative research as well as quantitative research. Qualitative research enables the researcher to capture and verify the information given by elders leading to a better understanding of information based on quantitative research.

An urgent priority for northerners is building capacity among northerners to undertake scientific research in the North. There is no major university in the North and as a result southerners are coming to the North in order to conduct research. It is felt that many of the southern researchers have little research experience, many are recent graduates, and there is concern that they are not properly culturally oriented. Hence, the need for research permits. Northerners want research to be initiated and conducted by northerners who already have a grasp of the environmental, social, historic and political contexts that shape northern health issues.

Aboriginal northerners are very interested in the establishment of northern institutions that can train Aboriginal youth in the North. They are concerned that they are losing their children to the South. They feel that they need their children at home but the youth need to go south in order to obtain an education. Although some students have remained in the North and accessed distance education programs, there are no researchers to help supervise students undertaking research projects. The northern communities stress the need for Aboriginal youth to have strong mentors and role models, who will encourage them to pursue their education in the sciences.

A specific research priority identified in each of the territories is the study of the effectiveness and benefits of traditional medicine. Some suggested that a potential research question could deal with the comparison of traditional medicines and western medicine in the treatment of specific illnesses. People are interested in determining if natural medicines can be just as beneficial as chemicals in treating illness. It was also suggested that the Aboriginal health system be developed.

It is also felt that research needs to shift its focus from sickness to wellness. Inuit, for example, feel that it is detrimental to the health of individuals to continually tell them that they are at the highest risk for disease. There is a general consensus that health research in the North should consider the people’s resiliency. Northern Aboriginal peoples have experienced a lot of adversity and they always “bounce back”. It is that spirit of overcoming hardships that they want reflected in research in their communities. People are interested in research on Aboriginal concepts of wellness, and wellness indicators. People said that they want health research to focus on the prevention of illnesses that are

affecting southern Aboriginal people in epidemic proportions such as diabetes. They want research on how to prevent illness before a crisis develops in the North.

The environmental impacts on health were raised as a critical issue that needs to be addressed. The people are concerned with the detrimental effects that environmental pollutants, contaminants and toxins have on their health. This concern is not only immediate but is also for the “seven generations” of people to follow. People are concerned with global warming, and the depletion of traditional food supplies. The changing environment has led to changes in migration patterns, and in the disappearance of some country foods. The people do not separate themselves from the environment, they are part of it, and what affects it affects them. It is in the environment that they find the herbs, medicines and foods that make them healthy.

People are also concerned with the changed social climates that their children are being raised in. Northern culture has undergone and is still undergoing very rapid changes. There is concern regarding the health impacts of moving away from country foods to a western diet that includes processed food. Concern was also expressed about the lack of access to healthy food choices and the decline in breastfeeding. As well the new, more sedentary lifestyle of Aboriginal northerners has had a considerable impact on the health status of the people. The health impacts of drastic social change is further impacted by the communication gaps that resulted between the elders, and the youth who have been raised in this period of social change.

The final northern health issue raised at the Northern Town Hall meetings was limited access to health services. Many Aboriginal people in the north live in small communities that are far from the capital cities. There are times in the year when communities are isolated from one another for weeks. The remoteness of communities is compounded by the expensive costs to travel between northern cities, to the capital, or to a major city in the south. Therefore people may have to wait for months in order to see a medical specialist. In emergencies people may be sent to a southern hospital where they are isolated from their family and friends. The foreignness of southern culture is intimidating to some Aboriginal northerners especially elders. There are few, if any facilities in the north that are capable of treating elders with diseases such as Alzheimer’s, so many get sent to the South where they are far from everything they know. Telehealth services is a suggested way to decrease the waiting list for people waiting to see a medical specialist, but there needs to be a way for Aboriginal women to safely give birth in their communities and for elders to be taken care of in a familiar environment. Health outcomes research has the potential to make transformative changes in this important area.

Specific Research Concerns

Whitehorse

Specific research concerns that were voiced in the Yukon are the desire for the community to become responsive to research trends and not to be left behind. There is encouragement for the development of research programs at the local level. They do not feel that research necessarily needs to have a national relevance, but perhaps a northern relevance. People also agreed that researchers coming to the North need to assimilate into the Aboriginal research culture, not the other way around.

It was also voiced that the communities want to link up to territorial money in order to fund research programs in the Territory.

Yellowknife

In Yellowknife the issue of ethics was not considered of paramount importance, since they have a licensing process in place that insures that researchers conduct ethical research or they are unable to engage in research in the Northwest Territories again.

Partnerships were viewed as an important part of the research process, in order to maximize funds and decrease response fatigue. Suggested research links included the Aboriginal Health Infoway and Aboriginal Peoples Survey (APS); NSERC and SSHRC; government agencies; and community organizations.

A specific research priority identified in Yellowknife deals with the effects that residential schools have had on northern Aboriginal peoples.

Iqaluit

There were numerous specific research areas that were identified in Iqaluit as being important areas for Inuit health. These include:

- Hearing impairment of young children in the North
- High rates of anemia in Inuit children
- Decline in breast-feeding among the Inuit and its effect on infant health; is baby formula good?
- Research into suicide prevention; not just data on suicide
- Mental health
- Cancers in women
- Socio-economic health indicators
- The Impact of residential schools on Inuit health

Conclusion and Next Steps

Canada is the second largest country in the world geographically and almost half of its land mass falls in the area north of the southern limit of discontinuous permafrost. Although Canada's North is so vast, it is sparsely populated with less than one percent of Canada's population. Yet much of the world's arctic marine and terrestrial environment falls into Canada's jurisdiction.

Canada has three territories that fall north of 60 degrees latitude the Yukon Territory, the Northwest Territories, and Nunavut. Aboriginal people make up a substantial proportion of the northern Canadian population. Twenty-one percent of the population in the Yukon, 48% in the Northwest Territories and 85% in Nunavut, identify themselves as having First Nation, Inuit or Metis ancestry.

A recent survey under-taken by NSERC and SSHRC indicates that Canada has fallen behind other nations in the area of northern research. In their 2000 report *From Crisis to Opportunity: Rebuilding Canada's Role in Northern Research* they illustrate numerous shortcomings in Canada's northern research strategy. Canada's spending on northern research has drastically declined and is minimal in comparison to the amount of research money spent in most other circumpolar nations. Another concern is the inability and reluctance of university faculty to recruit graduate students into northern research programs, because of the lack of funds available to researchers to undertake northern research projects. NSERC and SSHRC identify a number of strategies that, if implemented, will stimulate northern research in Canada. Suggestions include the creation of a Northern Research Chair program; graduate scholarships and post-doctoral fellowships for students to pursue northern

research; the support of innovative, multi-disciplinary northern research projects; the development of northern Community-University Research Alliances (CURA-North); equipment, infrastructure and logistical support.

In addition to the northern research concerns illustrated by NSERC and SSHRC, northern Aboriginal peoples have a number of concerns that must be addressed before research can be undertaken in their communities and on their lands. Top among the list of research concerns is the issue of research ethics. Northerners have developed their own protocols that require researchers to acquire a research license before they can engage in research in the territories, because too often researchers have not engaged in good practices and as a result Aboriginal peoples are reluctant to participate in research

The CIHR IAPH and INMD held a series of Northern Town Hall meetings in the capital of each territory in order to share with northern stakeholders the mandates of CIHR and of their respective institutes, and to listen to the health research concerns and needs identified by the northern Aboriginal and research communities. Seven key research needs were voiced at each of the meetings and therefore warrant further discussion and serious consideration by the research community. These needs include Aboriginal involvement in the research process; inclusion and respect of Aboriginal knowledge; training and capacity building; environmental health research; research into the effectiveness of traditional practices; resiliency and wellness research; and access to health services via health outcomes research.

In addition to these concerns, each region identified research priorities and needs that were unique. That is each territory had additional needs and concerns that were not focused upon in the other meetings. Therefore researchers must not only focus on general northern issues, but must look at region specific priorities as well.

Next Steps

CIHR has the potential to bring northern research back to the forefront of Canadian health research. The CIHR should engage researchers, the northern communities, and other stakeholders in a broad based health research consultation. Each of the thirteen institutes that make up the virtual CIHR network can use this report in order to help develop their strategic plans and strategic health research priorities. The northern Aboriginals community has expressed its interest in being more actively involved in research, and in having their research concerns added to the Canadian health research agenda. The research community needs to start thinking seriously about integrating a northern research component into the research agenda. The CIHR institutes should include strategic initiatives that deal with northern, Aboriginal, rural and remote issues. This can be done through institute specific initiatives, as well as through cross-institute collaborations.

Each of the CIHR institutes should not only include northern health research as a strategic priority, but should ensure that any northern health research that involves Aboriginal peoples and is funded by CIHR meets the high ethical standards that the Aboriginal communities demand. Only through the conduct of ethical research and the use of good practices, may the health research dialogue between the Aboriginal and research communities be maintained and sustained.

NSERC and SSHRC have indicated a number of incentives that could get the research community interested in northern research again. The IAPH and INMD have outlined a number of additional suggestions that were voiced at the CIHR Northern Town Hall meetings, which could stimulate the interest and sustained involvement of the northern Aboriginal peoples and communities in health research. What it comes down to is relationships. It is important that the research agenda is

developed in cooperation with the community, not nationally, to ensure that it is responsive to community needs. It is also important to make sure that relationships are maintained through the process, and that communities are always in the loop.

Appendix 1: Circumpolar map produced by the American Central Intelligence Services



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Appendix 2: Conference Participants

September 25, 2001- Whitehorse, Yukon

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Conference Participants

September 27, 2001- Yellowknife, Northwest Territories

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Conference Participants

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END NOTES

ⁱ Canada's Geography, Catalogue No. PF3-2/31-2001, ISBN 0-662-65624-5, © Minister of Public Works and Government Services

ⁱⁱ Facts on Canada: The Yukon, Catalogue No. PF3-2/13-2001, ISBN 0-662-65606-7, © Minister of Public Works and Government Services, 2001

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