Research with Arctic peoples: Unique research opportunities in heart, lung, blood and sleep disorders. Working group summary and recommendations

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RESEARCH WITH ARCTIC PEOPLES: UNIQUE RESEARCH OPPORTUNITIES IN HEART, LUNG, BLOOD AND SLEEP DISORDERS

Working group summary and recommendations

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ABSTRACT

Arctic peoples are spread over eight countries and comprise 3.74 million residents, of whom 9% are indigenous. The Arctic countries include Canada, Finland, Greenland (Denmark), Iceland, Norway, Russia, Sweden and the United States. Although Arctic peoples are very diverse, there are a variety of environmental and health issues that are unique to the Arctic regions, and research exploring these issues offers significant opportunities, as well as challenges. On July 28-29, 2004, the National Heart, Lung, and Blood Institute and the Canadian Institutes of Health Research co-sponsored a working group entitled “Research with Arctic Peoples: Unique Research Opportunities in Heart, Lung, Blood and Sleep Disorders”. The meeting was international in scope with investigators from Greenland, Iceland and Russia, as well as Canada and the United States. Multiple health agencies from Canada and the United States sent representatives. Also attending were representatives from the International Union for Circumpolar Health (IUCH) and the National Indian Health Board. The working group developed a set of ten recommendations related to research opportunities in heart, lung, blood and sleep disorders; obstacles and solutions to research implementation; and ways to facilitate international comparisons. These recommendations are expected to serve as an agenda for future research.

(Int J Circumpolar Health 2006; 65(1):79-90.)

Keywords: Arctic Peoples, Indigenous, research, heart disease, international collaboration
Working group objectives
Under the co-sponsorship of the National Heart, Lung, and Blood Institute (NHLBI) and the Canadian Institutes for Health Research (CIHR), the Institute for Aboriginal Peoples’ Health (IAPH), invited speakers, NHLBI staff, and observers (see Appendix I for list of participants) participated in a working group to address three objectives related to research with Arctic Peoples and to develop a list of recommendations for future research. The three working group objectives were:

1) Identify and prioritize scientific opportunities for research on heart, lung, blood and sleep disorders that may be uniquely addressed with Arctic peoples,

2) Identify obstacles to implementing health and intervention research studies and methods to address them,

3) Facilitate international comparisons.

Working group presentations
Dr. Barbara Alving, Acting Director, NHLBI, provided opening remarks and the charge to the working group. She stressed the importance of current efforts between the United States and Canada to build partnerships and collaborations, and suggested that their common interest in Natives of the Arctic may offer an additional opportunity. She acknowledged the success of current NHLBI-funded projects in the Arctic, and noted that more could be done. She wished the participants success in assisting the NHLBI and the CIHR in identifying and prioritizing those opportunities. Finally, she thanked the CIHR-IAPH for co-sponsoring the working group, and expressed her desire that it would lead to further collaborative efforts with the NHLBI.

Session on research priorities
The first speaker, Ms H. Sally Smith, is a Yup’ik Eskimo, co-chair of the working group, and current Chair of the National Indian Health Board. She provided a broad overview of the health of Alaska Natives and urged the participants to recognize that the interests of the NHLBI and CIHR may, or may not, overlap with those of the Native community. She noted that the total population of Alaska is 627,000 people; half live in Anchorage. Natives represent 19% of the population and are a diverse group. She contrasted their health priorities in 1950 with those of today, noting the decrease in infectious diseases, continuing high rates of injuries and accidents, and the increase in chronic diseases, including cardiovascular disease (CVD). She noted that CVD rates have remained stable in Alaska, while declining for two decades in the lower 48 states. Citing results from the Behavioral Risk Factor Survey, she explained that half of all deaths in Alaska Natives can be related to lifestyle choices. Community concerns focused more on alcohol and substance abuse, declining traditional lifestyle, and the effects of contaminants. She stressed that current needs include a system to monitor the health behaviours of tribes, a surveillance system to monitor chronic disease, including disease registries, and intervention studies to prevent and treat diseases with rising incidence.

Barriers to research in Alaska are numerous. Historically, research is seen as not offering much benefit and potentially harming the community. Distrust increased because of investigators taking and never giving back to the community. Often, research results were shared with the scientific community
before being shared with the Native community. Other barriers include limited formal education, leading to a lack of understanding of research, short supply of Native scientists, lack of educational programs to train students interested in biomedical research, and a dearth of mentors to train and inspire students. Potential solutions include the creation of mentorships, the development of advanced degree programs in Alaska educational institutions, simplification of the grant application and reporting processes, emphasis on community partnerships for research projects, and more rapid responses for funding decisions. Distance learning programs may offer a solution to the formidable barrier of geography. Programs to train clinicians have begun to make inroads. However, few are recruited to research, because clinical needs are so great. Natives have made great progress in managing their health care. Now they want to manage their health research.

Dr. Jeff Reading, Director of the CIHR – IAPH, voiced strong support for developing more collaborations and partnerships. He noted that several have been developed in the past three years including one with HHS Secretary Thompson and another with Australia and New Zealand. The CIHR-IAPH remained open to additional collaborations related to Arctic Health. Dr. Redding then offered a Native perspective on research from Canada. He presented the conclusions of a report entitled “Dialogue on Northern Research”, summarizing a meeting held in early 2004 that included Aboriginal representatives, researchers and government agency representatives. Dr. Reading noted that it had been well-received by the Native communities, that enjoyed being heard, and by the researchers, who felt less isolated following the meeting. Recommendations included increasing capacity within the communities regarding research, giving greater weight to traditional knowledge in reviewing applications, establishing community-based research, and developing an integrated northern policy. Specific needs include developing more infrastructure and people for research, offering more educational alternatives within northern communities, establishing a community relevance review as a necessary step in the research approval process, giving equal, or greater, weight to experience and knowledge of Native people than to formal education, and consulting with the communities earlier in the process.

Dr. Peter Bjerregaard presented the results of research with the Inuit in Greenland, which represent 90% of the population of Greenland. The government of Greenland is run by the Inuit; decisions on research are made by the Greenland government and the researcher. Conditions for research are similar to Northern Alaska and Northern Canada. There are no roads between villages. All transportation is by air, or by boat; towns and villages are small. Health priorities are related to lifestyle and include suicide, alcohol, tobacco and the metabolic syndrome. Research priorities include societal development and health, social inequality, child health, interventional research, and human biology and disease.

Three surveys have been completed on Greenland Inuit, in 1993-94, in 1997-99, and in 1999-2001. Surveys focused on diet and CVD risk, westernization, blood pressure, obesity and physical activity. Mortality statistics indicate that the notion that CVD is low is a myth. Available data indicated CVD was
more frequent in Greenland than in Denmark; ischemic heart disease (IHD) is similar, but the incidence of stroke is much higher. Diabetes rates are 25% higher than in Denmark and 70% is undiagnosed. Lipid levels rise with obesity but, for any given waist size, lipids are lower in Greenland than in Denmark. He suggested that obesity may be different among the Inuit, conferring lower risk than for Caucasians. High density lipoprotein (HDL) levels are higher in Greenland than in Denmark. The metabolic syndrome prevalence is higher in men, but lower in women with greater westernization. Carotid ultrasound data indicate that atherosclerotic plaques are equally prevalent in Greenland and Denmark. The main obstacle to research with the Inuit in Greenland is a lack of infrastructure. For example, many of the Inuit speak only Greenlandic, so interviews must be done in that language. In addition, research costs are high, because of the low density of the population and high travel expenses.

Dr. Kue Young presented results from research with Inuit in Canada. Early data indicated IHD of the Inuit was 50% of the rate for whites, cholesterol levels and triglycerides were low, diabetes prevalence was low, and dietary intake of polyunsaturated fatty acids was high. As in Greenland, obesity did not seem to confer the same degree of risk as for non-Natives. The proportion of the Native population currently smoking cigarettes was very high compared to non-Natives. Genetic risk factors varied, but in both directions, e.g. ACE high-risk alleles were less frequent, but ApoE high-risk alleles were more frequent.

Dr. Larisa Tereshchenko provided results of analyses on the Native population in the Tyumen Region of Siberia, Russia. The Native population comprises 38,000 Natives, including nomadic and non-nomadic Yamal Nenets (72%), the Khants (23%), and Selkups (5%). Their diet was high in raw fish from the sea and rivers, and includes meat and vegetables, but not much starch. Mortality is higher than non-Native Russians in the area, but about the same as the country as a whole. Diseases with high incidence, or prevalence, include tuberculosis, rheumatic fever and congenital heart disease. The prevalence of alcoholism is very high among non-nomadic Yamal Nenets, but not among the nomadic Yamal Nenets. The prevalence of hypertension is lower than the non-Native population. Coronary artery disease incidence is low, with few myocardial infarctions. The prevalence of obesity is low compared to non-Natives.

Dr. Barbara Howard, co-chair of the working group, presented results from the GOCADAN Study. The study included examinations of 1,214 Eskimo men and women aged 18+ from the Norton Sound Region of Alaska. Data indicate a high prevalence of atherosclerotic plaques. The prevalences of diabetes, insulin resistance and metabolic syndrome are low, particularly compared to American Indians. In addition, the study identified unusual gender differences with Eskimo men having much lower rates of diabetes and metabolic syndrome. Hypertension rates were low. Total cholesterol levels are about the same as in the U.S. population but with lower LDL levels and significantly higher HDL levels than the U.S. population. The prevalence of cigarette smoking is very high among Eskimos. Inflammatory markers (highly sensitive C-reactive protein and fibrinogen) are high and the infectious disease burden is high.

Dr. Elizabeth Nobmann presented data on the diet of Alaska Natives, primarily from the GOCADAN study. One major risk factor that
differs between traditional Alaska Natives and the general U.S. population is diet. Fish consumption among Alaska Natives is six times the consumption of the general U.S. adult population. This difference in fish and sea mammal consumption accounts for higher levels among Natives in monounsaturated fatty acid consumption and omega-3 fatty acid consumption. Dietary sources differ by generation, with younger generations relying more on market foods. The younger generation has a diet higher in carbohydrates, but lower in fat, polyunsaturated fatty acids (PUFA) and omega-3 fatty acid intakes. Primary sources of omega-3 fatty acids among Native foods are seal oil, salmon, other fish and seal blubber. Sources of omega-3 fatty acids differed by age; however, native foods are the primary source for omega-3 fatty acids and vitamin B-12. Little data are available on the changes in dietary intake by season. There needs to be a standardization of the nutrient database for foods across countries since items such as fish and market foods differ between countries.

Dr. Laurie Hing Man Chan presented dietary data from the Center for Indigenous Peoples' Nutrition and Environment (CINE) in Canada, with particular emphasis on contaminants. He presented results from three dietary surveys, including Dene'/Metis communities along the Mackenzie River, the Yukon First Nation communities in the Yukon, and the Inuit communities across Arctic Canada. Together, these surveys include 24-hour dietary recalls on more than 3,600 individuals. Diets are a blend of traditional foods and market foods. Traditional foods include sea mammals, land animals, birds, fish and seafood, and plants. Inuit consume a higher percentage of calories from traditional foods and have a greater variety of traditional foods available. Inuit eat primarily caribou, sea mammals and fish. Yukon First Nations and Dene'/Metis eat primarily moose, caribou and fish. Analyses show a higher consumption of carbohydrates, sucrose and saturated fat in meals that do not include traditional foods. Traditional foods also contribute to contaminant exposure including mercury, toxaphene and chlordane. However, traditional foods also offer important socio-cultural benefits that define the Inuit. Thus, the consumption of traditional foods represents a balance of risks and benefits that must be addressed in partnership with the Native communities. The online nutrition course in Nunavut is an example of the outputs from such partnerships (http://www.cine.mcgill.ca/nunavut/).

Dr. Hakon Hakonarson reported on the efforts of deCode Genetics to mobilize the resources within Iceland to address genetic causes of disease. The strength for genetic research in Iceland is the phenomenal genealogical database. Records have linked genotype and phenotype data, including medical records, to produce a data base that can quickly explore scientific questions linking distant relatives. Genotyping included 1200 markers per subject for more than 100,000 subjects; the goal was to identify genes that at least double disease risks and account for a large percentage of patients. Examples of success include the NRG1 gene for schizophrenia, the BMP2 gene for osteoporosis, and the FLAP gene for myocardial infarction (MI) and stroke. The approach of deCode includes three steps: (1) use hundreds of families with thousands of patients to map the general location of genes for broadly defined phenotypes, (2) saturate regions of interest with hundreds
of additional markers to refine the search, and (3) confirm findings in another population. DeCode continues to look for collaborators with extensive genealogical and medical records to facilitate additional research and to replicate findings.

Dr. Peter Bjerregaard presented results from collaborative efforts in studies of the Inuit in Greenland and other countries. He explained that Arctic populations are very diverse. In North America, there are hundreds of recognized tribes; in Eurasia, there is even more diversity. However, the Inuit/Eskimos ranging from eastern Siberia, northwest Alaska, Northern Canada and Greenland are more similar and have become the focus of collaborative international efforts. In the 1990s, there were four surveys using somewhat similar methodology; they included more than 2,000 participants from Kivalliq, Nunavut, Canada; Nunavik, Quebec, Canada; Bering Strait Region, Alaska; and West Greenland. Data suggested that the pathology of CVD was more complex than originally assumed. HDL levels were high across studies. The relationship between obesity and lipids varied from that observed in the non-Native populations. The metabolic syndrome appeared to show gender differences in relation to westernization. The small size of the Inuit populations in any one country, the homogeneity within a country and the environmental heterogeneity between countries, support the need for a circumpolar Inuit study. Obstacles to the existing and future efforts included the lack of synchronization and of common protocols among studies across countries, and the need to standardize protocols within a given country with respect to previous work. International leadership is needed to develop a more coordinated effort. Additional methodology development may also be needed (e.g. valid physical activity measure).

Discussion revolved around the pros and cons of starting an entirely new effort versus building on existing studies. It became clear that research results across studies, even with varying protocols, provided support for atypical risk factor patterns and disease prevalence and incidence that offered unique research opportunities. Table I provides a summary of the risk factor levels of Native populations compared to the general population of the country (or to Denmark in the case of Greenland), as compiled in studies since 1990. Table II provides similar comparisons for disease incidence and/or prevalence. Of note, there were no references to sleep research results in the discussion, suggesting that little, or no population-based research has been done in the Arctic on this subject. A carefully focused effort to establish a central database and to synchronize longitudinal surveillance for existing studies may be the most efficient first step.

**Barriers and solutions to arctic research**

Dr. Ruth Etzel described the organizations delivering health care to Alaska Natives. She noted that Alaska Natives have made more rapid progress in self determination than many other Native groups in the United States. They have assumed ownership and management of the Alaska Native Medical Center and other hospitals and health care centers, and are now assuming more responsibility for health research done in their communities. An advantage for health research is the centralized, computerized medical record system, initiated many years ago by the Indian Health Service, for all health care of the Alaska Native
### Table I. Risk factor status of Native population compared to non-Native population by country and study.

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>United States (Alaska)</th>
<th>Greenland</th>
<th>Russia Yamal Nenets</th>
<th>Canada NWT NUNAVUT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Alaska Siberia Eskimos</td>
<td>GOCADAN Eskimos</td>
<td>Inuit</td>
<td>Inuit</td>
</tr>
<tr>
<td>Inuit</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SBP</td>
<td>L (1)</td>
<td>L</td>
<td>L (2, 3)</td>
<td>L (3, 5)</td>
</tr>
<tr>
<td>DBP</td>
<td>L (1)</td>
<td>L</td>
<td>L (2, 3)</td>
<td>L (3, 5)</td>
</tr>
<tr>
<td>HDL Chol</td>
<td>H (6)</td>
<td>H</td>
<td>H (2, 7)</td>
<td>H (4, 5)</td>
</tr>
<tr>
<td>LDL Chol</td>
<td>H (6)</td>
<td>N</td>
<td>N (7)</td>
<td>N (4, 8)</td>
</tr>
<tr>
<td>TG</td>
<td>L (6)</td>
<td>L</td>
<td>L (10)</td>
<td>L (4, 5, 8)</td>
</tr>
<tr>
<td>Cigarette Smoking</td>
<td>H</td>
<td>H</td>
<td>H (10)</td>
<td>H (4, 8)</td>
</tr>
<tr>
<td>Glucose</td>
<td>L (11, 12)</td>
<td>L</td>
<td>N/H (2)</td>
<td></td>
</tr>
<tr>
<td>Insulin</td>
<td>L (11, 13)</td>
<td>L</td>
<td>N/H (2)</td>
<td></td>
</tr>
<tr>
<td>Metabolic Syndrome</td>
<td>L (13)</td>
<td>L</td>
<td>L</td>
<td>L (5)</td>
</tr>
<tr>
<td>BMI</td>
<td>H (14)</td>
<td>N</td>
<td>L/H (2)</td>
<td>L (5)</td>
</tr>
<tr>
<td>Waist</td>
<td>H (15)</td>
<td>L</td>
<td>L/H (2)</td>
<td></td>
</tr>
<tr>
<td>Infection</td>
<td>H</td>
<td>H</td>
<td>H (10)</td>
<td></td>
</tr>
<tr>
<td>PUFA Intake</td>
<td>H (16-18)</td>
<td>H</td>
<td>H (10, 19)</td>
<td>H (10)</td>
</tr>
<tr>
<td>Alcohol</td>
<td>H</td>
<td>N</td>
<td>N (10)</td>
<td>H (10)</td>
</tr>
<tr>
<td>Physical Activity</td>
<td>L</td>
<td>N</td>
<td></td>
<td>N</td>
</tr>
<tr>
<td>Apo E4</td>
<td>L (6)</td>
<td>H</td>
<td>H (20)</td>
<td>H (21)</td>
</tr>
</tbody>
</table>

H=Higher; N=Neutral; L=Lower
Findings with no references were presented at the working group meeting
L/H represents men/women respectively

### Table II. Disease prevalence/incidence of Native population compared to non-Native population by country and study.

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>United States (Alaska)</th>
<th>Greenland</th>
<th>Russia Yamal Nenets</th>
<th>Canada NWT NUNAVUT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Alaska Siberia Eskimos</td>
<td>GOCADAN Eskimos</td>
<td>Inuit</td>
<td>Inuit</td>
</tr>
<tr>
<td>IHD</td>
<td>N (13)</td>
<td>N (22)</td>
<td>L</td>
<td>L (22)</td>
</tr>
<tr>
<td>Stroke</td>
<td>H (22)</td>
<td>H (22)</td>
<td>L</td>
<td>H (22)</td>
</tr>
<tr>
<td>RHD</td>
<td>H (23)</td>
<td>H (23)</td>
<td>H</td>
<td>H (23)</td>
</tr>
<tr>
<td>Congenital HD</td>
<td>H</td>
<td>H</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>H (10)</td>
<td>H</td>
<td>H</td>
<td>H (10)</td>
</tr>
<tr>
<td>Hypertension</td>
<td>N (1)</td>
<td>L</td>
<td>L (2)</td>
<td>L (2)</td>
</tr>
<tr>
<td>Suicide</td>
<td>H (24)</td>
<td>H</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Obesity</td>
<td>H (14)</td>
<td>L/N</td>
<td>H</td>
<td>H (5)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>N (12, 13)</td>
<td>L</td>
<td>H (25)</td>
<td>L (9)</td>
</tr>
</tbody>
</table>

H=Higher; N=Neutral; L=Lower
Findings with no references were presented at the working group meeting
L/H represents men/women respectively

### Table III. Comparison of values of Native community versus research community from the Native perspective.

<table>
<thead>
<tr>
<th>Natives</th>
<th>Researchers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing</td>
<td>Ownership</td>
</tr>
<tr>
<td>Cooperation</td>
<td>Competitiveness</td>
</tr>
<tr>
<td>Humility</td>
<td>Achievement</td>
</tr>
<tr>
<td>Conflict avoidance</td>
<td>Direct communication</td>
</tr>
<tr>
<td>Responsibility to community</td>
<td>Individualism</td>
</tr>
<tr>
<td>Circular</td>
<td>Linear</td>
</tr>
<tr>
<td>Listening</td>
<td>Talking</td>
</tr>
<tr>
<td>Decides with issues</td>
<td>Decides with numbers</td>
</tr>
<tr>
<td>Holistic approach</td>
<td>Detailed, specialized approach</td>
</tr>
<tr>
<td>Filled with spirit</td>
<td>Void of spirit</td>
</tr>
<tr>
<td>Subjective</td>
<td>Objective</td>
</tr>
<tr>
<td>Lives in balance with the environment</td>
<td>Controls the environment</td>
</tr>
</tbody>
</table>
population. Dr. Etzel noted the different value systems of traditional Alaska Native communities and many non-Native researchers (Table III). Alaska Natives prefer research that is rooted in the community, not implanted in the community. They seek research that is driven by community needs, rather than by the researcher’s needs.

In the past, much research involved flying in to study health issues with little focus on working with Alaska Native communities over the long term. Most Alaska Native communities prefer a research model that is based on building long-term relationships between community members, who serve as research subjects, and researchers. Such a model helps to empower the community. Alaska Native health corporations have implemented changes to help establish a greater role for community members in research. Native leaders have assumed responsibility for the careful review of all proposed research projects. In Anchorage, research project proposals are reviewed by multiple institutional, community and governmental entities. This process can take nearly a year, which may be perceived as a barrier to research within Alaska. Another issue that may be perceived as a barrier is the issue of data ownership. Native health care organizations maintain the right to approve all abstracts, manuscripts and reports and to specify the parameters for access to data and specimens. Because Alaska Natives believe in sharing, when it is of value to their community or mankind as a whole, they are likely to be supportive of well-designed research projects and data-sharing.

Dr. André Corriveau presented results and perspectives on research from the Northwest Territories (NWT) in Canada. The NWT includes 34 communities and about 41,000 inhabitants; about half are Aboriginal. Eight official languages and another 15 non-Aboriginal languages are spoken there. The government is a consensus-style public government. The population is young, but projections over the next two decades indicate that those over 45 years old will be the fastest growing component. Thus, chronic diseases are expected to increase. The prevalence of cigarette smoking in the NWT is double that in Canada, but may be starting to decline. Mortality from circulatory diseases is somewhat lower than in Canada; mortality rates from injury and respiratory diseases are higher. The incidence of tuberculosis is almost eight times higher in the NWT than in all of Canada. The incidence of sexually transmitted infections, already high, continues to increase. Alcohol consumption is higher for all ages, for both men and women, in the NWT. There are three challenges facing the NWT. The first is to lessen the burden of preventable conditions and mortality by reducing high risk behaviours and providing more prevention and intervention efforts. The second is to continue addressing the health care needs of children and youth, while also meeting the needs of the rapidly growing elderly population. The third is to maintain a stable, integrated system with defined accountability, appropriate governance, adequate access to specialists and appropriate technology to complement service delivery. With regard to health research, the government has moved to issuing research licenses, based on ethical and community support considerations, that are required in order to conduct research, or to collect specimens within the NWT.

Dr. Sven Ebbesson provided his perspective based on the Alaska Siberia Project and the
GOCADAN Study in Norton Sound Eskimo villages. Barriers to research include the small numbers of researchers in the North, inadequate infrastructure, logistic and climatic difficulties, and unfamiliarity with the needs and customs of the Native population. He stressed the importance of working with, and through, the village councils for approvals and guidance for research. Most importantly, he emphasized the need to return meaningful research results to the participants and their community. This will build long-term relationships that will lead to better research over time.

Dr. Ebbesson stressed the importance of investigators spending adequate time in a given village to develop an understanding of the needs, sensitivities and customs of the people. It takes time to understand how villages are organized and to be accepted within the village. Once the community understands that a primary goal of the research is to reduce health problems, enthusiastic support follows.

Facilitating international comparisons

Dr. Natalie Tomitch, Fogarty International Center (FIC), described the expanding role of the FIC as the coordinating agency for all Arctic research for the National Institutes of Health. The mission of FIC was to support research and training internationally, in order to reduce disparities in global health. Dr. Tomitch reviewed the 27 Institutes and Centers making up the NIH, and justified the value of having a common point of contact for international issues. She acknowledged the opportunity presented through this working group for the FIC to coordinate the establishment of an international collaboration of one, or more, of the NIH Institutes and Centers with organizations representing other Arctic countries.

Building capacity and establishing collaborations are important components of the FIC mission.

Carl Hild represented the American Society for Circumpolar Health and the International Union for Circumpolar Health (IUCH) for this meeting, but noted he had additional perspectives through his affiliations with the Alaska Native Tribal Health Consortium and the University of Alaska Anchorage (UAA). He explained that the IUCH, established in 1986, offered an existing organization and journal devoted to collaboration among the eight countries with interests in the Arctic. He reviewed the history of international collaborations in the Arctic and the development of the IUCH. He noted that the IUCH, established in 1986, offered an existing organization and journal devoted to collaboration among the eight countries with interests in the Arctic. He reviewed the history of international collaborations in the Arctic and the development of the IUCH. He noted that the IUCH, established in 1986, offered an existing organization and journal devoted to collaboration among the eight countries with interests in the Arctic. He reviewed the history of international collaborations in the Arctic and the development of the IUCH. He noted that the UAA has developed a Consortium Library that has a National Library of Medicine web site focused on health disparities of western Arctic populations – Arctic Health (www.arctichealth.org). In 1988, the Institute for Circumpolar Health Studies was established at the UAA. He suggested there were many other organizations with similar aims related to Arctic research, but there was little communication among them and few outcomes as a result of their efforts. He recommended that the FIC, as lead contact for health programs to the Arctic Council, create an NIH Arctic Research Coordinating Committee to address health disparities and regional capacities and to conduct coordinated circumpolar investigations.

The three person panel to discuss facilitating international comparisons included Dr. Bjerregaard, Dr. Young and Dr. Ebbesson. Dr. Bjerregaard emphasized the primary reasons
for international collaborations: (1) Inuit/Eskimos are in small numbers scattered across several countries, and (2) collaborations will result in larger numbers and more variation in environmental exposures. The two most important issues for international collaborations are continued exchange of experience and the development of comparable survey instruments for items such as surveillance, diet, physical activity, anthropometry and social networks. Dr. Young suggested there was a need for an international network for circumpolar health to promote research, facilitate communication and dissemination, and strengthen health information. He recommended a web site as the best mechanism for communication and data management. He noted it would serve a different purpose from the IUCH, because it is focused on the needs of researchers and would promote collaboration. Dr. Ebbesson urged investigators to become more involved in the community in their efforts to conduct research there. He acknowledged their primary interests are intervention and prevention studies. He suggested that there is a need for initial funding for coordination among the interested countries under the sponsorship of a government agency, or international organization, that wants to assume a leadership role.

The meeting concluded with a list of ten recommendations.

Recommendations for research priorities

1) Primary prevention/intervention studies can be initiated immediately to reduce the incidence of cardiovascular diseases (particularly stroke) and respiratory diseases (particularly tuberculosis and chronic obstructive pulmonary disease), and to prevent the development of risk factors, such as obesity and diabetes.

2) Unique clinical outcomes with unusual prevalence/incidence that may benefit from further epidemiologic investigation include the low incidence of deep vein thrombosis and the high incidence/prevalence of congenital heart disease, rheumatic heart disease, sudden infant death syndrome, anemia, and infections such as respiratory syncytial virus.

3) Risk factors with unusual prevalence that may benefit from further epidemiologic investigation include obesity, the metabolic syndrome, HDL, omega-3 fatty acids, infection/inflammation on atherosclerosis, and contaminants and indoor air pollution.

4) Extremes in the physical and social environment offer opportunities for research on the effects of contaminants and the effects of seasonal changes, including cold, extended light/dark cycles, and dietary patterns, on CVD risk factors, sleep patterns and psychological well-being. Northern communities also offer some homogeneous populations suitable for genetics research and many isolated communities suitable for randomized community-based intervention trials.

5) Methodological research is needed to develop protocols and data collection instruments to standardize surveys of Native populations across countries for recruitment, dietary assessment, definitions of health status, physical activity assessment, socio-economic status, modernization/westernization, criteria for obesity, and culturally-sensitive interventions.

Recommendations for barriers and solutions

6) Follow guidelines already established by Indigenous Peoples, such as the WHO-CINE guidelines (http://www.cine.mcgill.
Recommendations for facilitating international comparisons

9) Encourage the Fogarty International Center to lead an effort in organizing an international consultation for the purpose of establishing a collaborative study of Arctic peoples.

10) Establish international cooperation agreements to initiate a circumpolar Inuit Study to overcome the high costs of research and the small samples available within any one country, and to incorporate the diversity of environment among Alaska Native and Inuit communities that exists across circumpolar countries

Conclusions

Because of the mission of the sponsoring agencies, this working group focused on heart, lung, blood and sleep disorders. Larger, more coordinated efforts that expand the scope of investigation to other conditions and diseases may be much more efficient, given the high cost and formidable barriers to research within and among countries with interests in Arctic Research. The working group participants would welcome such an omnibus research effort. However, in the absence of such an effort, the working group acknowledged that the interest and leadership provided by the current working group participants represented a promising opportunity to address research with Arctic people. It is hoped that these recommendations will be explored by health agencies, both individually and collaboratively, within and among Arctic countries in the coming year, in order to enhance the research agenda with Arctic peoples.

REFERENCES


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Appendix I

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