

SDWG PROJECT PROPOSAL

<p>Project Title:</p> <p>Review of cancer among circumpolar indigenous peoples [CircCAN]</p>	<p>Lead Country/Project leader(s):</p> <p>AHHEG/Kue Young/Leanna Ellsworth Canada Denmark/Greenland ICC</p>
<p>Total Cost of Project:</p> <p>\$140,000 CAD</p>	<p>Relationship to other AC Working Groups</p>

Rationale

In February 2011 the Arctic health ministers signed the Nuuk Declaration. The declaration provides guidance for circumpolar countries and calls for a collaborative response to shared health concerns. It recognizes the importance of long term observation, monitoring and surveillance of health changes in Arctic populations and the value of circumpolar comparative studies.

Cancer is an emerging health problem among circumpolar indigenous peoples and concerns have been repeatedly voiced by indigenous peoples' organizations. Effective prevention and control measures require valid and reliable surveillance data to support planning and evaluation. This review will provide the needed baseline evidence.

While circumpolar countries, , have well established national cancer registries, few have the capability to distinguish indigenous from non-indigenous people among cancer cases in their databases. A circumpolar review will bring together relevant stakeholders to assess the current state of knowledge, identify data gaps, and propose strategies to close these gaps and improve our understanding of cancer in indigenous populations.

The proposed project is similar to a previous circumpolar review of cancer among Inuit in Alaska, Canada, and Greenland over the period from 1989-2003. That project, conducted during 2007-08, provided Inuit organizations alarming new evidence of the cancer threat and assisted their planning and lobbying for cancer control services. That project predated the formation of the Arctic Human Health Expert Group (AHHEG) and was not endorsed by the Arctic Council. The current project was approved at its meeting in Umeå in June 2011 and is now submitted to the Arctic Council's Sustainable Development Working Group (SDWG) as an AHHEG project.

Objectives

We propose to respond to the intent of the Nuuk Declaration and assemble an international team of health researchers, planners, policy makers and representatives of indigenous peoples' organizations to:

- (1) review and describe the patterns and trends of cancer among circumpolar indigenous peoples;
- (2) identify and describe current services and programs in cancer prevention and control relevant to indigenous peoples;

(3) disseminate the information to stakeholder groups to support the development of cancer control strategies specific to indigenous peoples.

Project Phases

This is a multi-year project, and will consist of the following phases involving different Arctic countries, regions and indigenous peoples:

Phase I: Inuit in Alaska, Canada (Northwest Territories, Nunavut, Nunavik, Nunatsiavut), and Greenland during 2013-2014

Phase II: Athapaskans in Alaska, Yukon, and Northwest Territories during 2014-2015, and completed before the close of the Canadian Chairmanship

Phase I is a follow-up of the earlier project and involves updating the database for another 5-year period (2004-2008).

Phase II is a totally new initiative involving partners that are collaborating for the first time.

Collaborating Partners

Collaborating partners include representation from Permanent Participants, regional health authorities, and regional/national agencies with authority and stewardship over cancer registries. Individual cancer researchers from all the Arctic countries will be identified by AHHEG and invited to participate and contribute to the study design, analysis and dissemination of findings.

Phase I: The following organizations have been involved in the previous review will be invited to participate upon approval by SDWG. In February 2013, the proposal was presented to, and endorsed by the National Inuit Committee on Health in Kuujuuaq, Canada comprised of national and regional Inuit health directors and representative of ICC-Canada.

- Alaska Native Tribal Health Consortium
- Inuit Circumpolar Council
- National Inuit Committee on Health (NICoH), ITK
- Northwest Territories Department of Health and Social Services
- Nunavut Department of Health and Social Services
- Nunavik Regional Board of Health and Social Services
- Nunatsiavut Department of Health
- Danish Cancer Registry
- National Institute of Public Health
- Greenland Department of Health

Phase II: The following organizations were present at a planning meeting in May, 2011 in Vancouver to discuss the proposal. Additional follow-up meetings will be held to finalize details.

- Alaska Native Tribal Health Consortium
- Gwichin Council International
- Arctic Athabaskan Council

- Council of Yukon First Nations
- Dene Nation
- Yukon Department of Health and Social Services
- Northwest Territories Department of Health and Social Services

Organization and Management

Project Co-Leads will be the co-chairs of AHHEG Prof. Kue Young, University of Alberta School of Public Health, Canada and Leanna Ellsworth, ICC.

CircCAN is a project of the Arctic Human Health Expert Group [AHHEG], a subsidiary of the Sustainable Development Working Group [SDWG] of the Arctic Council. It was approved by its meeting in Umeå in 2011.

The project is developed and will operate under a collaborative model which fulfills the Nuuk Declaration's direction to improve circumpolar collaboration and increase participation of indigenous peoples and other Arctic residents.

Study Methods

Cancer cases in Alaska and northern Canada (Phase I and Phase II) and Greenland (Phase I only) are reported to and registered in well-established, population-based cancer registries. This project will follow internationally accepted methods and procedures in classification and coding, and the calculation of age-standardized incidence rates.

Data for Alaska Natives (which include Eskimos, Indians and Aleuts) are collected by the Alaska Native Tumor Registry (ANTR), a state-wide population-based registry which has been in existence since 1969. It is currently maintained by the Office of Alaska Native Health Research and the Alaska Native Epidemiology Center of the Alaska Native Tribal Health Consortium in Anchorage, Alaska. ANTR covers Alaska Native patients living in Alaska at the time of diagnosis who meet eligibility criteria for health care benefits from the Indian Health Service and its contracted providers. Procedures for data collection and coding follow standards of the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute.

Statistics Canada, Canada's national statistical agency, operates the Canadian Cancer Registry (CCR), a person-oriented system, which ensures that individuals are registered in only the jurisdiction of residence at the time of registration. CCR receives cancer data from all provincial and territorial cancer registries where internal record linkage and national death clearance are done annually. It then returns the data to the contributing registries. Data on cancer cases diagnosed among permanent residents of the three northern Canadian territories (who may obtain cancer care services outside the territories) are maintained by the respective Department of Health and Social Services of Yukon, NWT and Nunavut. Identification of indigenous people status in the territorial cancer registries is readily available in NWT and Nunavut, but is incomplete in the Yukon, which requires additional programming. The Inuit regions of Nunavik and Nunatsiavut are within provincial jurisdictions (Quebec and Newfoundland & Labrador respectively) and have no identifiers for indigenous people status in their registries. Attribution of

cancer cases to Inuit patients for these regions can only be based on geographical residence.

The Danish Cancer Registry registers cases from both Denmark and Greenland. Through data linkage with the Greenland population registry, cases occurring among individuals born in Greenland and resident in Greenland at the time of diagnosis can be identified. [The use of “born in Greenland” as a proxy identifier for Greenland Inuit is a long-established practice with well recognized deficiencies]. Previously a database of cases from 1989-2003 was created by J. Friberg and colleagues at the Department of Epidemiology Research, Danish Epidemiology Research Centre, Statens Serum Institute in Copenhagen. This database will be updated.

While there are about 1000 Inuit in Chukotka, Russia, the population is very small and the number of cancer cases extremely low based on previously published data. However, we shall request our RAIPON colleagues and ICC contacts in Chukotka to investigate whether Inuit cases can be identified from existing data sources in Chukotka.

The final report will provide an epidemiological overview of the time trends and age-sex patterns of cancer in the various indigenous populations in the different regions, according to cancer sites (eg. lung, breast, etc), using standard statistical, graphing and mapping techniques. A literature review will describe cancer control programs in circumpolar countries and also identify potential risk factors that may explain the observed trends and patterns. This report will serve as the baseline document which will inform peer reviewed articles and knowledge translation documents.

Project Deliverables and Timeline

The output of this project will be : (1) Presentation of findings to Permanent Participants (phase 1 ICC and NICoH), to AHHEG, and SDWG/Arctic Council ; (2) documents and media for dissemination among Permanent Participants organizations and regional health care agencies; (3) scientific papers for publication in medical journals and presentations at indigenous/health related conferences such as the Inuit Studies Conference and International Congress on Circumpolar Health. The data collected by this project will be consolidated with other data in the Circumpolar Health Observatory, a SAON task and also Arctic Council authorized project [<http://circhob.circumpolarhealth.org>]. The information will be organized into interactive maps and downloadable data spreadsheets.

Phase I

- September – December 2013: data extraction at Alaska, Northwest Territories, Nunavut and Danish/Greenland cancer registries;
- January – March, 2014: compilation of “master table” aggregating data from the three regions; review of preliminary results
- April – June, 2014: presentations to stakeholders, eg. National Inuit Committee on Health of Canada, ICC Health Committee, and ICC General Assembly; preparation of final report

Phase II

- March 2014 – convene stakeholders meeting.

- June – September 2014: data extraction at Alaska, Yukon and Northwest Territories cancer registries;
- October – December, 2014: compilation of “master table” aggregating data from the three regions; review of preliminary results
- January – March, 2015: presentations to stakeholders; preparation of final report

Proposed Budget and Funding Sources

Funding (both in cash and in-kind) has been secured through a recent grant to Kue Young from the Canadian Institutes for Health Research to enable this project to be implemented. The budget can be broken down as follows:

Phase I

• Meeting with stakeholders to review of preliminary results	\$20,000
• Salary of data analyst/programmer	\$20,000
• Administrative support services	\$10,000
• Miscellaneous travel [presentations]	\$10,000
Subtotal	\$60,000

Phase II

• Planning meeting with stakeholders	\$20,000
• Salary of data analyst/programmer	\$20,000
• Administrative support services	\$10,000
• Miscellaneous travel [presentations]	\$10,000
Subtotal	\$60,000

Dissemination and Knowledge Sharing

Preparation of data briefs and media for policy makers	\$10,000
Translation of documents into relevant indigenous languages	\$10,000

GRAND TOTAL	\$140,000
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