

4.7 International Inuit Cohort Study: Developing the next phase (Inuit Health Cohort)

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ABSTRACT

The International Inuit Cohort was born from an international collaborative effort to gather pertinent data from Inuit circumpolar populations in order to identify differences and trends in this population. This cohort study will address long-standing questions with respect to Inuit health research. Many studies among Inuit populations are limited by a lack of statistical power, weak external validity and absence of temporal links and causality between disease and potential aetiologic factors. Indeed, the small size of communities (between 50 and 5000) living in different regions of the Arctic limits the use of epidemiological studies to determine rates of health outcomes. This initiative is based on three different companion studies conducted among Inuit adults in Canada and Greenland. Each study has a cross-sectional and a longitudinal component. The protocols used were developed in close collaboration and have are very similar. To date, all three baselines surveys and measurements have been completed and results have been delivered to communities. The baseline surveys were carried out among adults (≥ 18 years) with Inuit/Yupik ancestry from across each circumpolar region. From 2004 to 2010, a total of 6223 participants (929 from Nunavik; 2835 from Greenland; 2459 from Nunavut, Inuvialuit and Nunatsiavut) participated in a 3-4 hours session with an English/Inuktitut questionnaire to ascertain a range of various lifestyle habits and health outcomes. All subjects participated in a medical and para-clinical examination and had a biological samples drawn. This project deals with all aspects of the Cohort, including its constitution as a databank and all activities to further gather data to augment the databank.

KEY MESSAGES

- The International Inuit Cohort represents the most comprehensive and extensive health study for the Inuit population living in the Arctic and sub-Arctic region.
- Analysis of circumpolar data is in its infancy.

- Hypertension is a concern across the circumpolar region.
- Community characteristics, such as the housing situation, is an important determinant of Inuit health.

OBJECTIVES

The original objectives for the project for 2011-2012 were:

- Preparation of the first peer-reviewed publication based on the Circumpolar Inuit Cohort on hypertension and risk factors.
- Initiate a research project on community well-being and cardiovascular health. Based on needs identified through consultation with Nunavik stakeholders, this objective was fine-tuned to initiate a research project on housing and health. Although the main focus is now on housing, community conditions are still considered as part of the housing environment.
- Undertake a preliminary cardiovascular follow-up of the Cohort in Nunavik.

Added to these are:

- Undertake a planning process to evaluate future directions of the International Inuit Cohort.
- Operationalize the International Cohort databank.

INTRODUCTION

Several studies have documented inequality in health status for Inuit populations in comparison with other populations. In general, Inuit populations demonstrate health status outcomes (i.e. mortality, morbidity and health perception measures) that are inferior to other Indigenous populations in Canada and to Caucasian populations. Demographically they are susceptible to a greater extent to any disadvantages associated with having a very young demographic profile for they are the

youngest Indigenous population in Canada (i.e. resource and infrastructure pressures including housing). Finally, the study of biomarkers (e.g. blood pressure, fatty acid signatures, environmental contaminant body burdens, etc.) also contribute to understanding and describing the scenario of epidemiological transition among Inuit populations and indicate the possible (even likely) onset of a chronic disease epidemic (cardiovascular, diabetes) triggered by this epidemiological transition whereby the traditional lifestyle and diet is significantly replaced by a more sedentary lifestyle in which market foods are much more present in the diet. The International Inuit Cohort Study is a composite of three cross-sectional health surveys conducted in Canada and Greenland between 2004 and 2009, creating the largest databank for Inuit health to date. Chronologically the first survey, referred to as the Qanuippitaa? How are we? survey was conducted in Nunavik in 2004 (929 adult participants). The second took place over a period of 4 years over the entire territory of Greenland (2005-2009 – 2834 adult participants). Finally, conducted in 2007 and 2008, the Inuit Health Survey covers a vast area including Nunavut, Nunatsiavut and Inuvialuit (2595 adult participants). A web site at <http://circumpolarcohort.crchuq.ca/index.htm> provides further information.

The three studies have pursued common goals and have adopted similar methods focussed on measuring the epidemiological transition of Inuit populations and the pursuit of knowledge to inform: the risks and benefits of key aspects of this transition as well as improving health outcomes (e.g. chronic diseases, self-inflicted injuries). The information gathered from participants over the course of the field operations have included variables that represent the determinants of health (e.g. food security and nutrition; education; employment; revenue; housing; culture; social support, and more..), demographic information, and health outcomes information (perceived health status; clinical health status) for the populations of these Inuit regions.

To date, the study represents a cross-sectional look across Inuit populations in the circumpolar North. The studies listed above are the first “data point” in time that has been collected from each participant. Longi-

tudinal follow-up of this cohort is required in order to answer critical questions that may lead to improving health status. All participants have provided consent to be contacted for follow-up investigation, and thus have consented to be part of the International Inuit Cohort.

2011 has been a year of reorganization for the International Cohort project. Significant delays have been encountered regarding the constitution of one single databank. In 2011, progress was achieved in preparing for a study on housing and health in Nunavik; on conducting a preliminary cardiovascular follow-up of the Cohort in Nunavik; and on securing funds for a planning workshop on the future of the Cohort. Throughout 2012 preparatory and planning activities will be significant. Specifically, activities will focus on 1) the constitution of the databank; 2) the carrying out of an exploratory study on housing and health to inform future surveys; 3) a planning workshop among stakeholders to discuss the future directions of the International Cohort and 4) studies on the International Cohort database will in earnest begin.

Background on the Housing and Health in Nunavik project:

It has become more and more evident over the last decade and with the results of the Inuit Health Survey, among others, that housing is an important and complex determinant of health. In recent years, poor housing conditions, lack of adequate and affordable housing in Inuit Nunangat has attracted local, academic, policy and media attention. Among Canada’s Indigenous Peoples, Inuit experience the highest level of overcrowded, inadequate housing (Inuit Tapiriit Kanatami 2004). Of all Inuit regions, overcrowding is worst in Nunavik where, in 2006, 49% of Nunavimmiut lived in overcrowded conditions, compared to 39% in Nunavut, 19% in the Inuvialuit region and 13% in Nunatsiavut (Statistics Canada, Census of population 2006); 3% of the non-Indigenous Canadians lived in overcrowded households in 2006. About 46% of Nunavimmiut lives in homes needing major repairs, compared to 31% in Inuit across Inuit Nunaat and to 7% of non-indigenous Canadians. To address the housing crisis in Nunavik, the construc-

tion of 800 housing units and investments to repair/improve the housing stock has recently been agreed under Québec's Plan Nord (Gouvernement du Québec 2011). In conjunction, new housing programs are also being implemented. Yet these measures do not respond to local needs or keep pace with increasing population. In addition, the compartmentalized room design of the Euro-Canadian house built in Nunavik is at odds with the Inuit culture and traditional way of life (Dawson 2008). In the years to come, the housing crisis in Nunavik is likely to be exacerbated by the economic development of the North, as planned in Québec's Plan Nord, possibly triggering needs for new housing units for migrant workers from the South.

Many aspects of internal housing conditions have the potential to influence health. In particular, cold and damp conditions and secondary tobacco smoke may cause respiratory health problems, and this has been showed in Inuit children (Banerji et al. 2001, Banerji et al. 2009, Kovesi et al. 2007). The effect of household density in the spread of infectious diseases, e.g. tuberculosis, is also documented (Clark et al. 2002). Poisoning may be caused by exposure to lead piping/paint and injuries may occur (as reviewed in Shaw 2004). Housing design, overcrowding and substandard housing might play a role in the aetiology of other health and social problems, such as unhealthy behaviours (e.g. smoking, alcohol and drug consumption), risk factors for cardiovascular diseases, e.g. high blood pressure, mental health problems, domestic violence, crime, educational attainment (an important determinant of health) (Canadian Institute for Health Information 2004). Other than studies focussing on children respiratory health, few have examined the influence of housing conditions on other indicators of physical and psychosocial health of Nunavimmiut. This is an important research and policy agenda: the Nunavik Regional Board of Health and Social Services has identified the housing crisis in Nunavik as a public health priority to improve the health of Nunavimmiut. Hence, understanding the housing-health relationship requires further investigations of the processes shaping housing conditions in Inuit Nunangat and their impacts on health and community well-being.

Although theoretical frameworks on housing and health have been developed (Dunn 2002, Shaw 2004), they are not adapted to the cultural and local context of Inuit community of Nunavik. Current and past research on health and its determinants in the Canadian Arctic have addressed, to some extent, the relationship between housing and health, but the information is either specific to a single community (Tester 2006) or provide an incomplete picture. Large-scale population surveys conducted (not exclusively) in Nunavik encompass questions on housing conditions (Statistics Canada 2006, SLiCA 2002), covering topics such as household tenure (own, rent; reasons for owning/not owning a house); whether a person is on a waiting list for social housing and for how long; amenities/assets in the home (TV, refrigerator, computer, etc); whether the house needs repairs and what type of repairs. Yet these surveys do not necessarily cover health issues as broadly. Conversely, health surveys of Nunavik (Qanuippitaa – How are we? Nunavik Child Health study) containing extensive data on perceived and clinical measures of health comprise only limited information on housing conditions, focusing almost exclusively on the number of rooms (or bedrooms) per house and the number of person per household (number of adults and of children).

There is therefore a need to develop a survey questionnaire that is adapted and relevant to the housing conditions in Nunavik, and their impact on Nunavimmiut's health and well-being. Developing such a survey questionnaire requires the collaboration of academic researchers and Nunavimmiut.

Background on the Preliminary Cardiovascular Follow-up of the Cohort in Nunavik:

Each participant to the Qanuippitaa survey who agreed to participate in the cohort component of the survey has also agreed to give us access to their medical file. As was done in 2005, in 2011-2012 a follow-up in the form of a morbidity and mortality surveillance study will be conducted in Nunavik's 14 villages. Medical records and death certificates of the Nunavik cohort partici-

pants will be reviewed (2005-2012) and all (and only) medical information will be captured into a questionnaire for analysis. This approach will enable follow-up of various associations between risk factors (dietary, social, environmental) and cardiovascular disease events (e.g. infarction, stroke) prospectively. Field work will be done to collect the data from each CLSC and 2 hospitals. The baseline cohort database will be enhanced with this data after having undergone a rigorous process for reviewing and classifying cardiovascular events.

In 2011-2012, we obtained co funding from the Northern Contaminants Program for this activity.

Background on the Cohort Planning Workshop:

The time has come for a dialogue on the state of and future of the Circumpolar Inuit Health in Transition Study, hereto referred to as the Cohort. With its thousands of participants, the Cohort is the largest health study of Circumpolar Inuit and as such represents a unique resource of immense potential for research - and therefore intervention. Participants and communities have received a wealth of information and knowledge about their health status and several peer reviewed scientific publications (from individual health surveys and not from pooled data across the three surveys) have contributed to the state of knowledge. The true strength of a cohort is in following it over time and in pooling data across the three populations (Qanuippitaa?, Inuit Health Survey, Greenland), allowing the identification of trends. With health inequalities between Inuit and both other Aboriginal populations and the rest of the Canadian population still very significant, this resource merits all the attention that is required to properly manage its future in accordance with priorities identified by and for Inuit populations.

This planning workshop will be the first in a series that will cover all Inuit regions of the Circumpolar North. As Nunavik is the region where the Cohort was first established in 2004, it is the region where the first planning workshop will be held.

ACTIVITIES

Analysis of Cohort Data:

Analysis of Cohort data (Canada and Greenland) on hypertension and risk factors was undertaken, however additional validation work will be required prior to finalization of a manuscript (calibration study is required given that different apparatus were utilised to measure blood pressure in Greenland and Canada).

Operationalization of the databank:

Permission from all PIs to merge the three datasets (Nunavik; Nunavut and IHS and Nunatsiavut; and Greenland) remains elusive throughout 2011. Permission will be granted in 2012.

A Management Framework for the Cohort databank will be drafted by end of March 2012.

One study on fatty acids and heart rate variability is underway and is reported under the Marine Fatty Acids in a Changing Canadian Arctic project

Mylène Riva spent three weeks in Copenhagen in November 2011 working on the Greenland Inuit Health in Transition Study to examine the association between housing conditions and Inuit health in Greenland, and between-community variation in risk factors for cardiovascular diseases and indicators of mental health. Three scientific papers are in course of writing, and they will be submitted to peer-reviewed journals before the summer 2012. An abstract from the paper focusing on housing and health will be submitted to the 15th International Congress on Circumpolar Health. This work represents initial steps in getting familiarized with this component of the Cohort and will allow future comparative analyses on housing and health between Nunavik and Greenland. This will then be extended in 2012-2013 using data from Nunavut, Nunatsiavut and IST.

Housing and Health in Nunavik project:

Using data from the Qanuippitaa – How are we? Nunavik Health Study, Mylène Riva has examined the

links between housing conditions and stress among Nunavimmiut; this is the topic of a scientific paper in preparation and will be presented as a poster at the IPY2012 Conference in Montreal in April 2012. The next series of analyses will examine, more largely, the association between housing conditions and health in Nunavik, focussing on indicators of mental health (e.g. psychological distress, alcohol consumption, drug consumption).

As mentioned above, housing is an important determinant of health. Yet in current health surveys, little information is available on housing conditions beyond the number of people per household, the number of rooms, and household assets and amenities. There is therefore a need to develop a survey questionnaire that is adapted and relevant to the housing conditions in Arctic communities and their impact on Inuit health and well-being. Developing such a survey questionnaire requires the collaboration of academic researchers and Nunavimmiut. For now such a research exercise is conducted in Nunavik. To undertake this project, complementary funding of \$15,000 has been applied for, and obtained, from the Nasivvik Center for Changing Environment and Inuit Health.

Preliminary fieldwork was conducted in Nunavik in October 2011 where four communities agree to participate: Kujjuaraapik, Inukjuak, Kangiqsujuaq, and Kangiqsualujuaq. Key representatives from the Kativik Municipal Housing Bureau, Kativik Regional Government, Makivik Society, and Nunavik Board of Health and Social Services are providing input to the project.

A preliminary questionnaire has been devised from existing survey questionnaires about living and housing conditions in the Canadian Arctic (Tester 2006, Statistics Canada 2006, SLiCA 2002); questions from these surveys were pooled and amended to be relevant for the context of Nunavik. This preliminary survey questionnaire will be discussed, modified and improved in collaboration with Nunavimmiut. Themes related to housing and health explored through discussions with participants around the questionnaire will explore: housing history; type of house and design; social com-

position of the housing unit; housing infrastructure; amenities available in the house; housing tenure and access to private housing; surroundings of the house and community conditions; health and well-being.

These themes will be explored through face-to-face discussions and workshops with regional and local stakeholders and community members. Inuit translators will be hired to facilitate discussions. Academic activities on the topic of housing will be conducted in with students in high schools in two communities (Kangiqsujuaq and Inukjuak); these activities have been developed with teachers under the geography curriculum (see below for more information).

The school-based activities will aim to gain the view of young people as to what they consider important aspects of their housing conditions and the type of houses they would like to live in when they become adults. The information provided by these activities will be integrated in the questionnaire. The research protocol will be submitted for ethical clearance from the Centre de Recherche du CHUQ on January 25th. Ethical clearance will be obtained before the projects begin.

Data collection will take place in Nunavik in March 2012 and data will be analysed in March and April 2012. A research report will be produced and will be presented to the participating communities in May and June 2012.

Results of this project (i.e. the survey questionnaires and discussions on housing conditions) will inform the development of a mixed-methods research program on housing and health in Nunavik that will be submitted for funding in October 2012 as part of Mylène Riva's application for junior researcher salary award. Involvement of community members and local and regional stakeholders in the project will set the groundwork for establishing research partnerships with communities in Nunavik and will also contribute to establishing a governance structure for the above mentioned funded projects and for future research projects.

This participatory approach to questionnaire development is central to identify priorities for research on housing and health and to foster the participation of Nunavimmiut.

A report of the project will be written and disseminated to community members, local stakeholders and regional decision-makers. The process of developing the survey questionnaire in collaboration with Nunavimmiut, community and regional decision-makers as well as the outcome (i.e. the survey questionnaire), is likely to be the topic of a scientific publication that will be submitted to a peer-reviewed journal.

There is scope for results of this project to be used to refine the public health strategy of the Nunavik Regional Board of Health and Social Services, aiming to improve the housing situation in the region and to better frame priorities for actions, notably in relation to overcrowding. In addition, the report could be useful for discussion on a regional consultation on housing and health in Nunavik in May 2012.

Preliminary Cardiovascular Follow-up of the Cohort in Nunavik:

Our research team has worked closely with the archivists responsible from both Nunavik coasts; Hudson Bay and Ungava Bay. They have authorized our access to all medical files needed, as well as having provided an area to work. All 14 Nunavik communities were informed of the project and provided with the exact dates for our arrival in their respective community. A health professional from our team spent a month, last October 2011, in Nunavik scanning cohort participants' medical files. Given the tremendous volume of scanning, and bad weather which impeded travel, a total of four of the fourteen communities were not visited (Quaqtaq, Kangirsuq, Aupaluk, Tasiujaq). Therefore, of the 939 cohort participants, 594 participants' medical files were scanned and 460 remaining are currently underway by two experienced research nurses who were involved in the 2005 mortality and morbidity study. Medical data has been extracted from 134 medical files and compiled

into a questionnaire. Data extraction and compilation into the questionnaire for the remaining files are being done simultaneously on site. The overall work of completion of the medical file review should be completed around mid-March 2012 and work on the constitution of the database will be started, but analysis etc. will continue into 2012-2013.

Cohort Planning Workshop:

A CIHR grant has been awarded (in 2011) to bring together researchers, health professionals, community representatives and other stakeholders with an interest in the International Inuit Cohort. The workshop will be held in June of 2012 in Kujjuak, Nunavik.

RESULTS

Analysis of Cohort Data:

Results on hypertension among Circumpolar Inuit populations are preliminary and require a validation study.

Housing and Health Project:

Preparatory work was undertaken in 2011 and the field work will take place in March 2012. No results are yet available. Scientific publications (see Activities and 2012-2013 Planning sections) are in preparation.

Preliminary Cohort Follow-Up in Nunavik:

Preliminary results indicate that 54 participants have deceased since 2005 (39 on the Hudson Bay, 15 on the Ungava Bay) and this result will be validated when the medical files review is completed.

DISCUSSION

Given that the research activities for this project are not at the stage of discussing results, there are none to report for 2011-2012.

CONCLUSION

Given that the research activities for this project are in a preliminary phase during 2011-2012, there are no conclusions to report for 2011-2012.

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Preliminary Cardiovascular Follow-up of the Cohort in Nunavik:

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Cohort Planning Workshop:

- The workshop will be made possible through CIHR financing and in kind support from the Nunavik Regional Board and Social Services.

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