

International Inuit Cohort Study: Developing the next phase

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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 are very similar. To date, all three baseline 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.

This project documents the changing physical, biological and socio-economic conditions that are affecting people in the Arctic and identifies policies and strategies to assist communities in dealing with these changes. The project builds on previous work on the vulnerabilities of Arctic communities, and it is feasible because of established collaborations with northern people and organizations. The project includes case studies in all four of the ArcticNet

IRIS regions. One main focus of the project involves integrating scientific and traditional knowledge of ice, permafrost, coastal dynamics and wildlife with information about community use of these ecosystem services. The other main thrust is to identify the opportunities in existing policies and co-management arrangements for adaptation strategies to help communities deal with changing conditions.

Key Messages

Interest for a Circumpolar Inuit Cohort and follow-up is high. It is seen as a commodity valuable not only to the scientific and health communities, but also in terms of the discourse at the international level which speaks on behalf of Arctic people at the global scale.

The development of a Circumpolar Inuit cross-disciplinary data platform was undertaken during year 2012-13 and will be operational in 2013-14 enabling the query of data from 2 or 3 or the Inuit Health survey datasets.

Housing and health studies indicate that living in inadequate overcrowded households is associated with poorer physical and mental health among Inuit. Reducing household crowding, through housing policies, is likely a key strategy to improve Inuit health and well-being.

Overall, studies of community conditions as determinants of Inuit health show that there is a complex patterning of risk factors for health in relation to community characteristics. More studies are needed to better characterise the social, economic and built environments of communities in order to understand their relevance for Inuit health and well-being.

Planning for a follow-up health survey in Nunavik will begin in earnest in 2013 with field operations slated for fall of 2014.

Objectives

- Enable and undertake Circumpolar Inuit health research based on the query of data from the three baseline health surveys (operationalise the interoperability among the three datasets)
- Prepare for the follow-up to the baseline health survey which took place in Nunavik, 2004 and collaborate in the preparation of survey follow-up in Greenland (exploratory research; workshop and planning; ongoing collaboration)

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. It indicates 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. 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. Longitudinal 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.

Activities

Pertaining to Objective 1 -

1.1 Development of Circumpolar Inuit cross-disciplinary data platform (collaboration with Laurie Chan, Ottawa U.; Kue Young, U of Toronto; Peter Bjerregaard, Greenland Health; Mélanie Lemire, Mylène Riva, Michel Lucas, Elhadji Annassour)

A planning meeting was held in Ottawa among the Principal Investigators and teams of the 2 Canadian Inuit Health Surveys to discuss mechanisms for enabling and facilitating the study of data from two or three of the Inuit health datasets (Nunavik; IPY; Greenland) and future datasets to be collected during follow-up cohort surveys.

Summer of 2012, Dr. Aline Philibert was hired for her extensive experience with large health datasets. She has developed a conceptual framework for a cross-disciplinary data platform. A detailed analysis of the comparability/interoperability of the three datasets is underway (several tasks are involved and require additional human resources see list below*). The results will provide 1) a data platform which is the documentation required for an investigator to decide on the feasibility and scope of a research question drawing on 2 or 3 of the datasets; and 2) information for decision making with respect to the feasibility of merging two or three of the datasets and 3) inform all PIs in the planning of future follow-up activities in terms of moving towards increasingly comparable datasets.

* The Rationale of the International Circumpolar Data Platform

- Data Platform Organization
- Data Inter-operability
- Consistent File Structure and Stable File Formats
- Contents of Data Files
- Quality assurance and back-up procedures
- Ethics and References
- International Circumpolar Data Platform Access and Security
- Copyright and Intellectual property Rights of the Data
- Consents for data sharing
- Data management responsibility

Consensus among the team on the conceptual framework of the cross-disciplinary data platform, the structure of the platform, partnerships between research teams, communities and others, applications and exports has been reached. Additional work on coding books from two of the surveys will be performed this winter/spring as well as organisation of a data inter-operability document between the three surveys (core deliverable).

1.2 Analysis of circumpolar cohort data

Pending the results of activity 1, the comparative analysis of circumpolar data remains limited. Several studies based on data from one of the three Inuit health surveys have been published, are in press or are in preparation however (list provided on request).

Related to Objective 2 -

Note: M. Riva is on maternity leave from August 2012 - July 2013 (approx.)

2.1 Housing and Health in Nunavik project:

This exploratory research project contributes to the second major objective of this ArcticNet project for it will inform health survey follow-up activities on what is accepted to be a critical health determinant in Inuit regions.

Housing conditions are a critical public health concern across the circumpolar north; this issue has been empirically examined in two papers. The first paper, "Household size and crowding are associated with higher allostatic load among Inuit", examines associations between household conditions (household size and crowding) and chronic stress (measured using an allostatic load (AL) index) among Nunavimmiut. Cross-sectional data (n=723 adults) are from the 2004 Nunavik Inuit Health Survey. Findings of this study were presented at the IPY conference in Montreal in April 2012; the paper will soon be submitted to a peer-reviewed journal.

The second paper examines the impact of household crowding and social structure on mental symptoms and comorbid behaviours among Inuit in Greenland (“Mental symptoms and comorbid behaviors among Inuit in Greenland: the role of household crowding and household social structure”). Write-up of the article is being finalized and results were presented at the 15th International Conference on Circumpolar Health, in Anchorage, Alaska, in August 2012. Analyses are based on data from 3108 Inuit aged 18 years and older collected during the Inuit Health in Transition Survey. Mental symptoms and comorbid behaviors considered were: feelings of depression and of anxiety; binge drinking; harmful drinking; and use of marijuana. Household crowding was measured by the number of people in the house, and the social structure by the adult to children composition of the household.

In preparation:

1. Riva, M., Plusquellec, P., Cartier, C., Juster, R.P., Déry, S., Dewailly, E. Household crowding as a source of chronic stress for Inuit in Nunavik: future implications for cardiovascular health? Forthcoming.
2. Riva, M., Lytken Larsen, C.V., Bjerregaard, P. Geographic and social inequalities in mental health symptoms and problem behaviours among Inuit in Greenland. Forthcoming.

2.2 Community conditions as important determinants of Inuit health

To date, most of the epidemiological research on Inuit health tends to attribute ill-health to individual causes, e.g. to behavioural risk factors. Such a perspective ignores that the distribution of health within population is a function of both the characteristics of people and the conditions of the places in which they live. Indeed, people with similar characteristics but living in communities with different social, built and physical conditions may have different health statuses. This supports the idea that knowledge on the distribution and determinants of population health is multilevel and

requires considering both the characteristics of people and the conditions of communities. More than fifteen years of multilevel research demonstrate significant associations between social and economic environment of communities and cardiovascular health and its risk factors as well as with mental health outcomes and comorbid behaviours. These associations persist after controlling for a range of individual-level factors, suggesting that environmental conditions are likely to be important in shaping the distribution of health risks, over and above people’s attributes. Such multilevel investigations have yet to be extended to Indigenous populations to assess the distribution and determinants of health outcomes and risk factors.

The salience of socioeconomic conditions of communities for risk factors for cardiovascular diseases (CVD) (“Variation in risk factors for cardiovascular diseases between inuit communities in Greenland”) and mental health symptoms and comorbid behaviours (“Geographic and social inequalities in mental health symptoms and problem behaviours among Inuit in Greenland”) is the topic of two papers, based on data from the Inuit Health in Transition Survey (Greenland). Risk factors for CVD considered included: smoking, obesity and hypertension; mental symptoms and comorbid behaviours included: feelings of depression and of anxiety, binge drinking and addiction to alcohol and drugs. Communities were characterized in terms of their urbanicity (towns vs. villages) and their level of affluence (levels of disposable income).

In preparation:

1. Riva, M., Lytken Larsen, C.V., Bjerregaard, P. Variation in risk factors for cardiovascular diseases between Inuit communities in Greenland. Forthcoming.
2. Riva, M., Lytken Larsen, C.V., Bjerregaard, P. Mental symptoms and comorbid behaviours among Inuit in Greenland: the role of household crowding and household social structure. Forthcoming.

2.3 Cohort Planning Workshop

A workshop entitled Inuit Health in Transition Study: The Circumpolar Cohort Nunavik Planning Workshop took place June 11th-13th, 2012 in Kuujjuaq, Nunavik. A total of 25 people representing Nunavik public health, health research from all Inuit regions, several Nunavik organizations, government and health sectors from Nunatsiavut, as well as from the national organisation Inuit Tapiriit Kanatami gathered for the workshop. The context for the workshop was the monitoring and studying of the epidemiological transition taking place among Inuit populations across the circumpolar world. The main purpose of the workshop is to provide a document that will help guide the planning process for Inuit Cohort follow-up activities with particular emphasis on the Nunavik region. The final report presents Key messages; Health priorities and related issues; Shaping a follow-up to the Qanuippitaa? How are we? health survey; and The Circumpolar Inuit Cohort. The final report is in translation and will be available in English and Inuktitut this winter.

2.4. Preliminary Cardiovascular Follow-up of the Cohort in Nunavik:

A database of medical charts from 856 of the Nunavik Cohort participants was constituted and is ready for analysis.

Results

1.1 Development of Circumpolar Inuit cross-disciplinary data platform (collaboration with Laurie Chan, Ottawa U.; Kue Young, U of Toronto; Peter Bjerregaard, Greenland Health; Mélanie Lemire, Mylène Riva, Michel Lucas, Elhadji Annassour)

A highly detailed data inter-operability (comparability document) document between Greenland and HIS is complete and the addition of the Nunavik dataset will be completed by end of March.

1.2 Analysis of circumpolar cohort data

Pending the results of activity 1, the comparative analysis of circumpolar data remains limited. Several studies based on data from one of the three Inuit health surveys have been published, are in press or are in preparation however.

2.1 Housing and Health in Nunavik:

Studies:

Results of the allostatic load study show that increased household size and crowding were significantly associated with an elevated AL index. This study is the first to find that living in more densely populated households is a source of chronic stress for Inuit.

Results of the Greenland study show that increased number of person in the house was associated with higher risk of reporting feeling anxious or depressed, but with lower risks of heavy drinking, use of marijuana, and marginally with harmful drinking.

The project “Housing, health and well-being in Nunavik: The views of Nunavimmiut”

The objective of this project was two-fold: 1) to better understand the perceptions of Nunavimmiut of the housing situation in their communities and the impact of housing conditions on their health and well-being; and 2) to collaboratively develop a questionnaire to measure housing conditions that is adapted to Inuit culture. Toward these ends, 25 Nunavimmiut were interviewed in February and March 2012. This project also involved the collaboration of organizations responsible for housing in Nunavik, i.e. the Kativik Municipal Housing Bureau [KMHB], Société d’habitation du Québec (SHQ), Makivik Corporation, and Kativik Regional Government.

Throughout the interviews, health and well-being issues were discussed in relation to physical and social dimensions of housing and the environment in which the houses are located. The physical aspects of a house discussed in relation to health and well-being included the heating of the house, with colds and coughs being

associated with cold houses in the winter. Risks of falls and injuries in the house were identified. The level of noise within the house (mainly coming from tenants and the furnace) as well as the lack of noise isolation between housing units and/or from outside was mentioned as being problematic. Noise “gets on [people’s] nerves” and “creates a stressful living environment”. A few participants mentioned problems with allergens, such as molds and insects in the bathroom.

Household overcrowding was seen as causing health and behavioral problems by many. Several noted that overcrowding created social problems in the house, for example lack of respect for others, problems with drugs and alcohol, eliciting arguments, violence and sometime sexual abuse of children. Others reported that living in an overcrowded house was a stressful situation, bringing increased responsibilities for domestic chores (cooking, cleaning, etc.). Some argued that the difficult housing conditions triggered anger and depression in the community. Participants also spoke about infectious diseases such as colds and tuberculosis in reference to overcrowding. More general repercussion of housing conditions on well-being and quality of life were identified, for example children’s achievements in school. Social problems at home and not being able to have a house (or being on the waiting list for a long time) influence the likelihood of being able to obtain and keep a job. The sense of belonging and control over one’s house is also susceptible to influence health and well-being. Participants spoke about the lack of choice when it comes to moving into a new house and the high cost of building and maintaining a house which prevent a large portion of the population to access private housing.

Most participants spoke about problems with housing shortage. The shortage of housing in Nunavik causes a problem of hidden homelessness in the region (people sleeping/living in shacks or cabin because they can’t have a house in town; people ‘couch surfing’ in relatives’ or friends’ house), as discussed by some participants. In addition, some participants spoke

about the obvious inequalities of housing conditions between Inuit and southern employees of government or regional organisations. Such unequal situation can create unnecessary tensions in the community which may have an impact on health and well-being.

Social cohesion and social support in the community are important for good health. In general, Nunavimmiut held positive views of their community, noting that their community was rather close-knit and peaceful. However, in some communities, participants observed that alcohol, drug consumption and vandalism were problematic, notably in areas of town where there were apartment buildings. In communities with alcohol outlets, streets where the bars are located were thought of as less safe. Indeed, some women reported not feeling safe in parts of their communities where there are problems with alcohol and drug consumption. Vehicular traffic was perceived as being unsafe for children, and loose dogs were a worry for some parents who, as a result, are not letting their children play outside.

A report of this project was produced in English and translated in Inuktitut, and shared with all participants and organizations involved. Discussions with Nunavimmiut allowed identifying how a broad range of housing conditions can influence health and well-being. Improving the housing situation is a priority in Nunavik to improve people’s health. This project showed the importance of addressing the issues of housing shortage and overcrowding. Better maintenance and heating, and rethinking the design of houses so they are more coherent with Inuit traditional way of life, also appear as important components of housing conditions to address. Insights gained into the different dimensions of housing will contribute to the development of a survey questionnaire to measure housing conditions in the Canadian Arctic, based on local and traditional knowledge and developed in collaboration with Nunavimmiut. This questionnaire will be used in the next phase of the Nunavik Inuit Health Survey to assess and monitor housing conditions and their influence on health and well-being; this questionnaire will be pilot-tested

beforehand. Results of this project are susceptible to inform and support social and housing policies aiming to improve the housing situation in Nunavik and the health and well-being of Nunavimmiut.

2.2 Community conditions as important determinants of Inuit health

Results show important geographic inequalities in risk factors for CVD and mental health among Inuit. People living in villages were more likely to report being anxious but less likely to report binge drinking and addiction problems. Risks of smoking, hypertension and binge drinking were lower in communities characterised by higher disposable household income. However, in these types of community, the risk of obesity and anxiety were higher. These two studies also show important social inequalities in risk factors for CVD and mental health among Inuit, especially in relation to gender and socioeconomic status.

2.3 Cohort Planning Workshop

Key Messages from the Workshop Final Report are presented below. Additional and more detailed workshop results are presented in the final report which will be available on the Nasivvik web site by the end of March, 2013.

The way forward for the health of Nunavummiut has multiple paths – on the one hand, that the approach of those with an interest in improving the health of the community be fundamentally more positive – instead of trying to understand what’s broken and why in order to fix it, take stock and celebrate what works with the intent of growing the positive. On the other hand, also invest in the healing that is required for those wounds that run deep. Experiences which are, for example, traumatic are serious and can be seen as the “weakest link” to the health of a society and thereby require immediate, adequate and appropriate attention.

Participants identified many wish-list items for the Nunavik health survey follow-up. Some of these fall within the traditional approach and methods typically adopted for health surveys, that of questionnaires and clinical measurements from individuals. For example, information about immunization and protection against sexually transmitted infections could be collected in this way. However, certain subjects such as understanding family dynamics; mapping community assets and social networks; how people interact with the later and develop a sense of belonging, may require a mix of qualitative and quantitative approaches and methods to data gathering and analysis. These fresh lines of inquiry were themes that were identified as very important to addressing community level health issues.

The purpose of a health survey or of following a cohort over time in the context of Nunavik Inuit should include finding solutions to current problems and/or supporting interventions. For example, the relationship with alcohol in Nunavik communities remains problematic and time has come to focus on finding solutions, and not simply establishing or measuring the extent of the problem. Youth, for many reasons mentioned, need to be part of this whole process. Their health needs - both as identified from their perspective as well as from a perspective of experience – need fleshing out and considered in health survey/cohort planning.

Interest for a Circumpolar Inuit Cohort and follow-up is high. It is seen as a commodity valuable not only to the scientific and health communities, but also in terms of the discourse at the international level which speaks on behalf of Arctic people at the global scale. However, administratively there is much that remains undetermined for the operationalization of a Circumpolar Inuit Cohort Databank. Such a process will touch on all ethical and functional aspects of data management including where the data will be housed and what process will be followed to provide a controlled access to it. Resources are needed to pursue the full process of creating, an “official” Databank.

The Nunavik region is gearing up for starting in earnest preparations for a follow-up health survey perhaps in the fall of 2014. Greenland Health has established that a follow-up survey will take place but will be more focussed than the baseline survey, due to resource restrictions. No dates have been suggested. The process for the regions covered by the IPY Adult Inuit Health Survey, is reportedly suffering from depleted resources and as such cannot at this point envisage planning a follow-up survey, moreover the data from the IPY survey is still relatively recent. Nevertheless, harmonizing the realisation of each of three components of the Circumpolar Inuit Cohort in terms of time remains a desirable goal to pursue.

2.4 Preliminary Cardiovascular Follow-up of the Cohort in Nunavik

No analyses have yet been carried out on the database.

Discussion

1.1 Circumpolar Inuit cross-disciplinary data platform

Once the inter-operability documentation is complete an evaluation will be performed to inform options regarding merging of datasets (winter/spring 2013). The ensuing “discussion” is not available at this time.

2.1 Housing and Health, Greenland Study

These associations were explained when considering the social structure of the household. Compared to households with children, the risk of feeling depressed was less likely among people living in ‘adult-only’ households. Risks of binge drinking and using marijuana were significantly higher in households composed only of adults. Although similar patterns of associations are observed in sex-specific analyses, household crowding and the social structure of the household appear to influence women’s mental symptoms and comorbid behaviours to a greater extent than they do for men.

2.1 Community conditions as important determinants of Inuit health

Overall, these studies show that there is a complex patterning of risk factors for health in relation to community characteristics. More studies are needed to better characterise the social, economic and built environments of communities in order to understand their relevance for Inuit health and well-being. This will be the focus of research for the period of 2013-2014. Results of these studies can be useful to support the formulation of public health and social measures targeting community conditions as possible strategies to yield population-wide health benefits. Write-up of these studies is underway.

Conclusion

1.1 Circumpolar Inuit cross-disciplinary data platform

Conclusion regarding best approach for querying 2 or more of the health survey datasets not available at this time (anticipated winter/spring 2013).

2.1 Housing and Health studies

These findings suggest that exposure to chronic stress associated with living in inadequate overcrowded households contributes to explaining the high prevalence of mental symptoms and comorbid behaviours among Inuit. The presence of children in the house appears to act as a ‘regulator’ of unhealthy behaviours.

Together, these studies indicate that living in inadequate overcrowded households is associated with poorer physical and mental health among Inuit. Reducing household crowding, through housing policies, is likely a key strategy to improve Inuit health and well-being. To better inform the formulation of housing policies, more research is needed to understand the pathways through which housing conditions “get under the skin” to influence Inuit health and well-being. As well, more research is needed to conceptualize and operationalize household

conditions in coherence with the Inuit culture. These issues will be tackled during the 2013-2014. As well further analyses will be conducted using data from the circumpolar studies to examine the role of housing conditions on other physical and mental health outcomes, as well as on food security.

Acknowledgements and References

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