

ORIGINAL ARTICLE

The development of a comprehensive maternal–child health information system for Nunavut-Nutaqqavut (Our Children)

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ABSTRACT

Objectives. Nunavut is the most northerly jurisdiction in Canada of which 85% of inhabitants are Inuit. Although most infants are born healthy, Nunavut leads the country for adverse early child health outcomes such as infant mortality, rates of birth defects, prematurity and low birth weight. Public health and community efforts are needed to understand and improve outcomes.

Methods. To inform these issues, a combined University of British Columbia/Nunavut Public Health Strategy effort has initiated a comprehensive maternal–child health surveillance system (from 16 weeks gestation to age 5). A diverse group of professional and lay stakeholders were brought together initially to determine local interest. Following this, a series of small working groups were held to decide on potential prenatal, perinatal and early child health variables, to be documented.

Results. Over 100 Nunavut participants have now had some role in the development of the system which has been initiated. Pre-existing standard prenatal forms and well-child assessment forms have been modified to include “Nunavut specific” variables of nutrition, food and domestic security, exposures in pregnancy, birth defects, development, chronic diseases of childhood and paternal information.

Conclusion. This comprehensive maternal–child health information system has been developed with the extensive input of health care providers and stakeholders, utilizing community and public health systems already in place. Careful assessment of local needs has contributed to database development, privacy protection, potential data utilization for health promotion and plans for dissemination of findings. It is hoped that this will be a user-friendly surveillance system, adaptable to other community and public health systems that will improve the understanding of Aboriginal maternal–child health determinants.

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Keywords: Nunavut, maternal–child health, birth defects, infant mortality, surveillance

Background

Nunavut is the most northerly jurisdiction in Canada, with about 33,300 inhabitants, of which nearly 85% are Inuit (1,2). There are great challenges to delivering active and preventative health care throughout this land mass of 1.8 million km². Although most infants are born healthy, Nunavut leads the country for adverse early child health outcomes such as infant mortality rates (3), birth defects (4), prematurity and low birth weight (4–7).

Infant mortality

Infant mortality rates (infants dying before their first birthday/1,000 live births) in Nunavut have been consistently reported on average to be three times that of the rest of Canada (3). A recent published analysis suggested that between the years 1990 and 2000, infant mortality in Inuit-inhabited areas was 3.45 times the Canadian rate (16.5 mortalities/1,000 live births compared to 4.6/1,000 in the rest of Canada) (8), a rate not seen in the general population of Canada since the early 1970s.

Importantly, deaths from Sudden Infant Death Syndrome (SIDS) were 6.3 times higher than the rest of Canada, at 5.2/1,000 live births compared to 0.7/1,000 in the rest of Canada (8). This information is crucial, in that excess deaths from SIDS may be prevented with reduced exposure to maternal cigarette smoking (9), positioning of infants on their backs while sleeping (10) and with recognition and management of genetic conditions which might predispose infants to SIDS (11,12). Until now, in Nunavut, there has been no systematic way to collect data on causes and determinants of infant mortality with a goal towards prevention.

Birth defects

In general, about 3% of all newborns (1/30) will be born with a major malformation. Genetic factors might increase the risk of birth defects, as well as exposures to alcohol, smoking and other substances. Nutritional status of the mother needs also to be considered in that micronutrients such as folate and vitamin A, both flagged previously as nutrients of concern in Arctic regions, are important in early development (13,14).

Birth defect rates have been a concern for nearly two decades in Nunavut. Since no surveillance system was in place, a baseline chart review of over 2,500 Inuit births taking place in Nunavut and Nunavik (arctic Quebec) between 1989 and 1994 revealed that the overall rate of major malformations was twice the rate of that seen in a Canadian provincial birth defect registry, the Alberta Congenital Anomalies Surveillance System (ACASS) (4). In particular, rates of septal heart defects (ICD-9 code 745) were nearly four times higher than expected. Another chart review, completed for Inuit births in Nunavut between the years 2000 and 2006, suggests that the rate of septal heart defects has decreased slightly, but remains three times higher than observed in the ACASS for the same time period (18.3 vs. 6.2/1,000 OR 3.0; 95% CI 2.23–4.2 $p < 0.0001$) (15). Furthermore, jurisdictional comparisons in Canada have confirmed that at least for the neonatal period, heart defects rates are significantly increased in Nunavut compared to the other Canadian jurisdictions in the north and south (16).

Risk factors for adverse birth outcomes

Rates of prematurity, small for gestational age births and low birth weight (under 2,500 grams) are important markers of perinatal health. Of

concern in Nunavut is that more than 80% of women report smoking during pregnancy, which can contribute to these outcomes (17,18). While overall evidence supports a relationship between maternal smoking and increased risk of prematurity (19,20), a previous chart review from the Baffin region of Nunavut between 1998 and 2000 (5) showed no clear relationship between premature births and maternal smoking. However, a recent study of 918 births in the Qikiqtaaluk region (Baffin Island) exploring quantities of cigarettes smoked and birth outcomes suggests that those mothers smoking more than 10 cigarettes per day are at significant risk for the stated adverse outcomes (17). At this time, the complex background that contributes to a decision to smoke more than 10 cigarettes per day at the first prenatal visit is unknown. For example, partner support, depression and income might all be contributors. Other substance use and a suboptimal nutrition status may also contribute to these outcomes (21). Furthermore, it is important to have an understanding of the positive effects of reduction and cessation of smoking during pregnancy as effective strategies are put into place.

A great deal of attention has been focused on the rates of foetal alcohol syndrome in Aboriginal populations and have resulted in public health efforts to raise awareness about the harm that alcohol intake during pregnancy can have on foetus (22). Interestingly, it has been shown through self-reported surveys and studies of alcohol consumption per capita, that the Inuit of the Baffin region drink significantly less alcohol (about one-quarter the amount) than their non-Inuit southern counterparts (23). Other studies of Canadian Inuit have suggested that although alcohol use during pregnancy is not common (about 10%), when drinking does

occur, it is likely to be consistent with binge drinking, which may be particularly risky to the foetus (24). The Nunavut Inuit Health Survey revealed that about 8% of pregnant women report having more than 5 drinks on a single occasion during their pregnancy (18). Prenatal alcohol exposure has rarely been studied in relationship to birth defects and birth outcomes in Nunavut. Although there are anecdotal reports of increased use of marijuana during pregnancy (17), the effects on birth outcomes have not been well documented.

Breastfeeding

Traditionally, Inuit children were breastfed for prolonged periods, well into their third and fifth years (25,26). In recent times, reports have been emerging suggesting that the Inuit of Nunavut have a rate of initiation of breastfeeding lower than the national average (18,27). Since breastfeeding has the potential of preventing infant mortality, reducing chronic diseases, improving immunity and strengthening the maternal–infant bond, exploration into the determinants of breastfeeding in Nunavut is crucial.

Respiratory infection

Infants in Nunavut have the highest reported rate of hospitalization for lower respiratory tract infections in the world, with an average of 306 admissions/1,000 infants (28), and for those infants with heart defects, the rate is even higher at more than 800/1,000 (29). A premature birth, exposure to smoking in the home, living in overcrowded conditions with poor ventilation (28,30) are all risk factors for respiratory infections leading to hospital admissions. Documentation and ongoing assessments of relevant determinants are needed in order to address this priority issue more comprehensively.

Other chronic diseases of childhood

It has been suggested that conditions such as autism and foetal alcohol syndrome may be lower in Nunavut communities; however, there are no statistics from Nunavut that might confirm or refute these observations. However, a study of the Canadian Pediatric Surveillance System has revealed that 24% of all cases of pediatric rickets reported in Canada are among the Aboriginal population (14% First Nations, 10% Inuit) (31). The impact of the northern climate could exacerbate the occurrence, although genetic predisposition to altered vitamin D uptake or synthesis might also play a role. An assessment of the success of current public health initiatives to reduce the risk of rickets would be useful.

Hearing loss has been considered an extremely important contributor to disability affecting a disproportionate number of northern Aboriginal children, possibly a secondary condition to chronic otitis media (OM). The Nunavut Inuit Child Health Survey suggests that more than 80% of children between the ages of 3 and 5 have been treated for OM (18); however, it does not reveal the extent of chronic OM or its association with hearing loss. Hearing loss affects early language development and academic success, having a potentially detrimental effect on an individual's economic contribution and the building of relationships. Surveillance of rates and determinants of hearing loss across Nunavut will provide broad epidemiological data important for service delivery as well as appropriate etiologic assessment.

It has been speculated that other chronic conditions of childhood (such as epilepsy) are on the rise in Nunavut; however, sound popu-

lation studies to determine if this is true have not been carried out. Obesity in childhood may predispose an individual to chronic diseases in later life, and there is now evidence that obesity in childhood is a major problem emerging in Nunavut (32).

Summary

The full extent of the adverse birth outcomes, birth defects and other chronic diseases of childhood in Nunavut need appropriate exploration and action. Current data sources, such as those collected for the Canadian Institute for Health Information (33) are not ideal as they are largely limited to analysing in patient hospital discharge summaries and death certificates, which can skew the results of small populations if data contains inaccuracies. Databases which include direct source reporting are known to be more informative. Although health surveys provide cross-sectional views that are helpful to provide background and to institute change, ongoing assessments of determinants and outcomes relevant to the population need to be planned carefully. The relatively low number of births in Nunavut (about 800/year) but the greater risk of adverse birth outcomes justifies the development of a comprehensive reporting system to understand and improve outcomes. Modelled after current provincial systems that collect prenatal, perinatal and birth defect information, a comprehensive system responding to local maternal–child health needs will provide the tools for further research and intervention to improve outcomes. A system that considers the issues as a continuum from 16 weeks gestation until pre-school was therefore explored and decided upon.

The Nunavut public health strategy: building a sustainable public health maternal–child health information system for Nunavut

The Canadian Congenital Anomalies Surveillance Network (34) met in January 2005 in Ottawa. At that meeting the Chief Medical Officers of Health from Nunavut, Northwest Territories and Yukon met to discuss the importance of a tri-territorial initiative for perinatal outcomes and birth defects. From there, the opportunity arose to apply to the Canadian Institutes of Health Research (CIHR) for funding as a component of a circumpolar health team grant. One section of this subsequently successful grant was dedicated to maternal–child health surveillance, prompting multilevel community discussions.

In March 2007, Gwen Healey of the Nunavut branch of the Arctic Health Research Network (35) organized a meeting held in Iqaluit, Nunavut, that included teleconferences with communities to discuss the interest and feasibility of population maternal–child health surveillance. Broad support from public health medical officers, local clinicians, nurses, midwives and community health representatives, as well as lay Inuit stakeholders, was confirmed.

In the meantime, extensive literature searches were performed by the UBC group to provide background on existing national and international maternal–child health (perinatal and birth defect) surveillance systems. In August 2007, a 2-day general meeting with multiple stakeholders was held in Iqaluit, Nunavut, to discuss the development of the Pregnancy Outcome and Child Health (POCH) Surveillance system. It was agreed that this population-based information system would be led by the Government of Nunavut through the Department of Health and

Social Services, but the aggregate information would be available to communities, health care providers and others interested in promoting maternal–child health. Several partners confirmed commitment, including the Nunavut branch of the Canadian Prenatal Nutrition Program (36) and Nunavut Tunngavik Incorporation (37). This initiative would help fulfill one of the major priorities of the 2008 Public Health Strategy for Nunavut, “Developing Healthy Communities” (38). It was proposed that the information system include territory-wide data from the prenatal, perinatal and post-natal time periods as a continuum. Risk factors, affecting outcomes including pregnancy exposures in each trimester, blood glucose in pregnancy, nutrition such as vitamin use, country foods and food security, socio-economic factors, birth outcomes, congenital anomalies, growth parameters, developmental disabilities and chronic diseases would be collected. Each field suggested was prompted by the potential of addressing a relevant question. The goal would be to build a long-term sustainable system for Nunavut with the purpose of determining factors that promote maternal–child health.

Fields development

Numerous consultations and discussions were held to determine the appropriate data fields recommended for collection. Working groups for (1) prenatal/perinatal and (2) post-natal data fields were struck. Drs. Arbour and Osborne attended each working group meeting with Samantha Lauson (project leader). It was learned that the majority of information of interest was already being collected through the existing Nunavut prenatal and perinatal forms (Prenatal Record, Labour & Delivery Summary, Newborn Summary). However, beyond the required fields

collected for the Canadian Institute of Health Information (33), there was no mechanism in place for systematic collection and analysis of the perinatal and post-natal data. There was an identified need for Nunavut-specific fields to be collected, such as details on teratogen exposures throughout pregnancy, nutrition including food security and determinants of maternal and infant anemia. These fields were considered a priority, in comparison to other standard perinatal fields (such as interventions at delivery) to address the needs of those in Nunavut. Numerous discussions were carried out, where local input influenced which fields would be most suitable for territory-wide surveillance, based on the needs of the people of the territory. Although other provinces served as models for the type of information, the needs were felt to be unique in this northern population where a broader view of health determinants would be needed to address the issues of concern.

Database development

Existing database systems nationally and internationally were assessed. Cost efficiency, technology support and ease of adaptation were all considered. It was decided that Nunavut's database would be an integration of 3 sub-database systems, adopting 2 that were already well-established and had been in existence for at least 20 years: the B.C. Perinatal Database Registry (39) and EUROCAT (40), a European multi-jurisdictional birth defect database. The third sub-database would be a custom-made, overarching system incorporating the 2 existing databases and the Nunavut-specific fields at every time interval from 16 weeks gestation until birth, 2 months, 6 months, 1 year, 2–3 years and preschool.

Form development

Once the database fields were decided upon, the Nunavut perinatal forms were assessed. It was decided to modify the existing Nunavut prenatal records in order to incorporate the suggested Nunavut-specific fields as well as the updated list of standardized core variables from CCASN (Canadian Congenital Anomalies Surveillance Network) (34). The prenatal records were modified for future use in consultation with the health care providers across the territory, including input from nurses, midwives, dietitians, dental professional and clinicians. At delivery, copies of these forms will be forwarded for entry into the database at the office of the Chief Medical Officer of Health. These prenatal records were professionally printed and distributed in July 2010 for piloting. Evaluations were completed and revisions made according to input in the spring of 2011.

In order to collect specific information on congenital anomalies, an additional form was developed, the "Birth Defects Reporting Form." This 1-page form is for use by any health care provider to report congenital anomalies in the population until pre-school. The Birth Defects Reporting Form is printed in duplicate, with 1 copy kept in the child's chart and another copy sent for data entry. This portion of the data collection will also be reported to the Public Health Agency of Canada.

Although more than a dozen public health assessments are performed on all Nunavut children, only information obtained at 2 months, 6 months, 1 year, 2–3 years and preschool will be included in the surveillance database. Standardized growth parameters have not been developed previously for Inuit children, and therefore will be developed from this information. Nutrition, including length of breastfeeding and food

security, will be assessed. Developmental conditions (such as autism or foetal alcohol syndrome) as well as the need for developmental support, including speech therapy, will be documented. Ear and lung infections, chronic diseases of childhood and hearing loss will be documented.

In addition to the Birth Defects Reporting Form, congenital anomalies will be documented for data entry at each of the 5 well child time frames. All current Nunavut forms (prenatal, delivery, birth defect reporting and well child) can be found at <http://medsci.uvic.ca/faculty/arbour.php> under *forms*.

Communication strategy

A communication strategy is underway. Territory-wide teleconferences have been held and brochures have been developed, for both the public and health care providers. Posters will be placed in health centres.

Privacy

The revised prenatal records and well-child assessments will be kept in the hospital and community health charts of the mothers and children, simply replacing previous records. The information will be considered confidential as is all patient chart information. Individual identifiers will be removed upon transfer of copies to the data centre, which houses epidemiology information for Health and Social Services Nunavut, but a unique identifier will allow accurate longitudinal collection of information. The information as entered in the database will be used only for population health assessments. From the database, no individual access will be possible, preventing any individual release to third parties. A new Public Health Act for Nunavut is currently being developed and will take into consideration the need for collection of health information to improve the health status

of residents but also protect patient privacy and confidentiality. In the interim, in June 2011, the Nunavut Cabinet approved the Nutaqqavut (Our Children) Health Information System (NHIS) under the Access to Information and Protection of Privacy Act to ensure protection of the health information.

Governance

As part of the public health strategy, a subcommittee with broad representation of all regions of Nunavut will oversee the activities of the information system with the input of Nunavut Tunngavik Incorporation.

Research advisory board

Community members, researchers and health care providers will have the opportunity to utilize the data to answer research questions. All research questions will need to be vetted through a stakeholder research advisory board considering the interests of the residents of Nunavut. Appropriate institutional research ethics board approval and Nunavut Research Institute (41) approval will be required as such approval is required for all research.

Surveillance in other Canadian jurisdictions

Other Canadian jurisdictions such as British Columbia, Ontario and Nova Scotia have been collecting data on prenatal risk factors and perinatal outcomes as a standard of practice. For example in British Columbia, the BC perinatal health program (42) through the BC perinatal database registry is now collecting approximately 300 fields of information, publishing reports online and continuing to update local regions as to their outcomes, which it has been doing for more than 15 years. Birth defect surveillance systems have been in place for longer periods of time in juris-

dictions such as British Columbia and Alberta. To our knowledge, although equally as important, early child health surveillance systems that record chronic diseases of childhood, development or growth parameters are rare in Canada. There is some precedent, however, in that the Health Status Registry of British Columbia (43) has been documenting birth defects, chronic and debilitating diseases from childhood up until the age of 21 for more than 50 years (44) and linking with other health databases in British Columbia such as to the BC Perinatal Data Base Registry is possible. In Nunavut, there has been no such mechanism for the collection of maternal or child health information.

Future directions

The development of the information system will allow comparisons for similar populations across Canada's North (Nunavik and Labrador) and internationally. For example, NHIS has comparable fields to some of the questions asked as part of the child cohort study (Ivaq) now underway in Greenland (45). Breastfeeding practices and growth parameters derived from Ivaq will likely be of common interest once similar data is generated from NHIS. Furthermore, the PRAMS (the pregnancy risk assessment monitoring system) is also a likely source of comparative data. About 75% of states within the United States are participating in this study, including Alaska where one in 6 mothers are sent a survey that attempts to address behaviours that might influence birth outcomes such as birth weight, prematurity and infant mortality (46).

In general, information such as birth outcomes and congenital anomalies might be of interest for comparison to a number of other circumpolar jurisdictions. Currently, efforts are underway to improve and standardize maternal child health

surveillance across the circumpolar world (47). At this time, biological maternal and newborn samples will not be collected as part of the public health information system in Nunavut; however, given community interest in contaminant or gene-environment interaction, this area could be explored in the future.

Conclusion

The development of the Nunavut Health (Our Children) Information System initiative takes into consideration the unique issues of this northern jurisdiction, developing a system relevant to its population's needs through broad collaboration. The goal is to understand and prevent adverse outcomes and to include information on favorable outcomes that will enhance understanding. The information system offers the opportunity to develop baseline statistics and to observe changes longitudinally with interventions and time. The involvement of various levels of the community ensured local relevance in that the initiative would take into consideration the opinions of front-line health care providers and other stakeholders. It is hoped that this information system model will be useful for other similar populations.

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