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The current state of birth outcome and birth defect surveillance in northern regions of the world

Laura Arbour, Vladimir Melnikov, Sarah McIntosh, Britta Olsen, Geraldine Osborne & Arild Vakt skjold

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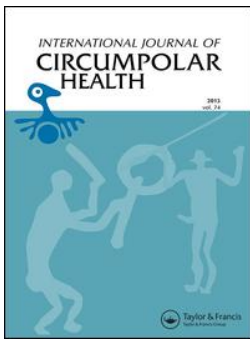
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ORIGINAL ARTICLE

# THE CURRENT STATE OF BIRTH OUTCOME AND BIRTH DEFECT SURVEILLANCE IN NORTHERN REGIONS OF THE WORLD

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## ABSTRACT

**Objectives.** Little is known about the rates of congenital anomalies in the northernmost regions of the world. As in other parts of the world, it is crucial to assess the relative rates and trends of adverse birth outcomes and birth defects, as indicators of population health and to develop public health strategies for prevention. The aim of this review is to catalogue existing and developing birth outcome and birth defect surveillance within and around the geographic jurisdiction of the International Union of Circumpolar Health (IUCH).

**Study design.** Descriptive study.

**Methods.** The representatives of the IUCH Birth Defects Working Group catalogued existing and developing birth and birth defect surveillance systems and the extent of information they contain to determine inter-regional comparability.

**Results.** Systematic population-based registration of birth outcomes including birth defects occurs to some degree in all circumpolar countries, but the quality of collection and the coverage in northernmost regions vary. There are limited circumpolar jurisdictions with surveillance systems collecting birth defect information beyond the perinatal period. Efforts are underway in Canada and Russia to improve the quality and comprehensiveness of the information collected in the northern regions.

**Conclusions.** Although there is variability in the comprehensiveness of information collected in northern jurisdictions limiting sophisticated comparative analyses between regions, there is untapped potential for baseline analyses of specific risks and outcomes that could

provide insight into geographic differences and gaps in surveillance that could be improved. (*Int J Circumpolar Health* 2009; 68(5): 443-458)

**Keywords:** Arctic, circumpolar, birth defects, medical birth registries, congenital anomalies surveillance

## INTRODUCTION

Little is known about the rates of congenital anomalies in the northernmost regions of the world. Worldwide such anomalies constitute a substantial proportion of infant and child morbidity and mortality placing an excessive burden on the health care systems (1) and on the families with an affected child (2). As in other regions of the world, it is crucial to assess the relative rates and trends of all anomalies, especially those amenable to prevention. Many of the existing congenital anomaly and birth registers were spurred by the thalidomide crisis in Europe in the 1960s (3). The importance of monitoring birth defect rates has recently been revitalized due to the preventive success of folic acid fortification and supplementation (4), reducing rates of spina bifida and other birth defects significantly (5–7). The importance of monitoring birth defect rates in northern populations cannot be overestimated because of combined conditions that may predispose them to increased risk and measures that may be taken to prevent them.

The circumpolar Arctic region is vast and the communities are often small and remotely located (e.g., Canada's 3 Arctic territories cover a region of more than 4 million square kilometres for a population of just over 100,000). Remoteness, harsh climate, a diet often low

in nutrients from plant foods (8), high rates of diabetes (9) and obesity (8,10), a high prevalence of cigarette smoking and alcohol abuse and exposure to persistent organic pollutants and heavy metals (11) are conditions that concern many northern peoples, and also increase the risk and burden of birth defects and other adverse birth outcomes.

Indigenous peoples inhabit the circumpolar regions in varying frequencies, from less than 1% in Iceland to higher than 85% in Greenland and the Nunavut Territory of Canada. The importance of understanding the population demographic lies in health outcomes where in Indigenous populations the life span is often lower, chronic disease rates are higher (12,13), and maternal child health indicators of well-being such as low birth weight, preterm birth and infant mortality are a concern (14).

The Birth Defects Working Group (BDWG) of the International Union of Circumpolar Health (IUCH) has representatives from all 5 adhering bodies of the Union: the American Society for Circumpolar Health; the Canadian Society for Circumpolar Health (CSCH); the Danish-Greenlandic Society for Circumpolar health; the Nordic Society for Arctic Medicine; and the Siberian Branch of the Russian Academy of Medical Sciences (15). The group's aims are to (1) establish a methodology of comparing birth defects rates in the circumpolar regions of the world, (2) focus

efforts on birth defects that might be amenable to public health preventative efforts, and (3) review and encourage culturally specific public health efforts in circumpolar regions that will prevent birth defects. The aim of this review is to catalogue existing and developing birth and malformation registries, within the geographic jurisdiction of the IUCH, determine what information is collected, how it is collected and consider whether inter-region evaluations might be possible.

## MATERIAL AND METHODS

The representatives of BDWG reviewed existing and developing birth and congenital anomaly surveillance systems in the jurisdiction of the IUCH and surrounding areas. Specifically, for the United States, registries in Alaska alone are included. In Canada, the jurisdiction of the CSCCH includes all Arctic and subarctic areas and all Indigenous peoples of Canada (16); for Finland, Sweden, Norway, Greenland, Iceland, the Faroe Islands, and Denmark all known registries are included. For Russia, the jurisdiction of the IUCH currently only includes Siberia, but for the purpose of this review, the Northwest region of Russia, the most populated area of the circumpolar north is also included. For each region covered, the national and regional databases have been included, with special focus on northern regions.

The information was derived from publicly available sources including published literature, public health documents, validated Internet sites and from researchers or health care providers with insight into the specific regions. The information collected included

the purpose of the surveillance system (birth or malformation); the gestation from which information is collected; the inclusion of spontaneous and elective abortions; the age of the child until which birth defects are included; the sources of birth defect ascertainment (for example, discharge summary coding or birth attendant reporting); the coding system used (International Classification of Diseases [ICD] or other); and whether Indigenous identifiers were included. The type of surveillance system (institution or population based) was also noted. Research databases were excluded from this review.

## RESULTS

### Alaska

The Alaska Birth Defects Registry was established in 1996 to monitor the prevalence and trends of birth defect and other congenital anomalies. Health care providers, hospitals and other facilities are required to report when they have cared for a child (until age 6) with a birth defect or a specified anomaly, including fetal alcohol syndrome (see Table I). The reportable list uses ICD version 9. Cases reported are matched to Vital Statistics Alaska Birth Certificates (17), which contains a limited amount of pregnancy information, including maternal age, onset of prenatal care, alcohol and tobacco exposures, birth weight and ethnicity. Furthermore, terminations of pregnancy must also be reported, including those that are terminated for congenital anomalies (18). Regular reports are published, including a comprehensive birth defects summary of births from 1996 to 2002. which was published in 2006 (19).

**Table I.** International comparison of circumpolar birth/congenital anomalies registries and databases.

	Surveillance system	Population-based	Pregnancy information	Indigenous identifier	Birth defects coding	Spontaneous or therapeutic abortions	Birth defects on stillbirths	Data sources
<b>CANADA</b>								
Yukon	Prenatal/perinatal database	No <sup>a</sup>	Yes >20 weeks gestation, cigarette smoking, alcohol use, medical conditions of the mother	No	ICD 9/10 from discharge summaries until one month. To increase surveillance to 1 year by 2010	No	Yes (>20 weeks or >500 grams)	Prenatal records, delivery records, hospital discharge summaries
National	Canadian Perinatal Surveillance System (20)	Yes <sup>b</sup>	Yes, perinatal Information and prenatal documents of cigarette smoking and alcohol.	No	Select birth defects derived from CCASS	No	Yes (>20 weeks or >500 grams)	Hospital discharge summaries (coded)
National	Canadian Congenital Anomalies Surveillance System	Yes <sup>b</sup>	No	No	ICD9/10	No	Yes (>20 weeks or >500 grams)	Hospital discharge summaries (coded)

<sup>a</sup>Hospital based but captures 90% of pregnancies and births in the Yukon Territory.

<sup>b</sup>Includes information on all hospitalizations in the country. Information is available on a provincial and territorial basis.

	Surveillance system	Population-based	Pregnancy information	Indigenous identifier	Birth defects coding	Spontaneous or therapeutic abortions	Birth defects on stillbirths	Data sources
<b>USA</b>								
Alaska	Alaska Birth Defects Registry (ABDR) (54)	Yes	No	Yes, Alaska Native	List of 43 reportable ICD9 conditions (codes 740–759), from birth to age 6	No	No	Birth Defects Registry Report form completed by health care providers, vital stats, hospital documents
Alaska	Alaska Vital Statistics (55)	Yes	Yes, some births by race, marital status, age, maternal education, adequacy of prenatal care, place of birth, type of birth, birth weight	Yes	ICD 9/10 for fetal and infant deaths	No: SA Yes: TA, reporting of all TAs through "Report of Induced TOP" form is mandated	Yes	Birth records, report of foetal death, report of death

Table I continued

	Surveillance system	Population-based	Pregnancy information	Indigenous identifier	Birth defects coding	Spontaneous or therapeutic abortions	Birth defects on stillbirths	Data sources
<b>DENMARK</b>								
Odense University of Southern Denmark	Congenital Anomalies Surveillance	Yes, but limited to all hospital based births in Funen county (99%)	Maternal age, gestation, birth weight, maternal smoking and medication during first trimester, maternal illness before and during pregnancy	No	ICD-10 to 5 years of age	Stillbirths from 22 weeks, and foetal deaths/spontaneous abortions from 20 weeks are registered. After 12 weeks, malformations are recorded for termination of pregnancy		Discharge diagnosis and hospital records from obstetric and pediatric departments, birth notifications, death certificates, post-mortem examinations and data from the cytogenetic laboratory. For live births, late diagnosed cases are included up to the age of 5 years
National	Medical Birth Register (56)	Yes	Yes, all pregnancies included. Smoking, birth order, birth variables	No	ICD-10 Presence/absence of congenital anomalies with no other specifics, neonatal period only	Yes, SA Yes, TA, at any gestational age	Yes	Form completed by midwives, hospital discharge records
National	Danish Hospital Discharge Register	Yes	No	No	ICD-10 (Q codes only), at any age	Yes	NA	All hospital discharges in Denmark
Greenland	Greenlandic Medical Birth Register	Yes	Yes, also a twin register	No	Collected in paper form only (not coded)	No	No	Form completed by midwives
Faroe Islands	Faroe Islands Medical Birth Register	Yes	Yes	No	ICD-10 until hospital discharge	No	No	Form completed by midwives

Table I continued

## Birth outcome and birth defect surveillance in the north

	Surveillance system	Population-based	Pregnancy information	Indigenous identifier	Birth defects coding	Spontaneous or therapeutic abortions	Birth defects on stillbirths	Data sources
<b>FINLAND</b>								
National	Medical Birth Register (57)	Yes	Yes, all pregnancies	No	ICD system, neonatal period only	Yes	Yes	Doctor's notice of birth, discharge summaries, death certificate
National	Register of Congenital Malformations (includes a Prenatal Registry) (58)	Yes	Yes, some info about exposures, complications & maternal health	No	ICD system to 1 year of age	Yes, TA. Prenatal Registry section collects info on selective TAs	Yes	Doctor's report, cytogenetics laboratories, MBR, other registers, death certificates
<b>ICELAND</b>								
National	Register of Births (within National Register of Persons) (59)	Yes	Yes, all pregnancies (>22 weeks)	N/A	ICD codes for birth defects noted at birth. Birth defects after that are collected at central hospital	No, TAs with birth defects registered in the abortion register (>12 weeks)	Yes	Maternity providers fill out a birth report
<b>NORWAY</b>								
National	Medical Birth Register (60)	Yes,	Yes, all pregnancies (>16 weeks). Prenatal documents, demographics occupation, meds/vitamins maternal health, pregnancy & delivery complications	No	ICD Neonatal period but may be registered up until one year	Yes, SA (>12 weeks) Yes, all TAs with the indication of a prenatally diagnosed congenital abnormality are registered	Yes	Form completed by physician or midwife. Data added to MBRN notification form at birth
<b>SWEDEN</b>								
National	Medical Birth Register (61)	Yes	Yes, all pregnancies included ( $\geq 22$ weeks) Social factors, drug & cigarette use, pregnancy & delivery history	No	ICD-10 for neonatal period only	No	Yes	Care record, delivery record, pediatric exam
National	Register of Congenital Malformations (62)	Yes	No, but links to Medical Birth Register	No	ICD-10 up to 6 months of age; heart defects up until 1 year of age	No, SA Yes, TA	Yes: all foetal deaths with congenital anomalies >22 weeks gestation	Reports are compulsory and obtained from departments of pediatrics, obstetrics and clinical genetics (cytogenetic reports)

Table I continued

Surveillance system	Population-based	Pregnancy information	Indigenous identifier	Birth defects coding	Spontaneous or therapeutic abortions	Birth defects on stillbirths	Data sources
<b>RUSSIA</b>							
Kola Birth Register 1973-2005 <sup>c</sup>	Yes	Yes, including maternal health & exposures	Yes	ICD-10 until hospital Discharge	Yes	Yes (≥28 weeks)	Birth and prenatal records
Murmanskaja Oblast Birth Registry	Yes	Yes	Yes	ICD-10 until hospital discharge	Yes (≥22 weeks)	Yes (≥28 weeks)	Birth records
Arkhangelskaja Oblast Malformation Register <sup>d</sup>	Yes	No	No	ICD-10 until hospital discharge	Yes (≥12 weeks)	Yes (≥28 weeks)	Birth records
Komi Malformation Register	Yes	No	No	ICD-10 until hospital discharge	No	Yes (≥28 weeks)	Birth records
Sakha (Jakutia) Malformation Register	Yes	No	No	ICD-10 until hospital discharge	No	Yes (≥28 weeks)	Discharge summaries, report of chief medical officer
Krasnojarskij Kraj Malformation Register	Yes	No	No	ICD-10 until hospital discharge	No	No	Discharge summaries, report of chief medical officer

<sup>c</sup>Montsjegorsk rajon in Murmanskaja Oblast

<sup>d</sup>Includes Nenetskij Avtonomnij Okrug

**Canada**

In Canada, the inhabitants of the 3 territories considered arctic and subarctic (Fig. 1) constitute less than 1% of the entire Canadian population, but the eligible population proportion reaches 4% when including Aboriginal people of all areas of Canada (about 1.4 million in total), which is the jurisdiction of the Cana-

dian Society for Circumpolar Health. For the entire country, some perinatal information and specific birth defects are collected as part of a national public health initiative, the Canadian Perinatal Surveillance System (CPSS), which includes information coded at discharge from hospital (20). Furthermore, for the years 1973–2002, in a broad effort to understand rates

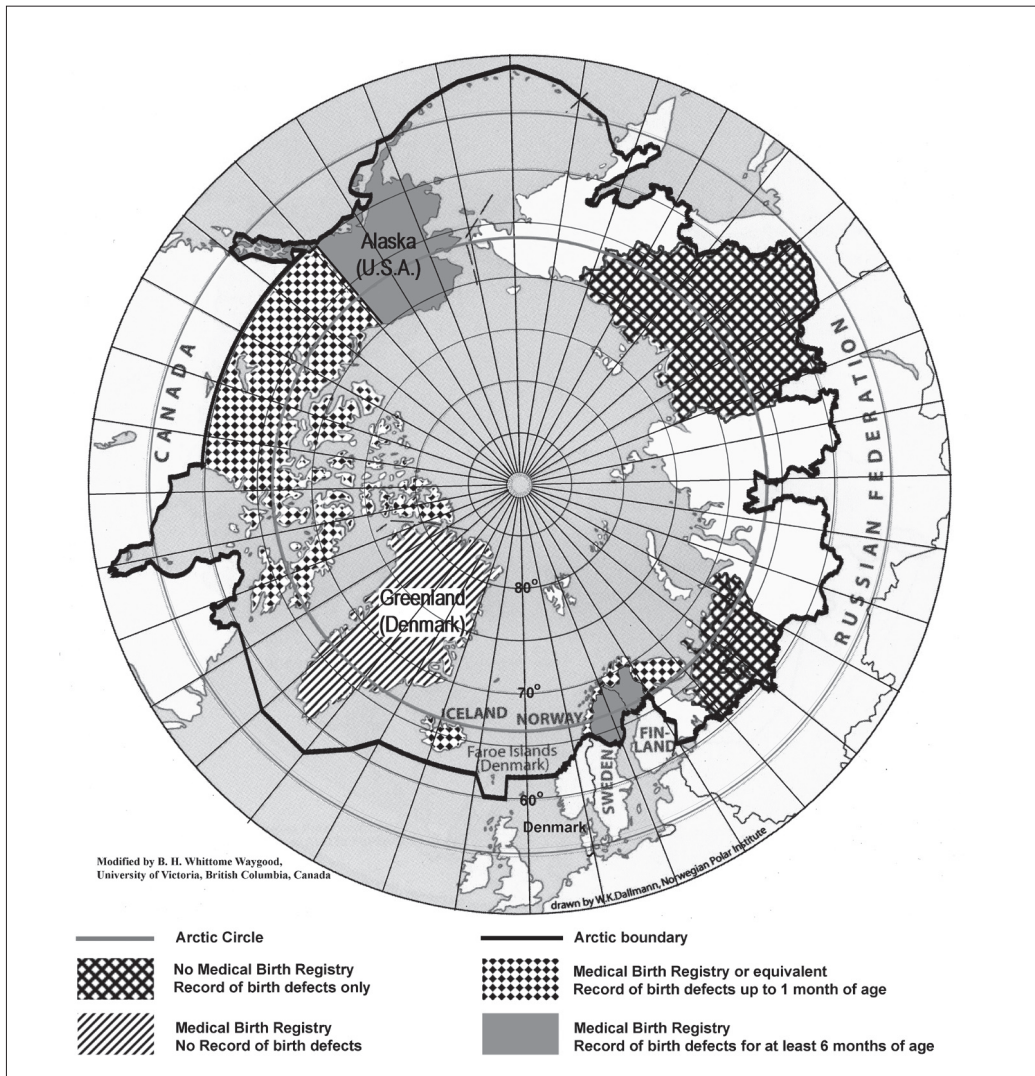


Figure 1. Medical Birth Registries or equivalents and Congenital Anomalies Surveillance systems in northern regions of the world. Map modified from Map 1 in Young TK and Bjerregaard P, eds., *Health Transitions in Arctic Populations* (Toronto, Ontario: University of Toronto Press; 2008), 171.

and regional variations in birth defects, the Canadian Congenital Anomalies Surveillance System (CCASS) (21) collected birth defect information until age 1 year from hospital discharge summaries on more than 300,000 births per year. Since 2002, birth defect information has been collected only until hospital discharge after birth or until 30 days of age if there is a readmission. In addition, the CCASS does not link or include other pregnancy information, termination of pregnancy information or birth defects on stillbirths and does not have ethnic identifiers, including those designating Aboriginal identity. More recently the CCASS provided data for specific birth defects for a CPSS published document in 2002 (22) that reviewed rates at birth of specific birth defects in Canada. For this publication, northern region data and Indigenous-specific data were not analyzed separately, and perinatal risk factors were not linked to outcomes.

Each Canadian province or territory has the ability to develop more comprehensive perinatal and birth defect surveillance systems if they so choose. British Columbia (BC) has had a comprehensive perinatal registry for 20 years (23) and the Yukon territory, one of the three northern territories, has been collecting perinatal information that includes early recognized birth defects under the same system for 10 years. Comprehensive birth defect surveillance systems are currently in existence in only 2 provinces, British Columbia (24) and Alberta (25), but the jurisdiction of these regions do not extend to the northern territories. Moreover, only in British Columbia has there been the ability to cross-reference Aboriginal identifiers historically to document Aboriginal-specific outcomes (26).

Currently, in British Columbia, data sharing agreements are under discussion with federal, provincial and Aboriginal governing bodies to determine when and how Aboriginal identifying data can be linked to registry data and utilized for future public health studies (27). The expansion of the Yukon perinatal database to include the collection of birth defects until 1 year of age is currently underway. Similar efforts are underway in Nunavut and the Northwest Territories. By 2010 all 3 northern jurisdictions should have established registries in place for the collection of perinatal and birth defect information until at least age one year. Although Indigenous identifiers are available for public health surveillance in NWT, discussions are underway in the Yukon to determine the use of Indigenous-specific information under data sharing agreements.

### **Greenland, Denmark and the Faroe Islands**

Denmark and Greenland both have medical birth registries, established in 1968 and 1972, respectively; however, the registries do not contain information on stillbirths. Some prenatal and perinatal information such as smoking status, birth order, gestational age and birth weight are available in both registries. Congenital anomalies are collected for the length of the birth hospital stay, which may vary from less than 1 day to 5 days. The completeness of the collection of birth defects is suboptimal in Greenland and is not available electronically. However, at least 1 study has been completed using registry malformation information from 1982 to 2002 (28). In Denmark, birth defects are also collected as part of the Danish Hospital

Discharge Registry, which has accumulated data since 1977. The coding is carried out by physicians when the discharge summary is completed. A 10 digit personal identification number allows unambiguous linkage between registries (29,30). Furthermore, 1 regional congenital anomalies register held at the University of Southern Denmark is a full member of EUROCAT. EUROCAT is a European network of population based congenital anomaly registers covering 1.2 million births per year, at 40 European sites (31,32). All live births, stillbirths, terminations of pregnancy from 12 weeks gestation for a region in southern Denmark are reported to this registry (about 5,600/year) (33). The Faroe Islands follows the Danish system, with a population-based medical birth register that is reported through the chief physician; however, there is no reporting of this information to the Danish Registry and there is no specific birth defects registry.

### **Iceland, Norway, Sweden and Finland**

Some of the best known and well-respected studies on birth outcomes have come out of the Nordic birth registries, which have been used as models for other countries around the world (34,35). Iceland, Norway, Sweden and Finland all have population-based comprehensive medical birth registers that include information on all newborns in their country. In all 4 countries, birth defects are collected on all infants until at least hospital discharge from birth. In Sweden and Finland, parallel congenital anomaly registries collect birth defect information using the ICD coding system up until the age of 6 months and 1 year, respectively. The medical birth

registries can be linked to the congenital anomaly and other available disease registries and research data bases (36) to allow linked epidemiological studies on a number of topics, including pregnancy exposures, paternal occupation, environmental exposures and association with maternal chronic disease (37–39). Available information on spontaneous pregnancy losses vary, but all 3 national surveillance systems include medically induced abortions, therefore birth defect rates can be more accurately assessed. Indigenous identifiers are not included.

Longitudinal linkage with subsequent pregnancies provides an opportunity to explore recurrence risks for specific birth outcomes, such as prematurity, birth defects and stillbirths as demonstrated by studies carried out using the Medical Birth Registry of Norway (40). More recently these registries have been used to explore the prenatal and early infancy determinants of adult onset chronic disease (41,42). The Finnish Register of Congenital Anomalies, the Medical Birth Registry of Norway, the Swedish Registry of Congenital Malformations and the Swedish Medical Birth Registry are members of the International Clearinghouse for Birth Defects (ICBD), allowing the opportunity to participate in international studies as per its mandate. The ICBD is an organization “that brings together birth defect surveillance and research programmes from around the world with the aim of investigating and preventing birth defects and lessening the impact of their consequences” (43). The Medical Birth Registry of Norway is a full member of EUROCAT and the Finnish Register of Congenital Malformations is an associate member.

### Russian Federation

In the north-western part of Russia there are 2 population-based birth registries. One is an extensive data collection of all births in Mončegorsk, in existence since 1973, and the other, which was established in 2005, covers all births in Murmanskaja Oblast (including Mončegorsk). These registries include data about birth defects diagnosed before the mother is discharged from the hospital (44,45).

In the late 1990s, with a goal to address a falling birth rate, the Russian Federal Health Ministry put legislation in place that required the reporting of birth outcomes such as perinatal and infant mortality and birth defects. Elective abortions for severe malformations were also reportable. Regions were required to report to the federal population-based genetic register, which was focused on inherited diseases and anomalies (46). In 2006, 34 regions of Russia participated in the program. The data for that year included more than 700,000 newborns (almost 30% of all newborns in Russia) (47).

Of the 34 participating regions with systematic registrations of birth defects, 4 are in the north. In the north-west, there are such registers at the central children hospitals in Arkhangelsk and Syktyvkar, which includes all recorded birth defects in Arkhangelskaja Oblast and Nenets Okrug (48) and the Komi Republic, respectively (47). The registration of birth information in Karelia is based in each delivery hospital. Similarly, Krasnojarskij Kraj in Siberia and Sakha Republic (Jakutia) (49) in the north-east have a central register of birth defects. In the remaining regions of Siberia and the north-east, the situation is the same as it is in Karelia. However, each

administrative unit reports each newborn with malformations to the head medical officer at the central administration, who compiles statistics for the unit to be reported within their region and federally.

### DISCUSSION

Although we believe that we have included all circumpolar population-based birth outcome and birth defects surveillance systems, it is possible that some surveillance systems covering small populations or based in individual institutions may have eluded our search or may be in development without our knowledge. For the purpose of the discussion of the information available, we will categorize our comments into 1) the comprehensiveness of coverage of surveillance systems in northern regions; 2) the presence of Arctic populations or Indigenous identifiers; 3) the ability to link prenatal determinants of outcomes; 4) the consistency of case ascertainment; 5) the adherence to international standards; and 6) the current and future ability to carry out comparative studies.

#### 1) *Comprehensiveness of coverage of surveillance systems in northern regions*

With the information available, we found that the systematic population-based registration of birth outcomes that includes birth defects occurs to some degree in all circumpolar countries (see Fig. 1). Of particular concern for our review, the northernmost regions of the countries may not be well represented in surveillance systems, and specific information about those regions may not be readily available if they are collected as part of

larger programs. For example, in Russia, most of the northern regions do not have a system in place, and although there is a population-based reporting system for birth defects at birth in Greenland, these anomalies are not entered into an electronic database.

2) *Presence of Arctic population or Indigenous identifiers*

Only the surveillance systems in Alaska and Murmanskaja Oblast currently release Indigenous ethnicity-specific information. In northern Canada, Siberia and north-east Russia, where the majority of the Arctic Indigenous populations reside, this information currently does not exist in the birth outcome/birth defect surveillance systems or cannot be utilized. In Canada, however, efforts are underway to develop data sharing agreements with Aboriginal groups to allow the information to potentially be utilized. Indigenous identifiers are not present in the surveillance systems of the Nordic countries.

3) *Prenatal determinants of adverse outcomes*

To consider the causes and ultimately preventative strategies for adverse pregnancy outcomes (i.e., low birth weight, stillbirth and birth defects), information linking each adverse outcome to the pregnancy information, including exposures, is needed. Presently, the registration in Denmark, Iceland, Norway, Sweden, Finland and Murmanskaja Oblast and Alaska facilitates such studies, but this is lacking in the other regions. Furthermore, paternal information, such as age, exposure status and occupation is rarely available, but is becoming increasingly recognized as valuable information (50).

4) *Consistency of case ascertainment*

Our survey reveals differences in ascertainment of cases between surveillance systems

that will potentially limit broad comparability of data. For example, gestational age from which collection of information commences on birth outcomes, pregnancy terminations for abnormality and birth defects on live and stillborn infants varies from 12 to 28 weeks (Table I). Furthermore, although most surveillance systems record birth defects at birth, with the exception of the Nordic countries, only Alaska currently records birth defects beyond the perinatal period, limiting circum-polar analysis of rates of anomalies that are not obvious at birth and not immediately life threatening, including many affecting internal organs.

The inclusion of termination of pregnancies (medical abortions) for foetal abnormality varies between the surveillance systems in our survey. For example, Norway collects information on birth defects associated with terminations of pregnancy from 12 weeks gestation, whereas some jurisdictions do not collect that information at all. Without full ascertainment of abnormalities detected prenatally with subsequent termination of pregnancy, actual rates of birth defects will be obscured underestimating the impact and potentially missing opportunities for prevention. Although the prevalence of anomalies at birth can readily be assessed in Alaska, Canada, Iceland, Finland, Norway, Sweden, Denmark, Finland and Murmanskaja Oblast, only in Norway, Sweden, Finland, Denmark and Murmanskaja and Arkhangelskaja Oblasts and in some places in southern Canada are pregnancy terminations for abnormality also included in the birth defect surveillance systems impairing precise comparisons of birth defect prevalence between countries and within Canada and Russia.

### 5) *Adherence to international standards*

For comparison of rates of birth defects between different systems and jurisdictions, adherence to standardized procedures and definitions in terms of diagnostics, diagnoses and registration, such as those required for the ICBBD and EUROCAT, are crucial. Currently, the birth defect surveillance systems in Canada, Denmark, Norway, Sweden and Finland are members of the ICBBD (43) and/or EUROCAT (31,32). Iceland, Greenland, the Faroe Islands and Russia are not affiliated with international efforts to standardize reporting of birth defects. All birth defects surveillance systems in the circumpolar Arctic should strive to achieve a common high standard for the reporting and collection of birth defects.

### 6) *Current and future ability to carry out comparative studies*

Although there are important differences between the surveillance systems, we have found there is still the potential to compare rates of specific perinatal outcomes in the current state of birth outcome and birth defect surveillance (sex ratios, rates of low birth weight, prematurity, high birth weight) and to compare some malformations in the circumpolar regions of the world. Major malformations readily detected at birth such as neural tube defects, limb abnormalities, facial clefts and microcephaly are all anomalies that could provide a baseline for comparison. Such a pilot study will also provide insights into the jurisdictional challenges of obtaining data for international comparisons.

Furthermore, there is recent positive development in both Russia and Canada where there is governmental support and jurisdictional will to improve comprehensive surveillance in the North. An important example is the recent

development of the register in Murmanskaja Oblast (45), established in 2005 and which has clearly demonstrated that it is possible and feasible to set up a regional population-based birth registry in Russia when there is an administrative will in a region. There are territory specific initiatives in the three northern territories of Canada where pregnancy risk and outcome data will be collected along with a validated birth defect reporting system for each birth until at least 1 year of age. In Nunavut, a territory with a high rate of infant mortality (51) and adverse pregnancy outcomes (52,53), the collection will continue until age 5 and will include other early health indicators. Other countries, such as Greenland, may follow suit in the near future.

### **Conclusions**

Our baseline survey of circumpolar birth outcome and birth defect surveillance systems yielded a number of regional and population surveillance systems that cover most but not all regions of the jurisdiction of the IUCH. Considerable variability in the extent of information collected will limit sophisticated comparative analyses between regions. Indigenous specific information is only rarely available. However, there is current untapped potential for comparative analyses of specific risk factors and types of birth defects that might provide insight into differences in rates in circumpolar countries, but more importantly, it will provide information on the specific gaps in birth outcome and birth defect surveillance in the northernmost regions of the world. Since adverse pregnancy outcomes, infant mortality and birth defects are all indicators of the health of a population, efforts to improve surveillance and establish robust methodologies for comparative anal-

yses are important steps in understanding and addressing health disparities that are common to many Northern regions.

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