



The development of a tri-territorial pregnancy outcome and child health registry

Laura Arbour
Susan Chatwood
Geraldine Osborne
Isaac Sobol
Andre Corriveau
Bryce Larke
Melissa Allan
Sarah McIntosh

Gwen Healey
Jody Walker
Norma Kassi



Circumpolar Health Research 2007



Source:
Stats
Canada

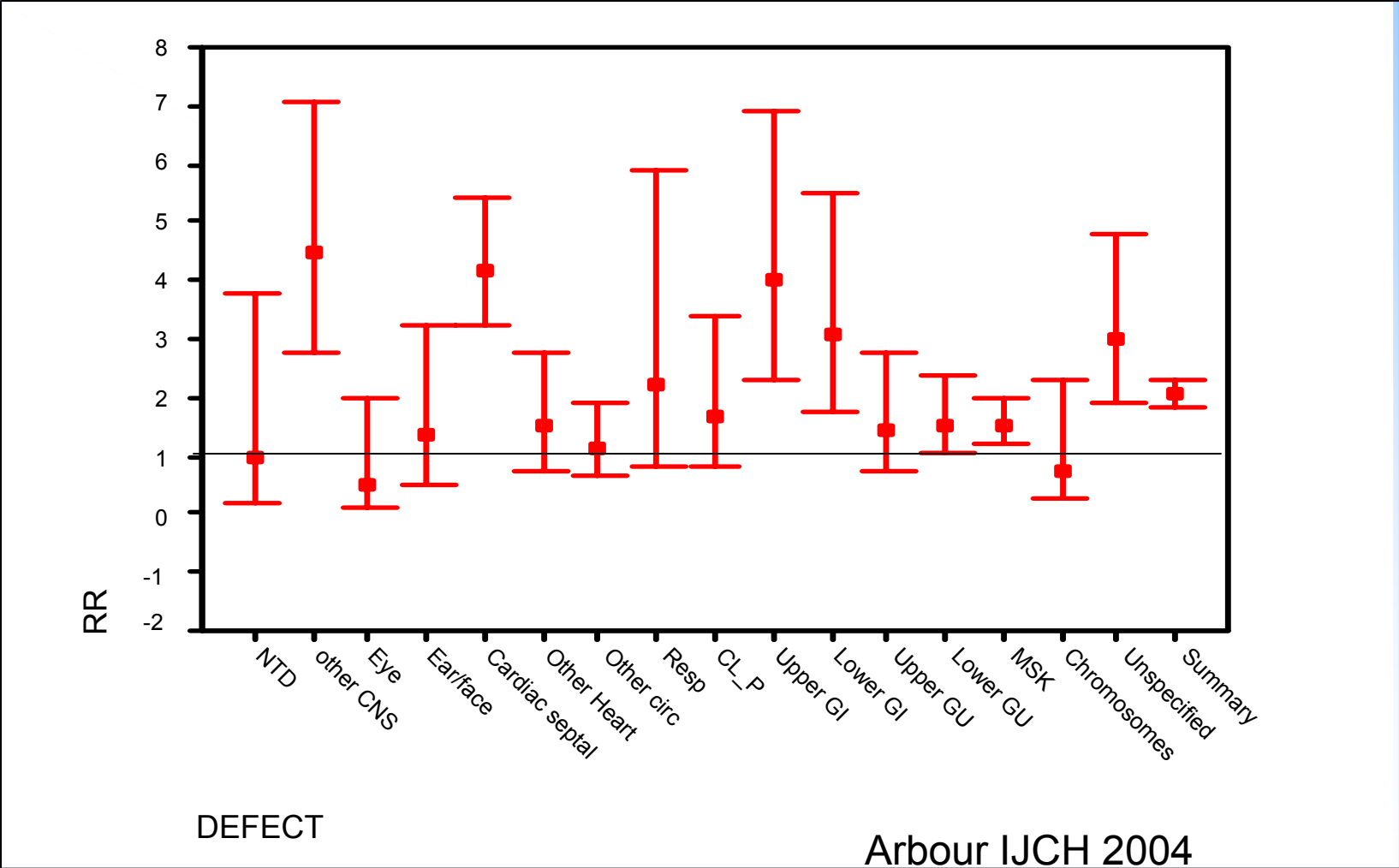
	population	% aboriginal	% less than 15 years	Infant mortality (5 years)
Nunavut	30,800	85% Inuit	36 %	15 /1000
NWT	41,900	50% Dene, Metis Inuvialuit	26 %	8/1000
Yukon	31,200	25% First Nations, Metis, Inuit	20 %	5/1000
Canada	32,000,000	4%	18%	5/1000

Causes of infant mortality

- MacCauley 2004
 - 10 year review of causes of mortality in Kivalliq region (87-96)
 - Infant mortality 32/1000
 - Prematurity and SIDS were lead causes
- Hodgins 1997
 - Congenital anomalies accounted for 2/3 of neonatal deaths in Nunavik



Estimated RR for birth defects in Inuit children from Baffin Island and Arctic Quebec –the baseline



Based on chart review of
2567 live births 1989-1994

Chart review of 1900 births and stillbirths from Baffin Island 1999-2004

Table 1: Baffin VS, ACASS comparison

	Post-fortification # of BD (Inuit)	Post-fortification rate/1000	Post-fortification # of BD (ACASS)	Post-fortification rate/1000	Odds ratio, 95% Confidence Interval	Chi square
Total (745)	34	17.89	1107	5.79	3.126 (2.215-4.411)	p < 0.0001
VSD (7454)	18	9.47	528	2.76	3.451 (2.152-5.533)	p < 0.0001
ASD (7455)	16	8.42	319	1.67	5.077 (3.066-8.407)	p < 0.0001

Table 2: 1989-1994 Vs 1999-2004

	Post-fortification # of BD (Inuit)	Post-fortification rate/1000	Pre-fortification # of BD (Inuit)	Pre-fortification rate/1000	Odds ratio, 95% Confidence Interval	Fishers exact
Total (745)	34	17.89	59	22.98	0.7745 (0.5057-1.186)	p = 0.2838
VSD (7454)	18	9.47	36	14.02	0.6724 (0.3806-1.186)	p = 0.2159
ASD (7455)	16	8.42	19	7.40	1.139 (0.5840-2.221)	p = 0.8333

Considerations for pregnancy outcomes in the North

- Distance to medical care
- Exposures to environmental contaminants (PCB's MeHg)
- Suboptimal nutritional status (folate, Vitamin A)
- Other exposures, smoking, alcohol use



Why should there be surveillance?



- Infant mortality, SIDS. Birth defects are all a concern in the North
- There is no sustainable way to evaluate rates, geographic or ethnic clusters, etiology, approaches to prevention
- Importance of the Impact of prenatal and early childhood influences on adult chronic disease

Two parallel initiatives: CCASN/Infant Mortality Network

NWT

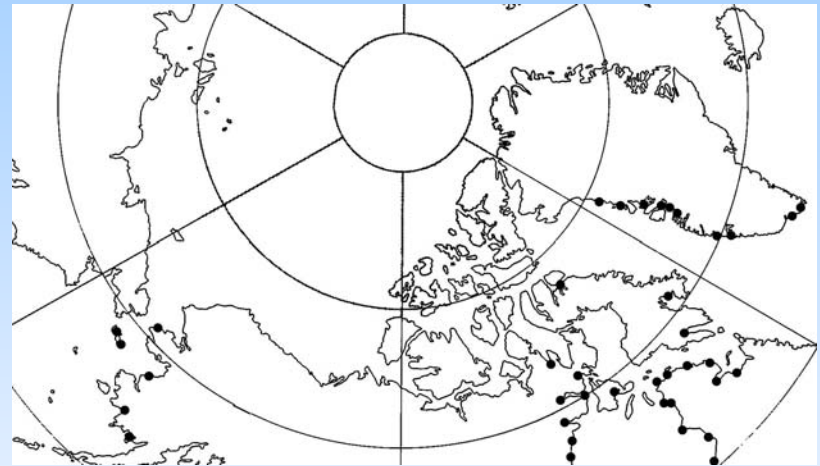


Development of a Congenital Anomalies Surveillance System in the NWT

Susan Chatwood BScN, MSc

CIHR Team in Circumpolar in Chronic Disease Prevention

- **The circumpolar team grant provides a unique opportunity to build a sustainable public health research tool**



Objectives

- To initiate a comprehensive, sustainable, privacy-protected pregnancy outcome, infant and child health surveillance system possibly with linked biological samples (blood spots) in the three territories.
- To assess burden, investigate etiologies (including genetic predisposition) and explore potential interventions of conditions occurring disproportionately in children of the circumpolar region.
- Long Term: To determine how pregnancy and early childhood influence the development of chronic disease

Why consider a registry for such small numbers?

- ***Small numbers are what we have!***
- Chart review, clinical study, vital statistics info is limited
- A pan-territorial registry would collect info on about ≈ 1600 births/year (10 births/territory/year)
- Could other jurisdictions join? Nunavik, Labrador, Greenland
- Over-lap compatibility with other registries such as BC-HSR, Alaska registry-other circumpolar countries

How can other registries inform the process?

- BCRCPC-<http://www.rcp.gov.bc.ca/>
- BC-HSR
- ACASS
- California Birth Defects program
- Alaska Birth Defects Registry
- Canadian Pediatric Surveillance System
- Other Circumpolar Registries (Norway)

Proposed Info to be collected

- From routine pregnancy form: Pregnancy –mother's age, *weight*, use of vitamins, exposures during pregnancy including medications, illnesses etc, *blood sugar*, place of residence, distance from medical care, pregnancy loss.
- From birth form Birth data-birth weight, HC, status at birth, obvious birth defects.
- Reporting form for up to one year for birth defects and other handicapping conditions.
- To follow birth conditions become reportable by health care professional ie: later detected birth defects, autism, FAS (others to be decided).
- Good models are Alaska Public health reporting form, ACASS, CPSP.

Why Not Just Birth Defects?

- Because the determinants of birth defects and child health begin in pregnancy
- To simply count birth defects and chronic diseases (because of the small numbers) will not allow interpretation

Public Health Vs research

- Combination of public health collection of info and research:
 - Anonymized information about health and pregnancy outcome may be collected, with no official consent, (for example, BC registry, ACASS as per most public health surveillance)
 - **Individual consent** during pregnancy for calling back for follow-up studies and use of blood spots allowing for ability to carry out case control studies. Directed questionnaires can then be utilized when needed

How can this be done?

- In order for this to be sustainable, the process needs to be supported by the population and policy makers of each region
- Privacy laws will only allow information to be collected without consent if under:
 - 1) Provincial/territorial health acts
 - 2) If a project has applied under the Freedom of Information and Privacy act.

What tools could be used to enter the data?

Who will enter and manage the data?

- Various data bases are under consideration
- BC HSR/BCRCPP
- Capacity for entry of pregnancy information, demographic, birth defects, chronic disease (until age 21)
- BCRCPP will collect the data manage data base at a low cost for any territory that does not currently have the capacity to collect their own (already done in Yukon)
- BC HSR will provide access to web data base and training to each territory at very low cost

Governance

- Each territory to be the controller of their own data base, although linking with others would be possible.
- Research from data base carried out only in consultation of territorial and over-seeing advisory committee with First Nations/Inuit stake holder representation
- “DNA on loan” as principle (CIHR Guidelines for aboriginal health research) .
- Follows the CIHR model of “integrated KT”

First Nations/ Inuit/ Metis Governance

- General consultation
- Good model of shared ownership of data in BC (BCFNCHC/HSR/Ministry)
- IPY Arctic Resiliency project provides funding for one graduate student plus travel for in depth consultation process as to how surveillance can be developed and used wisely with full involvement of Aboriginal groups
- Ideally this graduate student, in consultation with aboriginal organizations and communities will provide an advisory model where each research project proposed goes through a local advisory panel and a tri-territorial panel consisting of aboriginal partners.
- Consistent with CIHR Aboriginal health Ethics Guidelines that propose local and national aboriginal review boards govern research

Goal

- Surveillance system that is privacy protected adherent to provincial/territorial/national health acts, but 'owned by the people'.

How will this make a difference?

- Better understanding of rates and clusters of birth defects, prematurity, SIDS, infant mortality.
- Because every pregnancy is entered, there will be an ability to carry out case control studies to understand biological and other determinants (genetic factors, distance to medical care, impact of exposures).
- Can be used as a sources to assess conditions on a short term basis considered a priority (hearing loss, head injuries).

How will this make a difference?

- The information derived can be used when considering supports and health care services for the children in need.
- Local aboriginal groups, health care providers and health care educators will have access to data to develop local programs that aim to improve pregnancy outcomes and prevent childhood chronic conditions.

Will this work?

- The success of the initiation of the surveillance system is dependant on community involvement and support
- The community is multifaceted, -public (aboriginal communities), the nurses in the nursing stations, GPs, pediatricians, obstetricians, Health and Social Services)

Where are we now?

- Sarah McIntosh: Background work, health acts, other registries around the world, visits, forms, minimal fields for CCASN and CPSS,
- Nunavut: Advisory board developed, numerous discussions (pilot project?)
- NWT: collection of birth defects to be initiated soon/ considering collection of prenatal data
- Yukon: already collecting 80% of prenatal data through the BCRCPC-Research assistant in Yukon to discuss with stakeholders.

What happens when the grant ends?

- The on-going success will be dependant on support of the territories, PHAC, CCASN.....

Challenges

- Challenges of consultation
- Complete collection of data
- Jurisdictional differences (within and between the territories)
- Human Resources





Image by Craig Mayhew and Robert Simmon, NASA/GFSC;
DATA: Marc Imhoff, NASA/GSFC; Christopher Elvidge, NOAA/NGDC
© 2004 National Geographic Society. All rights reserved.

National Geographic's *Exploring Space*
Collector's Edition Vol. VII