



BC WOMEN'S HOSPITAL  
& HEALTH CENTRE  
*An agency of the Provincial  
Health Services Authority*



BC PERINATAL HEALTH PROGRAM

*Optimizing Neonatal, Maternal and Fetal Health*



**CIHR IRSC**

Canadian Institutes of  
Health Research

Instituts de recherche  
en santé du Canada

# LINKING PERINATAL DATA IN BRITISH COLUMBIA

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# A LITTLE BIT ABOUT US...

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# LEARNING OBJECTIVES

At the end of this lecture, you will:

1. Understand the landscape of perinatal data in British Columbia.
2. Know the key steps necessary for successful perinatal data access applications
3. Be able to think creatively about ways to obtain information from data within confidentiality and data restrictions.

# BC PERINATAL DATABASE REGISTRY

- Maintained by the BC Perinatal Health Program
- All live births and stillbirths over 20 weeks gestation in BC
- Initiated in 1996, complete ascertainment of all births in BC by 1999

# BC PERINATAL DATABASE REGISTRY

- Comprehensive database which serves the purpose of monitoring and surveillance in relation to perinatal outcomes, care process and resources, with goal of improving maternal, fetal and newborn care
- Database is routinely used to summarize, interpret, and report on perinatal events, outcomes and processes at community, regional and provincial level
- Maternal characteristics, socio-demographic factors, preconception health status, antenatal complications, mode of delivery, birth outcomes (including neonatal status at birth), postnatal/postpartum morbidity prior to discharge from birth hospital.

# BC VITAL STATISTICS AGENCY

- Comprehensive data on all live births, stillbirths and deaths in BC
- BC MSP & Health Canada: medical billing info
- Health Status Registry:
  - congenital anomalies, genetic conditions, selected disabilities
  - Hospital admission/discharge abstracts
  - HSDA/HA
  - UBC Medical Genetics
  - BC Children's Hospital
  - Public Health Nurses

# POPULATION DATA BC

- A multi-university, data and education resource facilitating interdisciplinary research on the determinants of human health, well-being and development.
- Support research access to individual-level, de-identified longitudinal data on British Columbia's 4.4 million residents.
- Linkage of data across sectors, such as health, education, early childhood development, workplace and the environment, facilitates advances in understanding the complex interplay of influences on human health, well-being and development.
- MSP payment info, Discharge Abstract Data (hospital separations), Consolidation file, Vital Stats files, Income band data

# POPULATION DATA BC

## Internal data holdings

- Health care and health services data
  - Medical Services Plan Payment Information (MSP)
  - Pharmacare
  - Discharge Abstract Database (Hospital Separations)
  - Home and Community Care (Continuing Care)
  - Mental Health
  - BC Cancer Agency
- Population and demographic data
  - Consolidation file (MSP Registration and Premium Billing)
  - Vital Statistics Births
  - Vital Statistics Stillbirths
  - Vital Statistics Marriages
  - Vital Statistics Deaths
  - Income band data
- Occupational data
  - WorkSafeBC Claims and Firm Level files
- Early childhood data
  - Early Development Instrument data
  - Middle Years Development Instrument data
- Spatial data
  - Integrated Cadastral Information (ICIS) data

## External data available

- Canadian Community Health Survey (CCHS)
- PharmaNet
- Perinatal data
- Spatial data



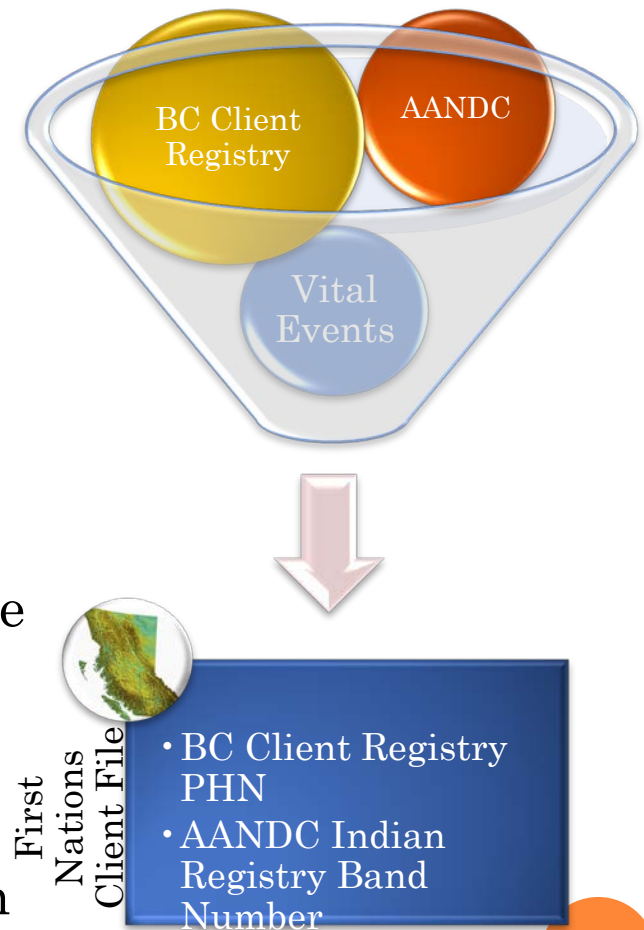
# RESEARCH INVOLVING FIRST NATIONS

## ○ Aboriginal Ancestry

- Self-identified ethnicity not routinely collected in any databases
- Restricted to First Nations identified as Status Indian on Federal registries
- Vital Statistics Agency uses data from First Nations and Inuit Health and Health Canada to identify women and fetuses/infants as Status Indian or non-Status Indian
- OR, the First Nations Client File (FNCF)

# FIRST NATIONS CLIENT FILE

- The First Nations Client File (FNCF) records registered First Nations BC Residents and their unregistered children whose entitlement-to-register can be determined – currently the best source for identifying status First Nations in BC.
- Data collected from Aboriginal Affairs and Northern Development is being matched against BC's databases to create the FNCF.
- The FNCF contains the BC Care Card PHN numbers, band number, demographic information and population denominators.



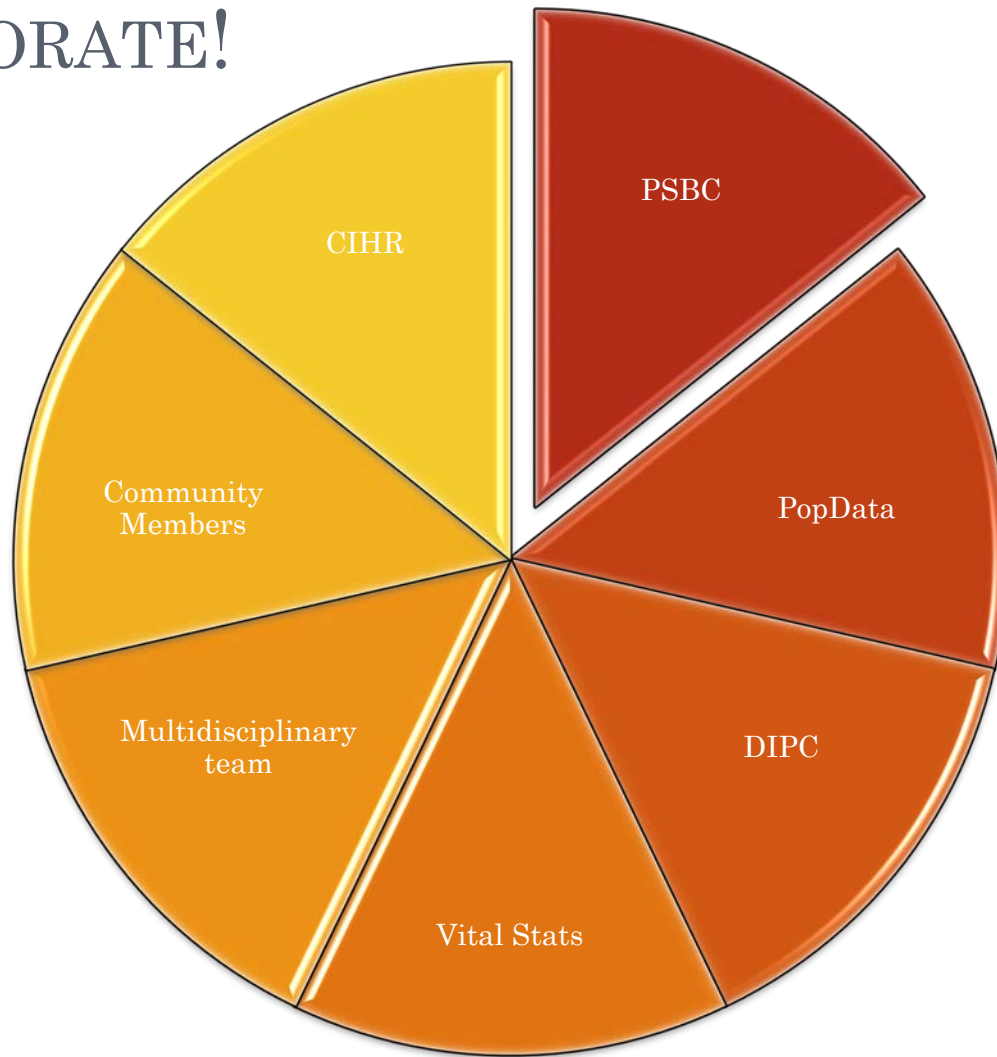
# FIRST NATIONS CLIENT FILE- CONT'D

- The FNCF is currently held in the Ministry of Health (MoH) and is governed by the Data and Information Planning Committee (DIPC), comprised of members from the MoH, First Nations Health Authority (FNHA) and Health Canada.
- The FNCF is a relatively new source of data, policies/processes are continuously being developed regarding its appropriate use and governance
- Due to limited resources, the FNCF is not available for external researchers at this time and is exclusively used to support health service programming needs of FNHA and its partners.

For more information about the FNCF, please contact:

Katherine Wang  
Data and Information Coordinator  
First Nations Health Authority  
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# COLLABORATE!



# *MEANINGFUL* COLLABORATION

## First Nations Health Information Governance:

refers to a structure, process and protocols by which First Nations in B.C. have access to First Nations Data and are influentially involved in decision-making regarding the culturally appropriate and respectful collection, use, disclosure and stewardship of that information in recognition of the principle that such information is integral to First Nations policy, funding and health outcomes.

**➔ Key: Involvement of First Nations throughout the project**

# APPLYING FOR DATA- KEYS TO SUCCESS

○ Ethics approvals



○ Institutional support



○ Attention to details



○ A clear proposal



○ The right team members



○ Avoid fishing!



○ Patience!



# FIPPA

The purposes of this Act are to make public bodies more accountable to the public and to protect personal privacy by

- giving the public a right of access to records,
- giving individuals a right of access to, and a right to request correction of, personal information about themselves,
- specifying limited exceptions to the rights of access,
- preventing the unauthorized collection, use or disclosure of personal information by public bodies, and
- providing for an independent review of decisions made under this Act.

# GETTING CREATIVE

- Geography is an important access issue in BC for maternal and infant health
- Postal code information could not be released due to confidentiality issues
- Major goal of the project was in jeopardy
- Created a walk-over file
- Now, could assess access issues in terms of distance, as well as forms of transportation to different levels of care



# GETTING CREATIVE

- Need mother's age?
  - Do not request birthdate (individually identifying)
  - Ask for calculation of mother's age at delivery
- Same for baby
  - Do not request baby's birthdate (individually identifying)
  - Ask for calculation of gestational age

# PUT IT ALL IN PERSPECTIVE

- Be courteous and patient!
- Multiple requests & own priorities
- They are liable
- Many people to answer to
- Always going to be a delay...plan for the unplanned

# DISCUSSION QUESTIONS



THANK YOU!