CONFERENCE 2015

THE RIGHT INFORMATION IN THE RIGHT HANDS AT THE RIGHT TIME

Join the conversation! How are you improving maternal-child health in your corner of the world? Be inspired by your colleagues! BORN is hosting a two-day conference and you are invited! www.bornontarioconference.ca

Keynote Speaker
Dr. K.S. Joseph, MD, PhD
The Power of Data

Keynote Speaker
Dr. Mark Walker, MD, FRCS(C), MSc Epi, MSc HCM
Reflections on Right Information, Right Hands, Right Time – The Future of Maternal Child Care

Session topics and speakers include:

Panel: Innovative Methods of Displaying Data to Enhance Meaning
Moderator: Graeme Smith, MD, PhD, FRCSC
Dashboards: Sandra Dunn, RN, PhD
Gapminder: Ziad El-Khatib, MSc, PhD
GIS/Neighbourhood Mapping: Mike Sawada, PhD

Right Information, Right Hands, Right Time...Still Problems Changing Practice
Ian Graham, PhD, FCAHS

Panel: The Intersection of Innovation, People and Privacy
Mari Teitelbaum, BSc Eng, MHA
Farhana Alarakhya, BSc Eng, MSc
Michael Fung Kee Fung, MBBS, FRCSC, MBA
Vicki Van Wagner, RM, PhD
Khaled El-Emam, PhD

Showcase of Success - Examples from Groups Who Take Data and Translate it to Information and Knowledge!
BORN Update on Congenital Anomalies Collection, Data Quality & Surveillance Initiatives

BORN Ontario Provincial Rounds
September 18, 2014
12:00-1:00 EST
Objectives

1. Overview of BIS Activities
2. Data Quality Review
3. Overview on congenital anomalies (CA)
4. Outline provincial and national CA surveillance initiatives
5. Review data quality for CA collected in the BIS

Speakers:
Heather Ramshaw, CA Coordinator
Chantal Wright, Quality Management Specialist
Erin Graves, Epidemiologist
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969 days since the BORN Information System went Live
635,242 births captured in the BIS.
1,338 potential missed screens reported to Newborn Screening Ontario.

Detect if affected by one of the 29 rare diseases.
Additional BIS Highlights

- Cycles from all IVF clinics (2013)
- Births from all 99 birthing hospitals & 84 midwifery practice in Ontario
- ~3,500 Antenatal Specialty visits in Ontario
- All prenatal screening results from 5 labs (~70% women screened)
- All newborn screening results from NSO (~100% of babies)
- All Level 2 NICU stays - 50% of Level 3
- Prenatal and Newborn Screening follow-up results from clinics

~ 7,200 unique users
Over 600,000 babies

Linked and matched across the continuum
7,193 system users across 406 organizations
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How is Information Entered?

Nurses, Midwives, Clerks, Labs

Manual Entry
- Real Time or
- Retrospective

Electronic Upload
- OBTV
- OBIX
- Meditech
Who uses the data?

• Hospitals & care providers
• Government & policy developers
• Public Health Units
• Local Health Integration Networks
• Researchers
• Professional associations and special interest groups

What is it used for?

BORN information is used for:
• Examining health services issues
• Performance measurement
• Trending over time
• Continuous quality improvement initiatives
• Policy development
• Evidence based decision making
• Supporting public health programming
• Informing research questions
• Generating perinatal and neonatal reports

Individual
• Patient summaries & reminders at discharge
• Identify patients who did not receive key interventions and provide reminders
Data entry ≠ Data Quality
Data Quality Framework

TIMELINESS
- Data currency
- Documentation currency

ACCURACY
- Comprehensiveness
  - Coverage
  - Capture & collection
- Completeness
  - Stakeholder non-response
  - Item non-response
- Precision
  - Measurement Error
  - Editing and processing
  - Technical specifications

COMPARABILITY
- Consistency
  - Data collection
  - Data dictionary
- Linkage
- Equivalency
- Historical comparability

USABILITY
- Interpretability
- Accessibility
- Documentation

RELEVANCE
- Adaptability
- Value

born: Better Outcomes Registry & Network
BIS Features and Functions

- **BORN Data Entry Guidelines** – Timeliness
- **Drop-Down Lists** – Accuracy & Comparability
- **Mandatory Fields & Data Validation Rules** – Accuracy
- **Point of Entry Validations** – Accuracy
- **Track Missing Data** – Accuracy
- **Data Saved in Secure Location** – Accuracy
- **BORN BIS Data Dictionary** – Comparability & Usability
- **Pre-Population of Data** – Comparability & Accuracy
- **Linkages of Cases** – Comparability
- **Feedback Mechanisms/Support** – Usability
- **BORN Committees** – Relevance
Tools to Enhance Quality

Webinars
• Briefings in deployment
• Training
• Enhancements
• Provincial, regional and by site

Site visits
• One on one

Other Tools
• Teleconferences with DQ managers
• Reference guides
• Field level help
• Page level Help
• BITS Bulletins
Other Resources

• 24 hr Helpdesk email or phone
• Website www.bornontario.ca
  • Training guides
  • Data Dictionary
  • Training videos
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Congenital Anomaly (CA), Abnormality, Birth Defect

Abnormalities of body **structure** or **function** that are present at **birth** and are of **prenatal** origin.

Structural Anomalies

Development
- Malformation
- Deformation
- Dysplasia
- Disruption

Health Impact
- Major
- Minor

Presentation
- Isolated
- Multiple congenital anomalies (MCA)
- Syndromes
Classification of Development

The term “malformation” is commonly used in daily practice and often in the literature as a generic term for structural anomalies.
Health Impact: Major vs. Minor

• Major
  – Serious medical, cosmetic and/or social consequences, requires treatment or psychosocial support.
  – Frequency: 3-5%

• Minor
  – Does NOT have serious medical or social consequences, usually does not require treatment
  – Frequency of one or more: ~ 15%
  – Clinically: multiple (3 or more) at increased risk of having also major or genetic syndrome

* Not always a clear distinction*
**Examples of Major Anomalies**

- Anencephaly
- Spina bifida
- Transposition of great vessels
- Hypoplastic left heart syndrome
- Reduction defect upper or lower limbs
- Cleft Lip (with or without cleft palate)
- Gastroschisis
- Down syndrome/Trisomy 21

**Examples of Minor Anomalies**

- **Eye**
  - Fused eyelids
  - Absence of eyelashes
- **Ear**
  - Lack of helical fold
  - Misplaced ear
- **Face**
  - Small lips
  - Short neck
  - Flat or wide nasal bridge
- **Hands and feet**
  - Clinodactyly
  - Single palmar crease
  - Overlapping toe
- **Other**
  - Accessory nipples
  - Umbilical hernia
  - Single umbilical artery
  - Ankyloglossia (tongue tie)
Visual summary of Presentation

Presentation
- Isolated
- Multiple congenital anomalies (MCA)
- Syndromes

Isolated anomaly

Multiple Anomalies

Isolated Sequence

Syndrome
Functional Anomalies

- Developmental disabilities: examples include types of cerebral palsy, deafness
- Metabolic disorders, inborn errors of metabolism: example phenylketonuria
- Hematologic diseases: examples include sickle cell anemia, thalassemia, glucose-6-phosphate dehydrogenase [G-6-PD] deficiency
Additional Comments

• **Causes and risk factors**
  - ~50% cannot be linked to a specific cause
  - Some known causes or risk factors
    - Socioeconomic factors
    - Genetic factors
    - Infections
  - Maternal nutritional status
  - Environmental factors

• **Prevention**
  - Improve diet i.e. folic acid and abstaining from use of alcohol.
  - Control diabetes
  - Avoiding exposure
  - Improving vaccination coverage
  - Education

• **Detection**
  - Preconception screening
  - Antenatal screening
  - Newborn screening

http://www.who.int/mediacentre/factsheets
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What is surveillance?

• The ongoing, systematic collection, analysis, and interpretation of health data

• Essential to the planning, implementation and evaluation of public health purposes

• Closely integrated with the timely dissemination of these data to those who need to know.

• The final link of the surveillance chain is the application of these data to prevention and control.
Canadian Congenital Anomalies Surveillance System (CCASS)

Overview of the Congenital Anomalies Surveillance Enhancement Initiative

Presented by Public Health Agency of Canada (PHAC) Representatives
November 2013 CCASS Provincial/Territorial Collaborators
Canadian Congenital Anomalies Surveillance System (CCASS)

- Federal surveillance system.
- Important component of the Canadian Perinatal Surveillance System (CPSS).
- First established in 1966 in response to the thalidomide tragedy.
- Provides national data on the prevalence of CA.
- Analyzes and interprets national data.
- Action Plan to Protect Human Health from Environmental Contaminants.
Timetable for Provincial/Territorial (P/T) Programs

**YT** (~390*) – Uses referrals & standard form.
**NT** (~680*) – Has mandatory reporting.
**NU** (~850*) – Perinatal up to 5 years of age.

**SK** (~4,000*) – Surveillance system cancelled 2014.
**MB** (~16,000*) – Identifying framework.

**ON** (~140,000*) – A registry which continues to integrate & expand data sources for more complete ascertainment (through BORN ON).

**NB** (~7,100*) – Established framework for surveillance, possibly through new provincial program.

**NS** (~9,200*) – Migration of existing system and integration other data sources.

**NL** (~5,000*) – Conducting CA surveillance through perinatal program. Data collection started 2013.

*births/year*
NWT Notifiable Diseases
Information for the Healthcare Provider on the new Congenital Anomalies Registry

Who should report?
Doctors, midwives, nurses.

How to report?
Download form. Attach all supporting documentation of diagnosis (results of metabolic testing, MRI, consults from specialists, etc.). This should be completed within 3 months of the diagnosis.

If in doubt, report!
The completed form must be provided within 3 MONTHS after the day of diagnosis.

A health care professional who suspects a congenital anomaly(ies) and/or syndrome is required to complete the NWT Disease Registry Congenital Anomalies Reporting Form and return to:

Office of the Chief Public Health Officer
Department of Health and Social Services
Box 1320 CST-6
Yellowknife, NT X1A 2L9
Phone: (867) 920-8646 • Fax: (867) 873-0442

As of January 1, 2011, the new Congenital Anomalies Registry will be in effect in the NWT.

What does this mean to you?
The reporting of the following newly diagnosed Congenital Anomaly(ies) and/or syndromes will be a requirement under the new Public Health Act for all children under 19 years of age, including stillbirths and fetuses less than 20 weeks.

November 2010
www.health.gov.nt.ca
Congenital malformations, other genetic conditions and selected disabilities

Below are a list of GENERAL categories for congenital anomalies. It is by no means comprehensive. A complete listing can be found in WHO International Classification of Disease (10th ed.). Specific ICD codes are listed in Schedule 1 Part 2 of the Disease Surveillance Regulations under the new Public Health Act.

**Blood & Immune System Disorders**
- Hereditary haemolytic anemias
- Disorders involving the immune mechanism

**Chromosomal Abnormalities**
- Chromosomal abnormalities (e.g. Trisomy 21)

**Digestive System**
- Congenital malformations of the upper or lower alimentary tract
- Other congenital malformations of the digestive system

**Endocrine, Nutritional & Metabolic Diseases**
- Congenital hypothyroidism
- Androgenetic disorders
- Inborn Errors of Metabolism (e.g. PKU)
- Cystic Fibrosis

**Eye, Ear, Face and Neck**
- Cleft lip and cleft palate
- Congenital malformations of the eye, ear, face and neck

**Genitourinary System**
- Congenital malformations of genital organs
- Congenital abnormalities of the urinary system

**Heart and Circulatory System**
- Congenital malformations of the heart or circulation

**Mental and Behavioural Disorders**
- Childhood Autism
- Fetal alcohol spectrum disorder (FASD)
- Fetus and newborn affected by maternal use of drugs of addiction

**Neuromuscular Disorders**
- Anencephaly and other congenital malformations of the brain
- Cerebral palsy
- Hereditary ataxia
- Muscular dystrophies and other myopathies
- Neurofibromatosis and Tuberous Sclerosis
- Spina bifida
- Spinal muscular atrophy and related syndromes
- Other degenerative diseases and disorders of the nervous system

**Musculoskeletal disorders**
- Congenital malformations and deformations of the musculoskeletal system (e.g. Osteogenesis Imperfecta)

**Hearing loss**
- Conductive, sensorineural, or mixed

**Respiratory System**
- Congenital malformations of the respiratory system

**Skin**
- Congenital malformations of the integument

**Others**
- Any other suspected congenital malformation

If you SUSPECT any congenital anomaly, please complete form and FAX to OCPHO (867) 873-0442
Provincial/Territorial (P/T) Programs

AB [ACASS] (~ 50,000*) – Established 1980; a passive system with active follow-up; includes live births, stillbirths, & fetal deaths <20 weeks; ascertained up to 1 year after delivery.

* births/year
Congenital Anomalies Surveillance Model

Current Model

Provinces/Territories

CIHI

CCASS Data process, analysis and interpretation

Reporting
- Publications
- ICBDSR
- Data requests

Proposed Future Model

Provinces/Territories
- Surveillance registries
- Reproductive care programs
- Perinatal programs
- Administrative databases

CCASS Data process, analysis and interpretation

Feedback

Reporting
- Publications
- ICBDSR
- Data requests

CIHI – Canadian Institute for Health Information; ICBDSR – International Clearinghouse for Birth Defects Surveillance & Research
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Landscape of Ontario

Physical – Geographic
- Population: 13.6 million; National: 35.16 million (2013)
- Canada's most populous province, % National: ~40%
- Second largest province in total area.
- ~94% of population concentrated within Southern ON
- 85.9% of the population living in urban areas

Health System
- 99 birthing hospitals & 84 midwifery practice
- Births ~140,000/yr; % National: 37%
- Deliveries - >95% hospital, 1-2% home, 1% birthing units (2013) & “other”
- Prenatal Care, Screening and Diagnostic clinics
- 6 MFM entering into Antenatal Specialty (AS) encounter in BIS
- Referral, other specialty clinics
- Provincial health care
- All individuals provided a unique identifier
Objectives – BORN ON CA Surveillance Project

- Maximize the **ascertainment** of anomalies data.
- Continue to add additional data sources to the BIS and improve **data quality**.
- Focus on **environmental effects** and examine appropriateness of care for women to facilitate **improving quality of life** for infants living with CA.
- Continue to **communicate** project progress to stakeholders.
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Types of Surveillance Programmes
• Population-based
• Active & passive case ascertainment
• Multiple data sources
• Case definition

Conditions: pregnancy with one of the selected suspected or confirmed fetal or congenital anomaly
Pregnancy Outcomes: live births, stillbirths ≥20 wks, and terminations for fetal anomalies following prenatal diagnosis
Age: prenatal and up to discharge from hospital
Coding: ICD-10-CA and database-specific codes
✓ Integrated and collected data which includes anomaly & anomaly-related elements into a single registry since 2012.
# BIS Newborn Anomalies

## Newborn Congenital Anomalies Suspected

<table>
<thead>
<tr>
<th>Category</th>
<th>Subcategory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiovascular</td>
<td>Bladder extrophy</td>
</tr>
<tr>
<td>Abdominal Wall</td>
<td>Body stalk anomaly (limb body wall complex)</td>
</tr>
<tr>
<td></td>
<td>Cloacal extrophy</td>
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<tr>
<td></td>
<td>Gastrochisis</td>
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<tr>
<td></td>
<td>Limb body wall complex (body stalk anomaly)</td>
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<td></td>
<td>Omphalocele (exomphalos)</td>
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<td></td>
<td>Pentago of Cantrell</td>
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<td></td>
<td>Umbilical hernia</td>
</tr>
<tr>
<td></td>
<td>Other - congenital malformations of abdominal wall</td>
</tr>
<tr>
<td>Gastrointestinal</td>
<td></td>
</tr>
<tr>
<td>Genitourinary Tract</td>
<td></td>
</tr>
</tbody>
</table>
Search BORN Data dictionary

Go to http://datadictionary.bornontario.ca

Then enter the keyword or a few letters of a word for what you are looking for example: “anencephaly” or “anenc”
Search BORN Data dictionary

Go to http://datadictionary.bornontario.ca

Click blue “GO”

Then enter the keyword or a few letters of a word for what you are looking for example: “anencephaly” or “anenc”
What to collect?

Ideally, all anomalies should be collected, irrespective of their health impact.

So ... in the BIS, minor anomalies are collected, but will not necessarily be counted in our final reports to stakeholders.

Due to large number of births in the province, BORN Ontario will focus reporting efforts on major anomalies at this time.
Success to Date (cont.)

✓ Secured an additional 10 years of funding.

✓ **Transferred** BORN datasets since 2009 [4 fiscal years] of 16 national core variables to PHAC.

✓ Developed **data quality reports** in the BIS to validate data, improve completeness & quality of anomaly reporting.

✓ Obtained **datasets** from CIHI for CA & termination data from 2002 through 2012.

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Assuring Data Quality

• High data quality means
  – High level of case ascertainment (sensitivity)
  – Ensuring minimum number of false positives (non-cases)
  – Anomaly classification with needed specificity

• Methods for achieving high quality data
  – Multiple data sources
  – Standard procedures (validation & classification)
  – Documentation
    • Flow charts, processes and procedures, data dictionary
  – Appropriate personnel (number and qualified)
Missing Anomaly Data 2012-2013

- For birth records with a Newborn Anomaly Identified (3,724)
  - 280 (7.5%) were missing data for both newborn anomaly confirmed and newborn anomaly suspected
  - 502 (13.5%) were missing data for one of the anomaly data elements (confirmed or suspected), but ‘None’ was selected for the other anomaly
Missing Anomaly Data (cont’d)

Data Source: BORN Ontario, 2012-2013
Data Sources: BORN Ontario, 2012-2014

Data Sources: BORN Ontario, 2012-2014

Data Sources: BORN Ontario, 2012-2014
Data Sources: BORN Ontario, 2012-2014

What Can Hospitals Do?

• We rely on the data submitted by hospitals for our surveillance
• Ensuring your data is as complete as possible
• Picking ‘None’ for infants without anomalies

• What can we do to help you enter this data?
Site Specific Follow-up

Over the next few months or so we will be asking your coordinators to start the conversation about congenital anomaly data quality

• Site-specific rates
• Estimates of missing cases
• Barriers to entry at your site
• Suggestions for us
Our Next Steps

• Increase ascertainment of stillbirths & terminations in BIS.
• Increase the number of anomalies recorded as confirmed.
• Publish data quality analysis of the BORN anomalies data
Ontario Congenital Anomalies Committee (OCAC)

Dr. Aideen Moore, Chair
Dr. Julian Little, Vice-Chair
Dr. David Chitayat
Dr. Kate Bassil
Ms. Susan Conacher
Dr. Katherine Fong

Dr. Karen Harman
Dr. Edgar Jaeggi
Dr. Ahmed Nasr
Dr. Patrick Shannon
Ms. Jennifer Milburn
Dr. Rory Windrim

Ms. Heather Ramshaw, OCAC Coordinator
Ms. Erin Graves, BORN Resource
Questions

www.BORNOntario.ca
info@BORNOntario.ca

Follow us on Twitter @BORNOntario
Thank you for attending BORN Provincial Rounds.

BORN is hosting a two-day conference to bring health care providers, policy makers, health administrators, educators, quality and risk management leaders, and researchers together to share experiences, enhance knowledge, foster partnerships, and promote research.

Join the conversation!

www.bornontarioconference.ca