Content

- Explanation of BORN Ontario
- BORN Ontario data holdings
- Data Access – The process
- Data de-identification
- Expectations regarding use of data
Who We Are

Vision

The best possible beginnings for lifelong health
Founding Members

- **Fetal Alert Network**
  - Congenital Anomaly Information
  - Nurse Coordinators

- **Maternal Multiple Marker Screening**
  - Prenatal Screening Information

- **Newborn Screening Ontario**
  - Newborn Screening Information

- **Niday Perinatal Databases**
  - Pregnancy, Birth, Newborn & NICU Information
  - Coordinators
  - Reporting

- **Ontario Midwifery Program**
  - Clinical Midwifery Information

Rationale

- There are rich sources of information for clinical care and surveillance that BORN will leverage to become the authoritative source for maternal/child health information
  1. For purpose of facilitating or improving the provision of health care
  2. Provide high quality data that supports evidence-based decisions, innovative health planning and health system management / evaluation
  3. Eliminate redundancies and enhance efficiency
  4. Mandate data standards
  5. Improve linkages between data holdings
  6. Follow individuals through the “continuum of care” or by “encounters” with the health care system
  7. Analyze utilization of services to identify individuals who have not been offered the services available
  8. Supporting research and innovation
Current State: Information Sources

- BORN (as OPSS) was granted registry Status under the Personal Health Information Privacy Act (PHIPA) in Nov 2009
- Registry status affords BORN authority to collect, use and disclose personal health information without consent “for the purpose of “facilitating or improving the provision of health care”.

Current State: Privacy
BORN is a PHIPA Registry

- Registry status affords BORN authority to collect, use and disclose personal health information without consent “for the purpose of “facilitating or improving the provision of health care”.

This special authority requires BORN to develop and adhere to rigorous privacy policies – and have them reviewed and approved by the Ontario Information and Privacy Commissioner.
Current State: Technology

- 5 separate data systems need to be integrated
- Rigorous RFP process resulting Dapasoftware Inc. being selected as the vendor of record
- The Build launched March 2010, scheduled to finish Summer 2011
- A phased, focused approach is enabling a Subject Matter Expert driven decision making
  - Linking & Matching
  - Data Definitions
  - Reporting Requirements
  - Privacy & Security
  - Change Management

BORN - Growth and Development

- To mirror the growth and development of the babies that are in the BORN system
- Goal is to ‘tell the story’ of the birth cohorts
- To add new data sources as they are ‘important to the story’
Current BORN Data Sets

- Niday Perinatal Database & NICU Module
  - Clean 6-yr perinatal database of hospital births (about 140,000 total births/year in province)
  - 100% capture in perinatal database at end of 2009. Slightly less each year before that (82% in 2004)
  - Contains info on maternal health history, the pregnancy, birth and early postpartum period
  - About 33/45 NICUs participating in data entry for NICU module – working on integration plans for others.
  - **Data collected and entered by HCPs, not abstractors**
  - Very little identifying information available for linking (no names or OHIP numbers yet)
  - Recent data quality audit (publication underway)
Current BORN Data Sets

• Ontario Midwifery Program Database
  - Not yet migrated to BORN, but can help facilitate data cuts and analysis
  - Has both hospital and home births where midwives were in attendance, prenatal and postnatal care
  - Many of the same variables as Niday
  - Midwives are primary care providers (home & hospital) for about 6-8% of births in ON

• Fetal Alert Network Database
  - Captures information on women whose babies are diagnosed with congenital anomalies and referred to FAN program for care
  - 1-3% of births in province would have a touchpoint with FAN
  - BORN working with FAN to develop strategy for better surveillance of postnatal anomalies

Current BORN Data Sets

• Newborn Screening Ontario
  - Data on all babies screened shortly after birth for 28 rare disorders
  - Data currently resides at NSO, but could be part of a data request.
  - Almost 100% of babies are screened
  - With new BORN system, data will come via a feed and be linked to prenatal and birth data

• Prenatal Screening
  - Data currently resides outside BORN, but could be part of a data request
  - Data on all women who choose to have prenatal screening and the outcomes
  - Five labs and 18 genetic centres provide input
  - About 65% of women in Ontario choose screening
  - With new BORN database, data will come via a feed
Types of Requests

- Aggregate (simple)
- Aggregate (complex)
- Record level data
- Analysis requests

Aggregate - Simple

- How many births in ON last year?
- How many nulliparous women had primary and repeat cesareans by LHIN regions
- What proportion of women had prenatal screening
- How many missed newborn screens in live births?
Aggregate Requests

- Individuals within data-contributing organizations have access and can compare themselves to the region*
- BORN Ontario regional coordinators can run some data for their regions
  *BORN Regional Coordinators can help with access
- New reporting software in the BORN Build will make reporting much easier and will have more depth for analysis.

Aggregate - Complex

- Smoking in Pregnancy in Ontario – by education, income quintile, neighbourhoods
- Specific perinatal outcomes by neighbourhoods
- Statistical testing for differences between regions, proportions, outcomes
Accessing Data for Research

- Data request form on BORN Website
  www.bornontario.ca
- Currently just lists data elements for Niday perinatal database but is expanding with new build
- New data dictionary in process for combined data elements
- FYI – we provide data in the least identifiable form possible and have policies re small cell sizes and denominators

Record Level Data for Research

- Estimation of obstetrical outcomes using pattern classification approaches
- Breastfeeding in multiple and singleton pregnancies (BRIM study)
- Maternal exposure to ambient air pollutants and the risk of adverse pregnancy outcomes.
- Macrosomia and related adverse pregnancy outcomes: The role of maternal obesity
- Survey of mode of delivery and maternal and perinatal outcomes in Canada
- Evaluation of a unique Canadian community outreach program providing obstetrical care for pregnant adolescents: A matched cohort study
- H1N1 in pregnancy – Maternal and newborn outcomes
Costs for BORN Data

• Implementation of new policy for record level data access or complex aggregate data requests
  – Flat rate fee or hourly fee depending on the complexity
  – Grad students usually exempt if for their own projects (not their supervisor’s team)

Analysis

• BORN does analysis based on researcher specifications and only presents aggregate data to researcher
BORN Decision Making Process

**APPROPRIATENESS REVIEW**
- Is the project feasible?
- Scientifically appropriate?
- Data elements relevant & necessary?

IF NO (to any) - REJECT

IF YES

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**AGGREGATE DATA REQUESTED**
- Is data actually aggregate?
  - Data Request Review Committee

IF YES

IF NO

**RECORD – LEVEL DATA REQUESTED**
- To REB for expedited review
  - Can question be answered with data at low-risk of re-identitification?

IF APPROVED

IF DENIED

- REB APPROVAL RECEIVED
  - Requesting organization and individual signs Data Sharing Agreement
  - Check PHRA requirements fulfilled
  - Decision recorded
  - B.F. created
  - Release PHI

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bored: Better Outcomes Registry & Network
BORN and eHIL

- Iterative process
- Researcher asks for data elements they want
- eHIL uses PARAT tool to assess the risk of re-identification.
- If risk is above threshold, back to researcher to ask them to modify request

PARAT Tool

- Privacy Analytics Re-identification Risk Assessment Tool
- Looks at potentially identifiable variables in combination and determines risk and suggests ways to reduce risk and/or suppression
- Example (in BORN Niday database)
  - Maternal DOB, Maternal PC, Maternal health problems, maternal aboriginal status
  - Baby DOB, Baby Wt, Baby Sex, Congenital Anomalies
## Example of Output

### Quasi-identifiers Selected

<table>
<thead>
<tr>
<th>Name</th>
<th>Type</th>
<th># Equiv. Classes</th>
<th>Generalization</th>
<th>Weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>MDOB</td>
<td>Character String</td>
<td>60</td>
<td>Year</td>
<td>-</td>
</tr>
<tr>
<td>BDOB</td>
<td>Date/Time</td>
<td>1826</td>
<td>Unchanged</td>
<td>-</td>
</tr>
<tr>
<td>GENDER</td>
<td>Character String</td>
<td>4</td>
<td>Unchanged</td>
<td>-</td>
</tr>
<tr>
<td>BWEIGHT_500</td>
<td>Character String</td>
<td>19</td>
<td>Unchanged</td>
<td>-</td>
</tr>
</tbody>
</table>

### Risk Assessment Results

<table>
<thead>
<tr>
<th>Re-identification Threshold</th>
<th>Risk Level</th>
<th>Records at Risk (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prosecutor Risk</td>
<td>High</td>
<td>62956 (98.819%)</td>
</tr>
<tr>
<td>Journalist Risk</td>
<td>Low</td>
<td>-</td>
</tr>
<tr>
<td>Marketer Risk</td>
<td>Low</td>
<td>-</td>
</tr>
</tbody>
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Explanation of PARAT and types of risk available at: [https://www.ehealthinformation.ca/knowledgebase/category/7/0/10/PARAT-Tool/text/ja](https://www.ehealthinformation.ca/knowledgebase/category/7/0/10/PARAT-Tool/text/ja)

## Example of Output – Alternate Suggestions

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<td>Year</td>
<td>-</td>
</tr>
<tr>
<td>BDOB</td>
<td>Character String</td>
<td>60</td>
<td>Month, Year</td>
<td>-</td>
</tr>
<tr>
<td>GENDER</td>
<td>Character String</td>
<td>4</td>
<td>Unchanged</td>
<td>-</td>
</tr>
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<tbody>
<tr>
<td>Prosecutor Risk</td>
<td>High</td>
<td>52849 (8.295%)</td>
</tr>
<tr>
<td>Journalist Risk</td>
<td>Low</td>
<td>-</td>
</tr>
<tr>
<td>Marketer Risk</td>
<td>Low</td>
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<tbody>
<tr>
<td>Prosecutor Risk</td>
<td>High</td>
<td>14456 (2.269%)</td>
</tr>
<tr>
<td>Journalist Risk</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Marketer Risk</td>
<td>Low</td>
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Advantages

- **For Researchers**
  - Access to data elements previously unavailable or severely limited
  - Reduced risk among their team members for re-identification
  - Forced to think about research questions and implications upfront

- **For BORN**
  - Reduces risk of any inadvertent re-identifications
  - Helps us meet best practices for data management
  - Very objective method for making decisions about data – actual risk identified and available to researchers
Disadvantages

• Iterative process can be time consuming
  – Trying to prevent this by working with researchers upfront to prevent ‘asking for everything’ and being realistic about timelines and what BORN will be able to provide.

BORN – The Future

• We look forward to working with you to answer important maternal-child research questions
Questions?

For further information:

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