Combining Data Sources to Enhance the Surveillance of Congenital Anomalies in Ontario

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Coordinated congenital anomalies surveillance (CA) in Ontario. BORN Ontario is a provincial program, mandated to create and maintain a definitive source of accurate information to monitor, evaluate and plan for the best possible beginnings for life-long health. Reliably identifying CA is important to improve the provision of health care to affected infants, to identify increases and decreases in rates over time in the province, to inform research into the causative factors of CAs and to inform public health programs and policies. BORN is also responsible for providing data to the Canadian national CA surveillance enhancement initiative. Ontario is the province with the largest numbers of births (140,000/year) and makes up about 37% of all births in Canada. In Canada, major CAs occur in approximately 3–5% of newborn infants and in 8% to 10% of stillbirths.

The BORN Information System (BIS) was launched in 2012. Data is collected at the point of care & integrated across the continuum into a single maternal-child registry. The BIS has developed data capture methods for anomalies detected in the fetus and newborn during clinical encounters before (antenatal specialty, prenatal screening) and at the time of birth (delivery and NICU admissions).

Objective: Using a combination of the CIHI Discharge Abstract Database (DAD) and the BIS, we jointly ascertained the rates of the six categories of CA in Ontario based on the PHAC 2013 report using data from 2012-13 and 2013-14: Down syndrome (DS), neural tube defects (NTD), 3 selected congenital heart defects (CHD), orofacial clefts, limb deficiency defects (LDD) and gastroschisis (GS).

Methods: The two databases were linked together using a combination of deterministic matching by health card number and probabilistic matching techniques to identify anomalies collected in either, or both databases. Data from BORN includes fetal anomalies detected through prenatal screening and antenatal specialty clinics, along with newborn anomalies identified prior to discharge from hospital or midwifery care. Anomalies collected in the BIS can be flagged as ‘Suspected’ or ‘Confirmed’ cases; this analysis was completed using only ‘Confirmed’ cases. DAD includes hospital records from birth through to one year of age (including termination, stillbirth and live birth records).

Results: Combined prevalence rates for all six anomalies in Ontario are higher than those previously reported for Ontario. While a relatively low percentage of anomalies were found in both data sources (0%-43%) the BIS data adds significantly to the rates found previously by PHAC when using CIHI DAD alone. The BIS-CIHI combined rates mirror trends seen in Alberta, where their well-established congenital anomalies surveillance system reports rates consistently higher than those found using CIHI alone. Furthermore, we use the ‘Suspected’ Anomalies to estimate a theoretical upper limit on the rate of these anomalies in Ontario.

Conclusion: This investigation of sentinel anomalies in Ontario improved the ascertainment of CA by using a combination of data sources. However, the lack of overlap between the two data sources is higher than expected. BORN is working to expand our ascertainment of all pregnancy outcomes (including terminations and stillbirths) and the ability to confirm suspected cases through incorporating additional data sources, allowing us to provide even more accurate CA rate estimates in the future. By improving capture of potential causative factors, cases of anomalies, & outcomes, we will be able to expand our surveillance work beyond reporting of sentinel rates.

Future Directions
- Expand ascertainment by incorporating additional data sources
- Perform record matching, apply capture-recapture & relative probability of ascertainment analysis methods to determine quality of data captured
- Validate interpretability and assess accuracy of BIS and CIHI cases

Table 1: Case Ascertainment of Confirmed Sentinel Anomalies in 2012-13 & 2013-14 BIS & CIHI (DAD) Data (combined) including Live Births, Stillbirths and Terminations

Table 2: Estimating Under Ascertainment of Anomalies by Combining ‘Suspected’ Anomalies to Estimate a Theoretical Upper Limit of the Rate in Ontario

Table 3: Newborn/Stillborn Case Ascertainment at or after Birth

Figure 1: Provincial and National Sentinel Rate Comparison

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Data Sources: Ontario rates calculated using CIHI Discharge Abstract Data (DAD) + BORN Information System (BIS) data.