



Better Outcomes Registry & Network
Registre et Réseau des Bons Résultats dès la naissance

A young child with curly brown hair is sitting on a grassy field, looking down at their hands. The child is wearing a white shirt with colorful polka dots. The background is a blurred green field and trees.

BORN Data Quality Report 2012-2014 – Executive Summary

April, 2016

Acknowledgements

Special thanks to Geoffrey Barnum, Dan Bedard, Sandy Dunn, Marlene Elliott, Erin Graves, Vivian Holmberg, Mike Kotuba, Monica Prince, Deborah Weiss and Jill Wylie for their data analysis expertise and historical reference.

Executive Summary

The Better Outcomes Registry & Network (BORN) Ontario is committed to high quality data to meet its mandate of being an authoritative source for maternal and child information. Clinicians, decision makers, policy makers, and researchers rely on valid and reliable data to support program management, benchmarking, evaluation, and quality improvement. Our goal is to ensure that data entered into the BORN Information System (BIS) is timely, accurate, and comparable as well as usable and relevant for stakeholders. To that end, the BORN Data Quality Framework (DQF) was implemented in 2013.

The primary purpose of this report was to examine/analyze the quality of the labour, birth and early newborn care data in the BIS from 2012-2014. The BORN DQF is based on five dimensions of data quality which in turn are divided into 19 elements and sub-elements. Bullet points under each dimension are used to demonstrate successful data quality initiatives at BORN:

1. **Timeliness** – How current or up to date data is at the time of release and whether the data is available for user needs within a reasonable time period.
 - Timely data submission of new births is critical to ensure missed screens are avoided (e.g. newborn screening). The median time to create a Birth Child encounter for 93,625 births in fiscal year 2012-2013 for manual entry sites (n=82) was 1.1 days and 1.0 day for fiscal year 2013-2014 (n=80 representing 92,110 births).
2. **Accuracy (validity)** – How well information within or derived from the database reflects the reality it was designed to measure.
 - There was good agreement between the BIS and the CIHI Discharge Abstract Database (DAD) in terms of births captured.
3. **Comparability (reliability)** – The extent to which data are consistent over time and entered using standard conventions making it comparable to other databases.
 - BORN was able to compare records in the BIS with those in the CIHI DAD in order to confirm maternal outcomes that were entered in the BIS.
4. **Usability** – The ease with which the data is understood and accessed.
 - BORN developed an online request process with a shopping cart format to facilitate access to data for BORN users. This new format allows users to select the elements directly on the website, bypassing any need to manually create a detailed list for submission.
5. **Relevance** – The degree to which the data meets the current and potential future needs of users.
 - BORN maintains a data use log which includes extensive details for every request submitted to BORN. This log allows BORN to easily identify topics of interest.

We recognize that there are other encounters in the BIS that require this same level of attention to data quality. We intend to complete a similar review as we bring in new sources of data within the BIS and for all other encounters. This detailed process took over a year and completion of an annual data quality report will be a regular and ongoing process. BORN will prioritize the report recommendations and develop a plan for action.

1. Timeliness

A. *Data entry time – how close to real time data entry occurs*

- Compare the specific data entry methods as described by the coordinators for any future evaluations on timeliness. The data entry methods are as follows:

Manual entry

manual entry < 24 hours Nurse
manual entry < 24 hours Clerk from chart
manual entry < 24 hours Clerk from worksheet
manual entry > 24 hours and < 7 days Nurse
manual entry > 24 hours and < 7 days Clerk from chart
manual entry > 24 hours and < 7 days Clerk from worksheet
manual entry > 7 days Nurse
manual entry > 7 days Clerk from chart
manual entry > 7 days Clerk from worksheet
manual entry > 7 days Coders chart abstraction

Upload

upload < 24 hours
upload > 7 days and < 1 month
upload > 1 month

- For future evaluations consider calculating creation time of other encounters and more than only hospital sites (i.e. Midwife attended home births and Birth Centre births, Family Health Teams, etc.)
- Access Admit Discharge Transfer (ADT) feeds at hospital sites which will improve timeliness of data submission of new births. With this feed, birth records can be created in the system within minutes to hours of a child being born. This will improve the downstream effects of better reassurance that no child has missed their newborn screening and ensuring more complete and accurate transmission of Healthy Babies Healthy Children (HBHC) Screening. Accessing an ADT feed, is also a great efficient way to reduce time and aid in resourcing issues.

B. *Validation time – data entry to validation/acknowledgement*

- Work with sites to develop a plan to have their data acknowledged in a timely manner.
- Work with sites to determine what the barriers are and find ways to remove these barriers.

C. *Data quality reports usage log*

- Continue to monitor data quality reports log to better gauge the reports' usefulness to stakeholders
- Learn how BORN can add value to reports that are less utilized.
- Re-evaluate usage of the missing reports six months after the new hyperlinks will have been added.
- Explore self-serve reports that sites could customize themselves.
- Continue to provide sites tools such as pivot tables and reporting webinars so that they could make better use of their reports.

2. Accuracy (Validity)

A. Validation of BIS data with CIHI data

- Continue to validate BIS data with CIHI data in order to evaluate accuracy and validity.
- Investigate the potential reasons as to why there is a discrepancy between the two databases.

B. BORN procedures to minimize data entry burden

- Continue to evaluate enhancements to the BIS in order to minimize response burden.
- Develop a survey in order to receive feedback from stakeholders in regards to enhancements they would like to have to reduce data entry burden.

C. Data quality survey of high priority data elements

- Create an annual data quality feedback process for high priority data elements.
- Develop specific processes to assess user feedback and data quality within one year following the introduction of all new encounters and data elements.

D. Assessment of calls to Helpdesk

- Continue to monitor helpdesk calls in order to evaluate support and user experience
- Coordinators will evaluate whether a decrease of calls to Helpdesk is because BIS users are contacting their respective coordinators or if BIS users are able to manage issues themselves.

E. Validation of BIS data through re-abstraction studies

- Complete another chart audit of high-priority indicators incorporating the lessons learned from the ART and NICU re-abstraction pilot studies.

F. Missing data rates for selected data elements

- Evaluate rates of missing values in hospitals where data is entered by a health provider versus a unit clerk or health records clerk.
- Evaluate which method is the best regarding data entry.
- Document all upload data mapping to Unknown.
- Assess the proportion of sites that are unable to use specific dashboard indicators due to their missing data

G. Full continuum submission audit

- Revise the Incomplete reports' logic to allow sites to enter the full continuum for each record in the BIS.
- Work with sites to help them identify and complete all records that are flagged by the Incomplete reports.

H. Evaluation of orphan records in the BIS

- Continue to monitor orphan records.
- Develop technical solutions and work with sites to decrease the number of orphan records.

3. Comparability (Reliability)

A. Report linkage of records with other datasets

- Continue to investigate other means of capturing maternal death data.
- Validate maternal death data with CIHI on a yearly basis.

4. Usability

A. *Develop a documentation system to record feedback on data limitations*

- Document all changes and data quality issues in the new BORN Data Dictionary tool.

B. *Fiscal year dataset closing process*

- Develop a standard definition for 'closed data sets'.
- Investigate why lag time to data entry being complete is increasing.

5. Relevance

A. *Data use log*

- Survey data requestors of BORN data to ensure that what BORN provides is meeting their needs.

6. Other recommendations

A. *Promote data quality internally; build a culture of data quality within BORN*

- Continue monthly Data Quality Team meetings.
- Continue to look at ways we can resolve data quality issues regarding Field Level Help and definitions on the user interface.
- Incorporate data quality objectives in staff's bi-annual performance objectives.

B. *Promote data quality externally*

- Continue conducting webinars, provincial rounds and site visits to continuously educate stakeholders on the importance of data quality and to have a better indication of stakeholders' comprehension regarding certain data elements.
- Work with sites that consistently have high missing data element values or have other data quality related issues in order to better understand how BORN can help them.

C. *Quality Improvement Projects*

- Continue working on quality improvement projects such as the BORN Data Dictionary tool.
- Continue exploring methods to improve data quality upon entry in order to improve the quality of the data provided to all stakeholders.

About the Better Outcomes Registry & Network (BORN)

BORN traces its roots to the 1980s and the Perinatal Education Program of Eastern Ontario (PEPEO). The program was led by Dr. Patricia Niday, who envisioned the use of data to support better obstetrical and neonatal care. As hospitals throughout the region began to see the value of aggregating data to examine outcomes and identify areas for improvement, PEPEO became the Perinatal Partnership Program of Eastern and Southeastern Ontario (PPPEO). Together with other Ontario perinatal networks, the organization began to lobby the provincial government for funding to expand the database, which was renamed the Niday Perinatal Database in the late 1990s.

When the Child Health Network for the Greater Toronto Area (GTA) member hospitals joined the program in 2003 – adding 51% of Ontario births to the system – the database was still housed within PPPEO and the Children’s Hospital of Eastern Ontario (CHEO); however, it then became known as the Ontario Perinatal Surveillance System (OPSS). Under founding director Jim Bottomley, OPSS developed the Niday NICU/SCN module, extended its partnerships and encouraged more Ontario hospitals to contribute data.

The government’s first provincial report on perinatal care was produced in 2006. Concurrently, reorganization with the Ministry of Health led to the formation of the Maternal Child Health Strategy Division. Responsible for a number of maternal child data sources in the province, the division quickly recognized the value of integrating data within a privacy environment to facilitate and improve care. The Ministry directed OPSS to bring together data from prenatal screening, the Fetal Alert Network (FAN) (for congenital anomalies), the Ontario Midwifery Program (OMP), the Niday perinatal and NICU/SCN modules, and Newborn Screening Ontario (NSO).

With new provincial funding, OPSS was rebranded as the Better Outcomes Registry & Network (BORN) Ontario in 2009. The five founding partner groups, BORN staff and project consultants worked to design and build the new BORN Information System (BIS) while still carrying out partner program activities, and using the existing data to support quality improvement and practice.

Full registry status under the Personal Health Information Privacy Act (PHIPA) was obtained in October 2011. The BIS was launched on January 23, 2012. The first year of data initially collected in the BIS is fiscal 2012-2013. Two additional Niday historical fiscal years (2010-2011; 2011-2012) are integrated and mapped to the BIS and available to users.

Development of the BIS

The BIS enables the collection of, and access to, data on every birth in Ontario by participating organizations. Sourced from hospitals, labs, midwives/midwifery practice groups (MPGs) and clinical programs, the data are collected through a variety of mechanisms including HL7 (Health Level 7), batch upload (automated extraction and uploads from health record systems), and manual data entry. Information is reported via standard reports, data dumps, and analytical tools within the BIS. Figure 1 illustrates the data sources included in the BIS from 2012 to 2014, it has since changed.

Since April 1, 2012, data have been collected from a number of sources including:

- Fertility clinics (since January 1, 2013)
- Prenatal screening laboratories
- Specialized antenatal clinics (information about fetal anomalies)
- Hospitals (pregnancy, labour, birth and early postpartum care information)
- Newborn screening laboratory
- Prenatal screening and newborn screening follow-up clinics

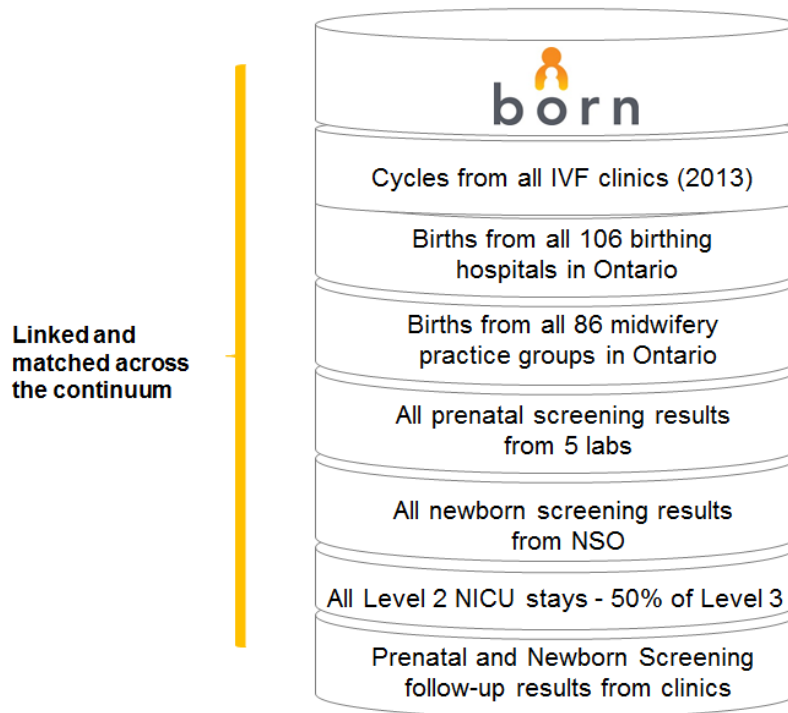


Figure 1 Data sources included in the BIS (April 2012)

Every birthing hospital and midwifery practice in Ontario contributes data to populate more than 100 searchable data element groupings in the BIS. Unlike CIHI, contribution of data to the BIS is done on a voluntary basis at point-of-care and not by abstractors. Thus, we rely on the good will of busy care providers. However, the value for them is easy-to-access, near real-time data.

The BIS – Features and Functions

The BIS data is collected from a variety of sources as ‘encounters’ (see Figure 2) that are flexible and scalable. These encounters reflect care at different time points by different organizations in time and are aggregated together into two authoritative files, the Aggregate Pregnancy and the Aggregate Infant. Additional data elements/encounters/data sources can be linked to this data as necessary using pregnancy and birth IDs.

| Encounter | Definition |
|--------------------------|--|
| Antenatal General (AG) | Captures information relevant to the antenatal period (i.e. obstetrical history, exposures, complications, etc.) |
| Antenatal Specialty (AS) | Captures maternal, pregnancy, and fetal information for those women who require specialized care management at a high risk maternal fetal medicine or prenatal genetic clinic. |
| Labour (L) | Captures information relevant to the mother's spontaneous or induced labour experience. |
| Birth Mother (BM) | Documents the mother's birth experience through to the first hour postpartum. |
| Birth Child (BC) | Documents the child's birth experience through to the first hour postpartum. |
| Postpartum Mother (PPM) | Documents the course of care experience by the mother from one hour post birth to discharge from hospital. |
| Postpartum Child (PPC) | Documents the course of care experienced by the child from one hour post birth to discharge from hospital. |

Figure 2 List and definition of BIS encounters

We strive to track most healthcare encounters of the mother-child care continuum. Figure 3, is the schematic of the BORN continuum, starting with CARTR Plus, which is the In-vitro fertilization cycle data, going through the antenatal period, prenatal screening, antenatal specialty (which collects detailed data regarding congenital anomalies), details of the labour, birth and postpartum period, and midwifery details. Everything in blue is a pilot area where BORN is looking to explore our ability to collect more data or have more of an impact (i.e. gestational diabetes follow-up, and capturing antenatal 1 and 2 forms from primary care).

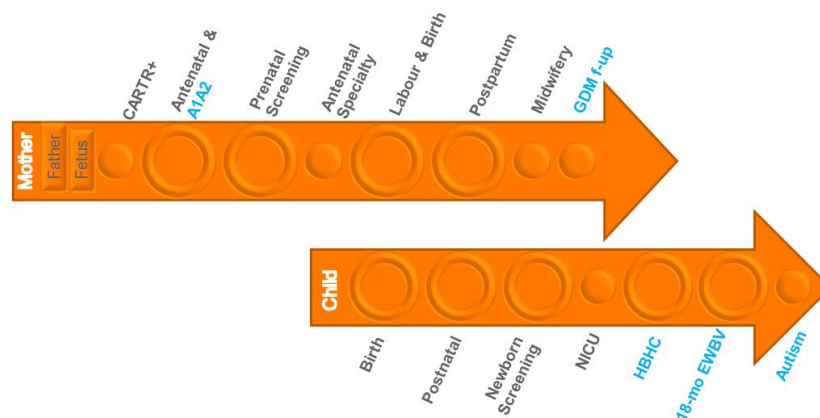


Figure 3 The BORN Information Continuum

The BIS contains validation rules that check logic, conformance and parameters. The logic rules check compliance between different elements collected within an encounter. Conformance rules ensure that mandatory elements are completed when required. Parameter rules compare the entered values against look-up tables stored in the BIS to ensure the data are within acceptable ranges before they are submitted. For sites doing manual data entry, data cannot be saved in the BIS unless it passes these checks. For sites that upload their data directly to the BIS from Electronic Health Records (EHRs), these rules are built into the specifications for the file before it is uploaded. The uploaded data is also validated against the same rules as the direct entry sites. If an error occurs, it is flagged and the upload site is notified to allow them to either correct the error directly in the BIS, or to resubmit the uploaded file. However, it should be noted that sites that upload data do have the option to default values that do not conform to the BORN rules to 'Unknown'.

Aggregation rules apply when the data from each encounter is combined into the Aggregate Pregnancy and Aggregate Infant files. These rules outline the procedure for how each data element that is captured in multiple encounters are consolidated into the aggregate files and which values take precedence when an element is recorded in more than one encounter. Having some important elements captured multiple times also helps to increase the accuracy of the data collected in the BIS. Some fields that are captured in multiple encounters in the BIS are pre-populated when they have been entered for a previous encounter. Users are expected to check if the pre-populated data is accurate. If they choose to update this data, it will not overwrite what was previously entered in a prior encounter, but the updated value may take precedence over the previous data and become the final value on the Aggregate file depending on the specific rule applied to each data element. For multi-select values, all positive values are merged in the aggregate.

In addition to the validation and aggregation rules built into the BIS, there are substantial data quality assurance tools and processes taking place as the data is collected. Beyond these processes, BORN analysts also conduct additional checks on the data before the fiscal year is closed.

BORN Support - Coordinators' Roles and Helpdesk

BORN coordinators work with different data submitters (e.g., hospitals, midwives, fertility clinics) to support and assist sites with the data entry, reconciliation and acknowledgement processes, and implementation of system changes (known as enhancements). BORN coordinators play an important role in liaising with our data submitters and working to ensure data quality. In addition, the BIS user interface (UI) has built-in functionality allowing a data entry person to click on a question mark icon, when available, to get a definition of a data element and the associated pick list values. If further assistance is needed, a 24/7 Helpdesk exists and provides live help for questions that may come up during the process.

Reconciliation Process

In addition to the role the BORN coordinators play in ensuring timely and accurate data is entered by the sites, the BIS also has a variety of administrative and reconciliation reports (Verification Reports, Data Discrepancy Reports and Incomplete Record Reports). These reports allow data submitters to view records flagged by the system as having missing encounters, possible errors, or different data entered for the same element in different encounters. In this way, those entering the data play a role in continuously improving the quality of the data they provide.

Acknowledgement Process

Each month, organizations are required to go back and acknowledge the records which they submitted. This process requires that they review the records and ensure that there are no outstanding errors on their data quality reports. All data must be acknowledged by the submitting organization before it will be available for comparative clinical reporting. This process of having each record submitted and reviewed ensures the data contained in the BIS is as accurate as possible.

Audit and Feedback Structure

The BIS enables near real-time reporting, ensuring timely data access for submitters. This provides the opportunity for organizations to quickly identify errors in the entered data and to improve data quality. Once data quality issues are addressed, data is acknowledged and is moved to the reporting portal where clinical reports are available to users. These reports allow users to see their own data, look at trends over time, and to compare their data against peer group and provincial rates.

Changes to Data Elements and Collection Processes

BORN Enhancement Cycle

Changes (or enhancements) to data elements collected in the BIS are made following a rigorous review process. Currently, BORN works under an enhancement cycle. However, in extremely urgent circumstances, BORN can add new data elements in response to a health crisis that requires accurate surveillance (e.g. in response to the H1N1 Pandemic flu).

Data Collection Review Committee

In addition to the regular enhancement cycle, BORN also has a Data Collection Review Committee that ensures BORN only collects the data required for its purposes and in accordance with our registry status under the Personal Health Information Protection Act (PHIPA). The committee reviews the currently collected data elements, reviews and approves any proposed new data collections and recommends a privacy impact assessment if needed for proposed data dictionary changes.

BORN Ontario Data Quality Framework

The *BORN Data Quality Framework (DQF)* was implemented in 2013. The BORN DQF is based on five dimensions of data quality which in turn are divided into 19 elements and sub-elements. Detailed breakdown of the dimensions, elements and sub-elements are provided in Figure 4.

Timeliness – How current or up-to-date data is at the time of release and whether the data is available for user needs within a reasonable time period.

Accuracy (validity) - How well information within or derived from the database reflects the reality it was designed to measure.

Comparability (reliability) - The extent to which data are consistent over time and entered using standard conventions making it comparable to other databases.

Usability – The ease with which the data is understood and accessed.

Relevance – The degree to which the data meets the current and potential future needs of users.

The primary purpose of this report was to examine/analyze the quality of the labour, birth and early newborn care data in the BIS from 2012-2014.

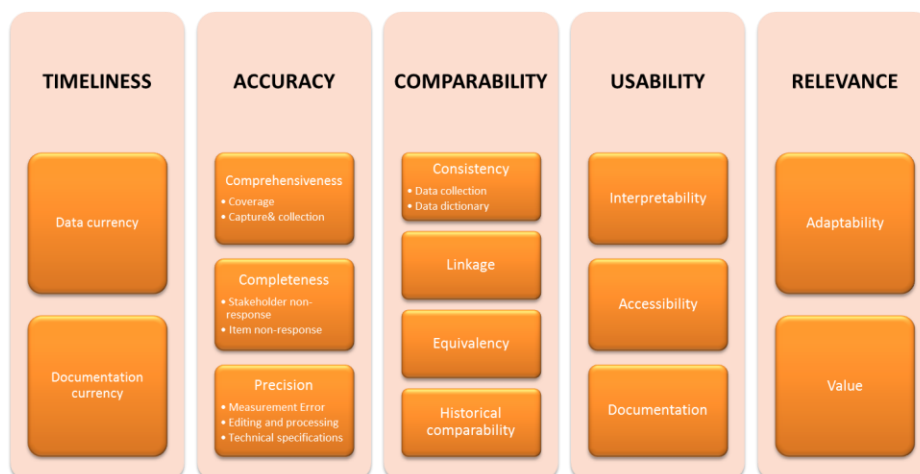


Figure 4 BORN Data Quality Framework – Dimensions, Elements and Sub-Elements

Data Sources

BORN Ontario, 2012-2014

CIHI DAD, 2012-2014

“Quality means doing it right when no one is looking.”
-Henry Ford

