

## **BORN Ontario – DATA QUALITY Framework**

**V11 – July 19, 2013**

### **BORN requires a comprehensive framework to:**

- Promote data quality in all aspects of our data work: collection, analysis, use and disclosure of information
- Mitigate risk associated with making health policy decisions or interpretation of research results based on poor quality data
- Assist with development of a data quality management plan (DQMP)
- Guide decisions on resource allocation to carry out the DQMP
- Align with criteria for data element addition/deletion/changes

### **The process used to develop this Data Quality Framework:**

- The data quality frameworks used by a number of organizations were reviewed in depth (e.g. Ministry of Health and Long Term Care (MOHLTC), Canadian Institutes for Health Information (CIHI), Statistics Canada, American Health Information Management Association (AHIMA), Institute for Clinical Evaluative Sciences (ICES), and Perinatal Services BC).
- The most complete and robust framework was from CIHI as it covered all aspects of data collection, analysis and use.
- We adapted common data quality domains to BORN's unique data collection, use and disclosure needs.
- Since BORN works with CIHI, and CIHI sends their data to ICES, there was agreement to have the same high quality approach to data management.

## BORN Data Quality Framework (adapted from the CIHI Data Quality Framework, 2009)

Data Quality Dimensions	Criteria	Implemented BORN Data Quality Processes	Potential BORN Data Quality Processes/Measures
<b>1. TIMELINESS</b> - Refers to how current the BIS data is at the time of release and whether the data is available to meet user needs within a reasonable time period			
<b>1a. Data currency (freshness of data at the time of release)</b>	<p>The difference between the date of data capture and the date data is available (time of data entry vs. time data is validated)</p> <p>Data processing activities are reviewed and documented yearly to ensure timeliness</p>	<p>BORN guidelines re: data entry and closure exist (e.g. hospital data entry in near real time with 1 month lag time for acknowledgement; IVF Data is due quarterly with acknowledgement due 3 months later)</p> <p>BORN coordinators monitor data currency</p> <p>BORN coordinators/SMEs review monthly acknowledgement reports and provide feedback and support to stakeholder groups</p> <p>PSO Outstanding Follow-up Information Report has been developed to track PSO follow up data entry that has been started but not submitted</p> <p>NSO DERF Status Report tracks both clinical workflow, and therefore inherently promotes timely data entry.</p>	<p><b>Data entry time</b> – how close to real time data entry occurs stratified by the different user groups entering data (fertility, hospitals, midwifery, labs)</p> <p><b>Validation time</b> – data entry to validation/ acknowledgement stratified by the different user groups entering data (fertility, hospitals, midwifery, labs)</p> <p>Data holding processing activities are reviewed and documented yearly</p>
<b>1b. Documentation Currency</b>	Data quality documentation is available for data requests or at the time reports are released	<p>Critical appraisal of the quality of the data is included in all published reports (overall, as well as specific to the indicators included in the report)</p> <p>As new data elements are added to the BIS auto-updates are created in the online data dictionary</p>	Annual data quality reports are available
<b>2. ACCURACY (VALIDITY)</b> - How well information within or derived from the BIS reflects the reality it was designed to measure.			
<b>2a. Comprehensiveness (coverage; capture and collection)</b>	<p><b>i. Coverage: under or over coverage</b></p> <p>Under or over coverage occurs when there is a difference between the population of interest and the population of reference</p> <p>The <b>population of interest</b> is the group of units for which information is wanted (e.g. all hospitals in Ontario, all midwifery practices, all PS labs, all IVF clinics, etc.)</p> <p>The <b>population of reference</b> (the one for which the statements are made) is explicitly stated in all reports</p> <p>Efforts are made to close the gap between the population of reference and the population of</p>	<p>Partner groups/organizations contributing data to the BIS are listed on the BORN website and included in all reports and communications (all hospitals providing labour and birth services, midwifery groups, NSO, PSO, ART)</p> <p>Reference population is defined in all reports (whether data is for a specific cohort / population, geographic region etc).</p> <p>Coordinators work with sites/groups with data issues to assist them as required</p>	<p>Data Quality Report will document:</p> <ul style="list-style-type: none"> <li>• Coverage</li> <li>• Particular issues in complete capture of the data</li> <li>• Annual rate of under- or over-coverage</li> </ul> <p>BORN will monitor data requests that were not able to be executed due to coverage concerns</p>

	<p>interest</p> <p>The rate of under- or over-coverage falls into one of the predefined categories:</p> <ul style="list-style-type: none"> <li>▪ <i>None or minimal</i> (&lt;1%)</li> <li>▪ <i>Moderate</i> (1%-3%)</li> <li>▪ <i>Significant</i> (&gt;3%)</li> <li>▪ <i>Unknown</i> (could not be determined)</li> </ul>		
	<p>The dataset has been validated by comparison with external and independent sources</p> <p><b>NOTE:</b> There is no other mechanism to validate IVF Clinic data in Canada</p>	<p>Yearly comparison of number of live birth and stillbirth records in the BIS compared to CIHI datasets</p>	<p>Validate BIS data with CIHI data (e.g. live births, still births counts) (July 2013). Assess and evaluate discrepancies identified and target problematic sites as necessary</p> <p>Yearly comparison of neonatal deaths once mechanism in place to capture this data from all NICU/SCNs.</p>
	<p><b>ii. Capture and collection</b></p> <p>BORN Practices that minimize response burden are documented</p>	<p>BORN goal - 100% capture of all births in Ontario, all IVF cycles, all NICU/SCN admissions, all prenatal and newborn screens, and short-term follow-up completed.</p> <p>BORN acknowledges response burden with voluntary participation and data entry. BIS is designed to reduce response burden (e.g. auto-calculation, pre-population, conditional and optional fields).</p> <p>BORN advocates for organizations to implement best practices for data entry to increase automation and reduce duplication</p> <p>BORN Coordinators assess response burden and provide support to reduce the burden</p>	<p>Report on BORN practices implemented to minimize response burden</p> <p>BORN will assess the impact of different models of data entry against data quality</p>
	<p>Practices exist that encourage cooperation for data submission and give support to data providers (e.g. stressing the importance of participation, the assurance of confidentiality, the provision of value-added utilities for cooperation such as robust reporting environment, publications, training, and specialized reports).</p>	<p>Robust reporting environment allows users access to their data in real-time</p> <p>BORN Communications used to encourage participation and readership (e.g. webinars, BORN Bulletins)</p> <p>Privacy policies and procedures developed to address confidentiality issues (e.g. privacy training for all staff) and participation agreements established where needed.</p> <p>BORN Coordinators provide feedback, support, education sessions and training (data entry, data quality reports, clinical reports, dashboards)</p> <p>Helpdesk support for data entry personnel for prompt response to issues</p> <p>BORN creates opportunities for users to provide online feedback in as many places as is feasible</p> <p>Super-users available at each site for training and support</p>	<p>Participant survey to determine whether the practices in place to encourage cooperation for data submission are useful/helpful and to assess user support needs</p> <p>Assessment of calls to Helpdesk to evaluate support required and user experience</p>

	<p>Data-capture quality control measures exist and are implemented by data providers.</p>	<p>Data-capture quality control measures currently implemented in the BIS include:</p> <p><b>Point of entry validation</b></p> <p>Mandatory data elements and data validation rules have been implemented to ensure data is complete and logical (e.g. <i>labour and birth or postpartum complication</i> cannot be "None" if <i>maternal outcome</i> = is "Transfer to ICU/CCU"</p> <p>Automated algorithm applied to all records to ensure the health card number (i.e. OHIP) is the appropriate length and format</p> <p><b>Consistency edit checks</b></p> <p>Verifying an intervention that can only be one type of answer (i.e. no Birth Child encounter created without a birth OR no VBAC without a prior cesarean)</p> <p><b>Dual capture</b></p> <p>Double entry of a variable (birth weight and gestational age)</p> <p>Duplicate IVF cycle report available</p> <p><b>Reconciliation process in place (missing or incomplete records)</b></p> <ul style="list-style-type: none"> <li>▪ Reconciliation Reports: for verification</li> <li>▪ Incomplete Record Reports</li> <li>▪ Missing Data Element Reports</li> </ul> <p><b>NSO Data Review</b> – a thorough review of each newborn screening short-term follow-up record is completed by a clinical expert</p>	<p>Validate health record data with data in BIS through re-abstraction studies:</p> <ul style="list-style-type: none"> <li>• Critical data elements important for every encounter (e.g. EDB, infant DOB, BW, GA) (July, 2013)</li> <li>• 1 year after implementation of a new encounter</li> <li>• 1-2 encounters / year thereafter (for selected data elements) (starting July, 2014)</li> </ul> <p>Seek user feedback (e.g. via interviews and focus groups) within the 1<sup>st</sup> quarter of a new encounter being added to the BIS to validate the data being entered and identify data quality issues (e.g. CARTR+ data May 2013)</p> <p>Validate BORN data with CIHI data (e.g. live births, still births counts) (July 2013)</p> <p>Audit frequency of full continuum (versus encounters) submitted</p> <p>Develop tools to support best practice in EMR upload mapping from source systems to BORN</p> <p>Encourage Year-End Reconciliation for data collection sites</p>
<p><b>2b. Completeness - Missing Data (stakeholder group and item non-response)</b></p>	<p><b>i. Stakeholder group non-response</b></p> <p>Non-response occurs when responses for entire units (organizations, regions, practice groups, labs) are missing</p> <p>The magnitude of stakeholder group non-response falls into one of the predetermined categories</p> <ul style="list-style-type: none"> <li>- <i>None or minimal</i> (&lt;2%)</li> <li>- <i>Moderate</i> (2-10%)</li> <li>- <i>Significant</i> (&gt;10%)</li> </ul>	<p>BORN Goal – 100% participation (all maternal/newborn hospitals, MPG, NSO, PSO clinics in Ontario and all IVF Clinics in Canada)</p> <p>Track the number of stakeholder groups entering data over time</p> <p>BORN Coordinators and SME support: Regular follow-up with all hospitals, IVF clinics, midwifery practices, genetics centers, and labs. A Data Quality Management Tracking Tool has been implemented.</p> <p>Communication (education and training sessions, abstract manuals, Data Dictionary) with data providers about issues, missing data, and any data entry problems identified</p>	<p>Rate and report on the magnitude of unit non-response</p> <p>PSO labs upload data weekly. The date range of exported data files need to be defined each time a file is exported. Potential error in specifying the date range can cause missing data (e.g. one day of data is missing because a start date of April 16 is entered instead of April 15). Work with Dapasoft to develop a mechanism to identify these missing data.</p>
	<p><b>ii. Item non-response</b></p> <p>Item non-response will be identified for <i>core data elements needed for data analyses</i> (e.g. birth weight, gestational age, location of</p>	<p>Missing data reports available within the BIS. BORN guideline - if &gt;30% missing data indicator will not be reported</p> <p>Validation rules in the BIS require entry of mandatory values before submission Mandatory data elements and data validation rules have been implemented to ensure data is complete and logical (e.g.</p>	<p>Yearly report of missing data for selected data elements and MND KPIs</p> <p>Trend missing data rates</p> <p>Develop criteria for lab data values versus clinical data values</p>

	<p>birth)</p> <p>The magnitude of item non-response falls into one of the predetermined categories:</p> <ul style="list-style-type: none"> <li>- <i>Reported</i> (0-10%)</li> <li>- <i>Caution</i> (10-30%)</li> <li>- <i>Not reported</i> (&gt;30%)</li> </ul>	<p><i>labour and birth or postpartum complication</i> cannot be “None” if <i>maternal outcome</i> = is “Transfer to ICU/CCU”</p> <p><b>BORN Coordinators provide support:</b></p> <p>Follow-up with all hospitals, IVF clinics, midwifery practices, labs</p> <p>Communication (education sessions, training, abstract manuals, Data Dictionary) with data providers about issues, missing data, and any data entry problems identified</p>	
<p><b>2c. Precision (measurement error; processing, editing and estimation; technical specifications)</b></p>	<p><b>i. Measurement error</b></p> <p>Error caused when a data element is coded or entered incorrectly.</p> <p>Causes: unclear definitions, lack of training causing numerous interpretations and variability of responses for subjective entries, over-editing of the data, weaknesses or mistakes in data upload specifications, poor mapping between data in EMR and data element/pick-list value in BORN, keystroke error.</p> <p>The level of measurement error falls into one of the predetermined categories:</p> <p>Percent agreement:</p> <ul style="list-style-type: none"> <li>• <i>Significant</i> (&lt;90%)</li> <li>• <i>Moderate</i> (95-90%)</li> <li>• <i>None or minimal</i> (&gt;95%)</li> </ul> <p>Kappa (degree of agreement after chance agreement has been excluded) (Landis &amp; Koch, 1977):</p> <ul style="list-style-type: none"> <li>• Poor (&lt;0)</li> <li>• Slight ( 0-0.20)</li> <li>• Fair (0.21-0.40)</li> <li>• Moderate ( 0.41-0.60)</li> <li>• Substantial ( 0.61-0.80)</li> <li>• Almost perfect ( 0.81-1.00)</li> </ul>	<p>Historical - Niday Quality Audit was completed for selected variables in 2009 (Dunn et al., 2011)</p> <p>Current supports:</p> <p>Implementation of automated procedures that are fully tested and reviewed as part of the BIS</p> <p>Need for good documentation stressed with users</p> <p>Training provided for all data entry personnel provided to help reduce measurement error</p> <p>Field level (hover over definition for each data element) help is used to clarify definitions</p>	<p>Validate health record data with data in BIS through re- abstraction studies to evaluate measurement error (e.g. coding error, incomplete data, evidence of processing errors, erroneous inclusions, duplications):</p> <ul style="list-style-type: none"> <li>• Critical data elements important for every encounter (e.g. EDB, infant DOB, BW, GA) (July, 2013)</li> <li>• 1 year after implementation of a new encounter</li> <li>• 1-2 encounters / year thereafter (for selected data elements) (starting July, 2014)</li> </ul> <p>Rate and report measurement error due to coding errors including sensitivity and specificity</p>
	<p>Data-capture quality control measures exist and are implemented by data providers.</p>	<p>Data-capture quality control measures currently implemented in the BIS include:</p> <p><b>Point of entry validation</b></p> <p>Mandatory fields and data validation rules have been implemented to ensure data is complete and logical (e.g. <i>labour and birth or postpartum complication</i> cannot be “None” if <i>maternal outcome</i> is “Transfer to ICU/CCU”</p>	<p>Audit how often the full continuum (versus just encounters) are being submitted</p> <p>Implement a review and reconciliation process for data discrepancies on the same record</p> <p>Implement mechanisms to reduce data discrepancy (e.g. consistent interpretation, pre-population only where necessary)</p>

		<p>Automated algorithm applied to all records to ensure the identification number (i.e. OHIP) is the appropriate length and format</p> <p><b>Consistency edit checks</b></p> <p>Verifying an intervention that can only be one type of answer (i.e. no birth child without a birth OR no VBAC without a prior cesarean)</p> <p><b>Dual capture</b></p> <p>Double entry of a variable (birth weight and gestational age)</p> <p><b>Reconciliation process (missing or incomplete records)</b></p> <ul style="list-style-type: none"> <li>▪ Verification Reports</li> <li>▪ Data Discrepancy Reports</li> <li>▪ Incomplete Record Reports</li> </ul>	<p>Review and adjust the linking and matching algorithm based on review of source of orphan or duplicate records</p> <p>Analyze free text field content annually to determine if new pick lists or data elements are required.</p>
	<p><b>ii. Processing, editing and estimation</b></p> <p>Quality assurance procedures are in place to verify the incoming data and the data that is being analyzed by BORN.</p> <p>All collected data elements are checked for validity and invalid data is flagged. The checks and modifications to the data are logical and consistent.</p>	<p><b>Standard Operating Procedures (SOPs)</b> – BORN is developing an SOP Manual to ensure consistent use of data and analysis methods. This includes information on:</p> <ul style="list-style-type: none"> <li>- How the data is collected in the BIS</li> <li>- Verification, cleaning and standardized analysis procedures</li> <li>- SAS coding for frequently performed calculations/data queries</li> <li>- Data anomalies or process implementation dates that might affect data quality</li> <li>- Proper training of BORN personnel processing the data</li> <li>- Guidelines for use of test data to verify if new processes for validation, analysis or data upload, are effective and have been implemented correctly</li> <li>- Post-load rules to correct miss mapped or systematically erroneous data</li> </ul>	<p>Documentation about data processing is available and maintained yearly</p> <p>Validity assessed periodically through re-abstraction studies:</p> <ul style="list-style-type: none"> <li>• Critical data elements important for every encounter (e.g. EDB, infant DOB, BW, GA) (July, 2013)</li> <li>• 1 year after implementation of a new encounter</li> <li>• 1-2 encounters / year thereafter (for selected data elements) (starting July, 2014)</li> </ul> <p>Review and adjust linking and matching algorithm upon review of source of orphan or duplicate records</p>
	<p><b>iii. Technical specification</b></p> <p>Technical specifications for the BIS are maintained to allow easy validation of the systems, programs, and applications.</p> <p>Changes to a data holdings underlying structure or processing or estimation programs have been tested</p> <p>Raw data is saved on a secure server</p>	<p>BORN maintains documentation about BIS development</p> <p>SOP detailing UAT testing of new encounters and data elements will be maintained on the BORN shared drive</p> <p>BORN Privacy Policy is in place</p> <p>Data security guidelines and processes exist</p> <p>Data is entered at the point of care or uploaded securely from hospitals, MPGs, clinics, and laboratory systems</p> <p>User ID/Password access required</p> <p>Raw data is stored on servers located in the CHEO secure location. Extracted PHI data used for analysis purposes is stored on a secure</p>	<p>Documentation about the BIS development and testing (e.g. programs or applications) is available, maintained, regularly reviewed and updated.</p> <p>Yearly documentation of the raw data storage location and security processes or changes in either</p> <p>PHI data – stored on a secure shared drive, and available to authorized people is logged with the privacy officer.</p>

		<p>shared drive, available to authorized people</p> <p>System architecture, validation and imputation rules for each data element are available to users and BORN agents for easy retrieval and review.</p>	
<p><b>3. COMPARABILITY (RELIABILITY) - The extent to which the data in the BIS are consistent over time and entered using standard conventions making them comparable to other databases</b></p>			
<p><b>3a. Consistency (Data Dictionary Standards; data collection standards)</b></p>	<p><b>i. Data Dictionary standards</b></p> <p>A Data Dictionary is available containing definitions for all data elements for which data is collected within the BIS</p>	<p>BORN Data Dictionary has been developed, and definitions aligned across encounters - source of truth or data element hierarchy defined and version to be used in different views/reports clarified.</p> <p>Data Dictionary is posted on the BORN website and is available for data entry and users</p> <p>Data Collection Review Committee has been established to review and update data elements</p> <p>As new data elements are added to the BIS auto-updates are created in the online data dictionary</p>	<p>Decision making criteria for adding /deleting/editing data items from the Data Dictionary are developed and used within committees and stakeholder groups</p> <p>A data element review process (Q1-2 fiscal years) with specific deadlines and guidelines will be implemented.</p> <p>Free text field content is analyzed annually to determine if new pick lists or data elements are required.</p>
	<p><b>ii. Data Collection Standards</b></p> <p>Data is collected at the finest level of detail that is practical.</p> <p>Original data elements used to derive values (e.g. BMI or LOS) are documented, accessible and data values are retained</p> <p>Standard data-submission procedures exist and are followed by data providers.</p> <p>Standardized training provided for all data entry personnel and users</p> <p>Data elements that are collected across organizations should be the same as well as having similar mandatory and optional data elements to facilitate meaningful comparisons across organizations</p>	<p><b>BIS data elements</b> - are well defined, feasible to collect and translate to information to support BORN's mission to facilitate provision or improvement of care</p> <p><b>Pre-population</b> - of common data elements between encounters to improve consistency and reduce duplication of data entry for BIS users.</p> <p><b>Limited use of free text fields</b> – promote use of verified predefined BIS pick-lists to improve consistency</p> <p><b>Derived elements</b> - Original data elements used to derive values (e.g. BMI or LOS) are not permanently deleted</p> <p><b>Technical and coding support</b> - available (e.g. data entry guidelines for manual data entry and automatic upload to the BIS. Data Dictionary, BORN Coordinators, Helpdesk)</p> <p><b>Audit of privacy violations</b> - associated with entry or upload or transfer of data to the BIS</p>	<p>Report any privacy violations associated with entry, upload, or transfer of BIS data</p> <p>Normalization review of data elements between encounters is completed annually</p> <p>Review mechanisms are implemented to reduce data discrepancy (e.g. consistent interpretation, pre-population only where necessary)</p>
<p><b>3b. Linkage</b></p>	<p>Geographical data (i.e. Postal Codes) is collected using the Standard Geographical Classification (SGC)</p> <p>The SGC is a classification of geographical areas used to collect and disseminate statistics. Within it, codes of standard geographic areas are organized and grouped into a hierarchical system. For linkage</p>	<p>This criteria examines whether linkage is possible and not whether linkage is actually performed:</p> <p>BORN collects a 6-digit postal code which is then linked to census data (<b>NOTE:</b> Ontario IVF Clinics only)</p> <p>Linkage of cases across encounters in the BIS is possible and is performed (<b>NOTE:</b> No linking of births for IVF Clinics outside</p>	<p>Testing linkages of existing and new datasets brought into BORN (e.g. A1A2, fertility, etc.)</p> <p>Review and adjust linking and matching algorithm based on review of source of orphan or duplicate records</p> <p>PSO labs are requesting to submit records with only first 3 digits of the postal code – evaluate implications</p>

	purposes, it is important that geographical data collected by each data holding be in agreement with the SGC. For instance, the capture of the <u>full</u> postal code is sufficient since it can be converted to the SGC by way of the Postal Code Conversion File.	Ontario)  Postal Code Conversion File (PCCF+) is used (after 2011, PCCF+ file was/will be used; May 2011 PCCF file was used for 2011-12 data).	
	Linkage of BIS records with other datasets (e.g. CIHI, ICES) is also possible and performed	Linkage of BIS records with other datasets (e.g. CIHI) is also possible and performed ( <b>NOTE:</b> exception – IVF Clinics)	Report linkage of records with other datasets (e.g. CIHI)
	Data is collected using a consistent time frame, especially between and within jurisdictions	BORN collects data on all births, NICU/SCN admissions, prenatal and newborn screening and congenital anomalies. Users can select reporting timeframes using BIS reports (e.g. fiscal year, calendar year, quarter, month, and day). Dates are collected at the finest level of detail (YYYYMMDD)	
	Identifiers are used to differentiate facilities or organizations for historical linkage	Unique identifiers are used in the BIS for organizations (e.g. organization name and organization ID)	Annual evaluation whether any new identifiers needed
	Identifiers are used to differentiate persons uniquely for historical linkage  Identifiers must be unique, be consistent over time and have the capacity to accommodate future individuals	Unique identifiers are used in the BIS for record level data (available from April 1, 2012)  Historical data – linking possible through use of multiple data fields (date of birth, gender, location of birth, birth weight, gestational age) when health card number not available (i.e. OHIP)	Investigate the possibility of incorporating the provider registry (e.g. CAPE) into the BIS as an additional identifier
<b>3c. Equivalency</b>	Equivalency refers to how well data can be mapped over time, especially when classification system identifiers are included (e.g. ICD codes).  Methodology and limitations for <b>crosswalks</b> (e.g. many-to-one or one-to-many relationships) <b>cross reference tables</b> (e.g. mapping data elements from different systems) and <b>conversions</b> (e.g. pounds to kilograms) are documented  The issues related to crosswalks, cross reference tables and conversions are identified	Data conversions are built into data entry screens (pounds to kilograms, converting height and weight to BMI)  Cross reference tables have been developed to map 1:1 BIS congenital anomaly data element pick list values to the ICD-10-CA codes  LGA/SGA values follow the Kramer definition standards  BORN has an active inventory of data collection models and known mapping errors	Validation checks of conversions, and data quality assessment of crosswalks and cross reference tables are completed  Mapping of diagnostic codes is documented by BORN epidemiologists
<b>3d. Historical Comparability</b>	Documentation on historical changes to the data holding exists and is easily accessible. The document should include changes to	In Dec 2012, the BORN DART team began compiling a document that outlines the historical changes to the BORN dataset from the legacy Niday data through to deployment of the BIS and will	Develop and maintain documentation for the BORN dataset  Test report functionality for accuracy using historical data mapped to the BIS (e.g. preeclampsia data element from Niday

	<p>concepts, methodologies, and data elements.  <b>Note: a set of manuals, each of which describes the current year changes, is not an acceptable form of historical documentation</b></p>	<p>continue as the BIS continues to develop</p> <p><b>Example:</b> Midwifery data received as collected in the old system was brought into BORN for future analysis. An extensive reconciliation process was completed to replicate numbers and frequencies in previously published Midwifery Outcomes Report data to ensure the legacy data as managed by BORN was consistent. Considerations/ conditions to describe inconsistencies are documented and the legacy data is now able to be shared with those submitting data requests.</p>	<p>mapped to hypertension in the BIS)</p>
	<p>Trend analysis is used to examine changes in core indicator values over time (e.g. Niday to BIS)</p>	<p>Last published quality study in 2011 (Dunn et al).  Trend analysis is included in scientific reports.</p>	<p>Define core data elements for trend analysis. For example: trend analyses for all of the data elements used in the MND (e.g. KPI trends as well as % missing data for elements used to define dashboard criterion)</p>
<p><b>4. USABILITY - The ease with which BIS data is understood and accessed</b></p>			
<p><b>4a. Interpretability</b></p>	<p>A mechanism is in place whereby key users can provide feedback to, and receive notice from, BORN about issues that are discovered after the release of BIS components.</p> <p>Key users are encouraged to use the BORN contact information to provide feedback on issues, limitations, or concerns</p> <p>Guidelines for revisions to BIS data elements are available and applied to BIS updates</p>	<p>BORN contact information is readily available on the BORN website and within the BIS and included with any data, training material, or reports released</p> <p>Users are encouraged to report limitations/issues related to the data elements and the BIS to the DART Manager (oversight) and their BORN Coordinator</p> <p>An external notification system exists for users to provide feedback on data limitations (e.g. <a href="mailto:info@bornontario.ca">info@bornontario.ca</a> or <a href="mailto:science@bornontario.ca">science@bornontario.ca</a>); BORN Helpdesk).</p> <p>BIS messaging system implemented to inform users of changes</p>	<p>Develop a documentation system to record feedback on data limitations</p> <p>Develop a process to log and track solutions related to issues identified through user feedback (e.g. data issue identified, source of report, date issue resolved)</p> <p>Establish a mechanism to acknowledge when issues are resolved</p>
<p><b>4b. Accessibility</b></p>	<p>A final dataset, that has been validated, is made available for analysis purposes to BORN staff once the fiscal year of data is closed</p> <p>Standard tables and analyses using standard format and content are produced and published on the BORN website</p>	<p>Participant organizations – have complete access to their data.</p> <p><b>EXCEPTION:</b> Midwives are not given full hospital user status and cannot access information in hospital encounters. Midwives enter complete information on their own encounters</p> <p>Recognition of the shared data ownership in DERF data (Regional Treatment Centers/NSO)</p> <p>For researchers or other users without direct access to BIS, aggregate data, record level data, standard tables, or analyses of data are available upon request (following BORN Data Request Protocols and Privacy Policy)</p> <p>A list of all standard reports, data cubes (once available) and stakeholders with access to reporting is maintained by BORN and posted on the BORN website for public access.</p>	<p>Record date when fiscal year data is available to users</p> <p>BORN data users have access to an online request process with a shopping cart format.</p>

<p><b>4c. Documentation</b></p>	<p>Current data quality documentation exists to give internal and external users information to decide if the quality of the data is suitable for their intended use.</p>	<p>Documentation (e.g. caveats and footnotes) for appropriate interpretation of the data included as part of standard reports and BIS reports</p> <p>Missing data is flagged and site completion numbers are included for comparison data</p> <p>The DART standard operating procedures (SOPs) are being developed to document data holdings and characteristics of data elements</p> <p>The BORN Data Dictionary is kept up-to-date and is publicly available</p> <p>BORN Bulletin and webinars are used to disseminate information about data limitations to users</p> <p>As new data elements are added to the BIS auto-updates are created in the online data dictionary</p>	<p>Report data quality framework and activities on the BORN website and disseminate any formal data quality publications</p>
<p><b>5. RELEVANCE - Degree to which BIS data meets the needs of current and future users</b></p>			
<p><b>5a. Adaptability</b></p>	<p>Mechanisms are in place to inform stakeholders of developments about the BIS and to funnel suggestions from users and BORN committee members to BORN.</p> <p>Future system modifications can be easily made to the BIS (e.g. adapt to an important emerging issue, to a new technical standard or to a major data quality limitation)</p>	<p>BORN Committees provide advice about changes required for data elements due to evidence/practice changes, and BORN provides feedback to these committees to inform decisions about new data elements that will be incorporated in the BIS</p> <p>Communication strategies are in place to connect BORN with the stakeholder community (e.g. BORN Bulletin, coordinator, announcement on BIS landing page)</p> <p>The BIS is designed so modifications can be easily made (e.g. BORN added 3 H1N1 related data elements during the 2009-2010 pandemic in order to study the implications on practice and patient outcomes).</p> <p>NIPT data capture on the PSOF with the introduction of the new technology to Ontario in January 2013 (new data elements going live June 2013).</p> <p>Data Collection Review Committee has been established to review and update data elements</p>	<p>BORN is developing a process to identify and evaluate feasibility of: adding new data elements, retiring old elements, revising current elements and pick-list values, reviewing literature about potential new data elements, and assessing capability to collect valid and reliable data</p> <p>Develop a document that outlines the steps necessary (technical and communication) when planning changes to deal with an emerging issue that requires a data change</p> <p>There are adjustments made to PSO screening algorithms sometimes to improve screening performance (e.g. the risk cut-off can be changed; some adjustment factors for different populations can be updated). These changes will have impact on data values of a screening record. Develop a system to retain this information for future reference.</p> <p>Review whether to continue with current upload process or make modifications</p>
<p><b>5b. Value</b></p>	<p>The mandate the BIS is to fill a health information gap</p> <p>The level of usage of the BIS is monitored: data use profiles, webpage hits, press articles, news items, citations, staff authored papers, media appearances/contacts with staff,</p>	<p>BORN's mission is to be the authoritative source of maternal-child health in Ontario</p> <p>BORN has established <b>rationale for inclusion of each data element in the BIS</b>, e.g. necessary to fulfill the prescribed registry status of 'facilitating or improving' care</p>	<p>Assess the perceived value of the BIS to for users</p> <p>Document use of the data (e.g. data requests, reports, projects, stakeholder group feedback, and by tracking MND live rate)</p> <p>With each new dataset incorporated in the BIS, measure collection of data and data elements against the pre-defined</p>

	conference and policy forum attendance, number and type of data requests, and where possible the use of reports	BORN has developed a tracking system to monitor and document data usage (e.g. <b>BIS User Report available</b> )	criteria contained in our privacy policy  BORN will evaluate requests for collection of new data sources against a new decision-making criteria consistent with privacy policies and data quality framework  BORN will evaluate requests for new report functionality
	User satisfaction is periodically assessed (e.g. through satisfaction surveys to solicit feedback on the perceived accuracy, timeliness, comparability and usability of the BIS data)	Informal feedback currently obtained through Coordinator linkage and exchange with each organization	User satisfaction (e.g. internal analysts, external stakeholders, client support Helpdesk) is assessed 1 year following introduction of a new encounters or reporting elements to evaluate user satisfaction with BIS data elements, system function, access, usability of the data and user experience.