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Data Resource Profile
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Data Resource Profile: Better Outcomes Registry & Network (BORN) Ontario

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Yours sincerely,

Stephen Leeder
Editor-in-Chief
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Title: Data Resource Profile: Better Outcomes Registry & Network (BORN) Ontario

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Key Features

- The Better Outcomes Registry & Network (BORN) Ontario was developed to collect pregnancy, birth and newborn information and outcomes data to facilitate and improve perinatal care in Ontario, Canada. With near-complete capture of all births in Ontario, it has evolved to be an invaluable resource for performance measurement, quality improvement, surveillance and research.

- The BORN Information System was launched in 2012 as the amalgamation of data systems from provincial programs servicing the maternal-newborn population. BORN Ontario also maintains the legacy datasets of its predecessors (2006-2012), and other data holdings have since been added.

- Data are submitted regularly by over 250 hospitals, fertility clinics, birth centres, midwifery practice groups, primary care organizations and prenatal and newborn screening laboratory and treatment centres. Over 1.3 million maternal-infant records have been captured to date.

- Data include maternal demographics, health behaviours, *in vitro* fertilization assistance, prenatal screening, pregnancy interventions and complications, intrapartum events, peripartum outcomes, intensive care and newborn screening information. Record-level data can be linked to a wide range of provincial administrative and clinical datasets to track individuals from conception to birth and across the lifespan.

- Aggregate and record-level data are available upon request via the Data Access Request Team. BORN Ontario data dictionaries are openly available to browse online.

Key words: BORN Ontario, birth registry, database, perinatal, obstetrics, health systems

Data resource basics

The Better Outcomes Registry & Network (BORN) Ontario collects pregnancy, birth and newborn information and outcomes data for nearly all births in Ontario, Canada. With nearly complete capture of the 140,000 births each year in Ontario – approximately 40% of births in Canada – BORN Ontario is the largest perinatal registry in the country.[1] The origins of BORN Ontario date to the 1980's as a system for tracking regional variation in pregnancy and childbirth outcomes across Eastern Ontario. Originally named the Niday Perinatal Database in honour of its founder, Dr. Patricia Niday, who, as director of one of Ontario's regional perinatal programs, advocated tirelessly for its provincial adoption. The regional program gradually expanded data capture and launched the Ontario Perinatal Surveillance System (OPSS). By 2006 most of the province was contributing data to the OPSS for analysis and reporting.[2]

In 2009, with funding from the Ontario Ministry of Health and Long-Term Care, OPSS was designated a prescribed registry under the province's Personal Health Information Protection Act, and re-branded as BORN Ontario. Prescribed registry status granted BORN Ontario the authorization to collect, use and disclose personal health information without consent to facilitate and improve health care. The new organization amalgamated the data systems of four programs servicing the maternal-newborn population: the Prenatal Screening Program, the Fetal Alert Network (high-risk antenatal health care for pregnancies complicated by congenital anomalies), the Ontario Midwifery Program, and the Niday Perinatal Database. These programs worked together to normalize their data and build a robust, new web-based data collection and reporting system. In April 2012, the BORN Information System was launched to collect, manage, protect and share critical data about every pregnancy, birth and child in Ontario. Newborn screening testing results from Newborn Screening Ontario were also included at launch, representing the first time such information was linked to perinatal datasets in Ontario. A reporting portal for data contributors went live in 2013.

BORN Ontario has evolved to be a secure data platform with multiple data holdings that can be linked to connect individual health records from conception to birth and into early childhood. The

Canadian Assisted Reproductive Technologies Registry (CARTR), which collects data on IVF cycles and

births outcomes data for fertility clinics across Canada, was added in January 2013 and re-branded

CARTR Plus. Other data holdings have since been added including, primary care data on young children

and results of standardized screening and assessments of child development through the provincial

Healthy Babies Healthy Children program. BORN Ontario also maintains legacy datasets from the

founding five partner programs (last data entry 31 March 2012) and CARTR (January 2001 – December

2012).

The present-day BORN Information System collects data from over 250 hospitals, fertility clinics,

birth centres, midwifery practice groups, primary care organizations, and prenatal and newborn screening

laboratory and treatment centres spanning all levels of care from pre-pregnancy to early childhood. To

date, over 1.3 million maternal-infant records have been captured. The following sections will focus on

the BORN Information System with reference to the Niday Perinatal Database for historical context.

Data collected

BORN data are collected on a voluntary basis from health information custodians involved in the care of

children, newborns and their mothers. Data are submitted through several mechanisms including, manual

data entry into a reporting portal by staff in birthing units and midwifery practice groups, Health Level

Seven (HL7) data feeds, and automated extraction and uploads from electronic health record systems,

where available. Data are submitted in close to real-time, or uploaded in batches, and include maternal

demographics, health behaviours, any IVF assistance, prenatal screening, pregnancy interventions and

complications, intrapartum events, peripartum outcomes, neonatal intensive care unit (NICU) care and

newborn screening data, each of which are classified by the nature of clinical encounter with the health

care system **(Figure 1)**. Linkage of data elements and encounters across data sources is facilitated by a

robust linking and matching algorithm utilizing unique individual (mother and child), pregnancy and birth

identifiers that are assigned upon the first record entry into the BORN Information System. Some data

elements are common across encounters, permitting the pre-population of some data fields to reduce

duplication of data entry efforts. This model enables both program-specific analyses by encounter and analysis of aggregated data by population and health system. A description of the data available in BORN is provided in **Table 1**.

Data quality

BORN Ontario data are used to support clinical program management, benchmarking, evaluation, and quality improvement across the province of Ontario. The data are also permitted to be used for research. As such, BORN Ontario upholds a comprehensive framework to promote quality in all aspects of data collection, analysis, use and disclosure of information.[3] Five essential dimensions of data quality are upheld (**Figure 2**).

Audits of the Niday Perinatal Database and BORN Information System have demonstrated good agreement with patient charts and clinical administrative hospital databases.[4–7] An external audit by Public Health Ontario concluded that the quality of BORN data exceeded that of other sources of reproductive health information.[7] A re-abstraction study of 29 variables from records submitted in 2014-2015, found >90% agreement between BORN records and patient charts for over three-quarters of the audited variables.[6] The remaining variables demonstrated fair-to-moderate agreement. These findings have informed ongoing improvements to BORN data dictionaries, data entry guidelines, and quality control processes.

The BORN Information System applies a series of validation rules to ensure data quality. Logic rules assess the compliance of data elements collected within a given healthcare encounter. Conformance rules ensure that mandatory elements are completed. Parameter rules compare entered values against reference tables to ensure that they are within acceptable ranges before they are submitted. The system also applies aggregation rules to determine how data elements across multiple encounters (e.g. prenatal screening, general antenatal visits and delivery) are consolidated into a single birth record. Where there is

discordance in data elements that are recorded in more than one encounter, aggregation rules provide guidance on which values take precedence. Thus, having some data elements captured multiple times across the pregnancy and birth continuum also helps to increase data accuracy and completeness.

Support mechanisms are in place for submitting organizations to identify and resolve errors in their data entries. The data validation rules described above facilitate generation of reports and flags for records identified with missing encounters, possible errors, or different data entered for the same element in separate encounters so that errors can be reconciled. All data must be formally acknowledged by the submitting organization and each month, submitters review their records to ensure that there are no outstanding errors. As a final checkpoint in this process, BORN data analysts conduct additional data checks at the end of each fiscal year.

Finally, online help tips and data element definitions are available within the data entry system, and regional coordinators are available to answer questions related to data entry, reconciliation and acknowledgement processes, and implementation of system enhancements. Regional coordinators are distributed throughout the province and work directly and regularly with the data submitters and the regional perinatal networks using the data to improve care. A 24-hour Helpdesk is also available.

Data privacy and security

BORN Ontario is a prescribed registry established under the Ontario Personal Health Information Protection Act, 2004A.[8] As such, personal health information within the BORN network is protected by administrative, physical and technological controls that adhere to industry best practices for privacy and security. BORN Ontario has implemented a rigorous program to protect personal health information in its custody from theft, loss, unauthorized access, copying, modification, use, disclosure and disposal. Regular audits and investigations are conducted to monitor and manage privacy compliance. BORN Ontario's

information practices and privacy policies are assessed by the Information and Privacy Commissioner of

Ontario every three years.

Governance and funding

The Children's Hospital of Eastern Ontario (CHEO) provides the formal governance structure and support

for BORN Ontario operations. The BORN Ontario Executive Team works in co-operation with leadership

at CHEO to provide medical, scientific and administrative oversight of day-to-day operations. Core

funding is provided by The Ontario Ministry of Health and Long-Term Care.

Data resource use

Contributing hospitals, labs, clinics and birth centres have access to their own data within the BORN

Information System. These data are used locally for practice audits and to support quality improvement

initiatives. In addition, various organizations and external partners may use BORN Ontario data for

planning and management of the health-care delivery system at organizational, provincial, or other

regional levels. These efforts have resulted in numerous successful initiatives to enhance the quality of

maternal newborn care delivery in Ontario through data quality assessments,[4–6] introduction of new health

services and programs,[9–12] and technology-based interventions.[13–17] The BORN Ontario registry is also an

invaluable research resource for addressing maternal and child health issues. BORN data have been used

extensively to address research topics including, the developmental origins of health and disease,

complications of pregnancy and childbirth, and evaluating short- and long-term maternal and child health

outcomes.

BORN dashboards

BORN has developed two electronic audit and feedback systems that provide hospitals offering maternal,

newborn and NICU care with site-specific feedback on a near real-time basis to facilitate practice change

on key performance indicators.[13–16] The BORN Maternal Newborn Dashboard was launched in 2012 with

six key performance indicators and has since become an instrumental tool for decreasing variation in

clinical practice and improving patient outcomes across the province. Evaluation of the Maternal Newborn

Dashboard 2.5 years after its implementation demonstrated corresponding improvements across several

key performance indicators. These include: rates of episiotomy, post-date induction at less than 41 weeks,

repeat caesarean section in low-risk women before 39 weeks, and appropriately timed group B

streptococcus screening.[14] A NICU Dashboard was also launched in 2018 with two key performance

indicators to support clinical practice improvement for neonatal care. Each dashboard displays a hospital's

performance on each key performance indicator relative to provincial benchmarks, provincial-level rates

as well as peer performance data from hospitals providing similar levels of maternal or neonatal care

and/or of similar birth volume. Engagement with local health professionals and organizations is ongoing

and helps ensure uptake of these dashboards and meaningful practice change.[13,15]

Perinatal research

Since its inception, BORN data have been used in Canada and internationally to produce nearly 100 high-

impact publications with broad medical and scientific reach. These publications cover a diverse array of

topics including, but not limited to, prenatal screening and diagnostic testing;[18,19] breastfeeding and

influencing factors;[20,21] use and outcomes of assisted reproduction;[22–26] trends in obstetrical interventions

and factors influencing use;[27–29] and factors influencing maternal and neonatal health outcomes such as

environmental exposures,[30–32] influenza immunization during pregnancy,[33–35] substance use,[36,37]

hypertension,[38,39] diabetes,[40–43] and obesity/gestational weight gain.[44–46] A compendium of published

research using BORN data is available online [https://bit.ly/2UXEX3I]**.**

Data linkage: long-term follow-up of women and infants

BORN data can be linked with other provincial data resources to facilitate long-term follow-up of women

and their children. ICES (www.ices.ca) is a provincial data repository containing longitudinal, coded and

linkable clinical and administrative records encompassing nearly all interactions that Ontarians have with

the publicly-funded health care system. Population-based health surveys, research-specific, and registry data are also integrated, permitting evaluation of health policy and care delivery as a whole across the province. In 2014, the Niday historical dataset (2006/07-2011/12) was transferred to ICES. A 2-year transfer of BORN Information System data spanning 2012/13- 2013/14 fiscal years was completed in early 2015; a second data transfer (2014/15-2018/19) is scheduled for 2020. Deterministic and probabilistic linkage of individual maternal and newborn records to master registration files at ICES facilitates linkage of BORN data to all other datasets held by ICES. Thus, linkage of these two repositories provides a unique opportunity to study population-level maternal and infant health outcomes ranging from the fertility treatment and perinatal period to many years after birth. Recent applications of ICES-BORN data include examining the effect of frequent blood donations before pregnancy on maternal and newborn outcomes;[47] evaluating the association between cannabis exposure in pregnancy and neurodevelopmental outcomes in children;[48] assessing the 5-year health outcomes of children born to mothers who received the 2009 pandemic H1N1 influenza vaccination during pregnancy;[34] exploring the link between prenatal and early life exposures to ambient air pollutants and the development childhood asthma;[49] the association between intrapartum epidurals and postpartum depression;[50] and risk of breast cancer following thoracic computed tomography in the perinatal period.[51] The potential applications of these linked data include interrupted time series analyses and using BORN to collect data for clinical trials and other interventions. Given that BORN Ontario is a relatively new entity, the potential use of these linked data will only continue to grow, particularly as other provincial data holdings become available.

Strengths and weaknesses

Ontario, Canada has rich network of health data repositories that can be used to provide comprehensive insight into population health and health care delivery. The BORN Ontario Registry is component of the network, providing the capacity to link pregnancy and newborn health records across multiple health systems and track individuals from conception and birth across their lifespans. The breadth of data held by the BORN Ontario registry makes it a foundational resource for answering perinatal

health-related questions. Strengths include: capture of all hospital births in Ontario (over 99% of all births in the province) and all midwifery-attended home and birth centre births; capture of extensive information about maternal and newborn characteristics, health histories and behaviours, outcomes and health services utilization; integration of multiple data holdings spanning the continuum of maternal child health care delivery; and a nearly 10-year data collection time frame. Notably, BORN data have been validated and demonstrate consistency with other clinical administrative datasets.

The BORN Ontario registry is not without limitations. BORN elements are subject to incomplete or duplicate data entries, misclassification and under-reporting. The BORN Registry is reliant on data sourced from medical records, clinical forms and patient interviews, and if data are not collected or entered into a patient's records they will not be available for abstraction into the BORN Information System. In addition, where manual entry may be performed by clerk staff or nurses, variability in the interpretation of case definitions can affect data quality, and incomplete or duplicate data entry and misclassification is a reality. Data entry errors and duplicate data entries are cleaned when identified. Collection of pre-pregnancy BMI is limited by early pregnancy weights or patient self-report, although recent efforts to standardize how this information is collected have improved data quality for this variable. Information on miscarriage and therapeutic abortions is historically difficult to ascertain, and under-reporting of socially sensitive variables including those related to substance use/abuse, intimate partner violence, and sexually-transmitted infections is also likely. Last, socioeconomic information at the individual or family level and healthcare provider identifiers are not available in BORN. Area-level socioeconomic information (e.g. education, income, marginalization and deprivation indices) can be obtained, however, through linkage to other resources including Canadian census data.

Data resource access

Access to legacy datasets and the BORN Information System

Data are accessible to contributors through the BORN Information System reporting portal. Each contributor has a designated lead who can grant role-based access for members of their group. Those who do not have access to the reporting portal, or who require data that are not available through this mechanism may pursue alternative processes to access BORN Ontario data resources. Legacy datasets and BORN Information System data are available to external requestors to support research, program evaluation, policy development and surveillance **(Table 2)**. All requests to BORN Ontario are managed in accordance with provincial privacy requirements.

Data requests can be made to the BORN Data Analysis & Request Team and initiated through submission of a data request inquiry form [https://forms.bornontario.ca/Data-Inquiry-Form]. From here, the application process varies depending on the type of information requested (aggregate tables or record-level data) and the support required **(Figure 3)**. BORN coordinators and data analysts work closely with external requestors to navigate data access approval processes, prepare analytical datasets and conduct analyses. At present, BORN Ontario does not provide a platform through which external requestors can interact with the data for research purposes. Research datasets are securely and electronically transferred to external requestors following completion of the all of the necessary approval processes.

Data dictionaries for Legacy data elements are available for download. The BORN Information System data dictionary is available online as an interactive library and may also be downloaded in portable document form. A data dictionary improvement project is currently underway. Notably, the data dictionary and data elements available from the Legacy datasets and the BORN Information System differ. New data elements and updated terminology were added to the BORN Information System in 2012 and may not available in the historical data. It is not always possible to link some of the older data elements to the new BORN Information System.

Access to data relating to Indigenous peoples in Canada

Data on pregnant individuals and newborns with a postal code where the majority of the population identifies with an Indigenous Nation (First Nation, Inuit and Metis peoples) are only available for public health activities or research analysis when there is evidence of stakeholder engagement and consent of the Indigenous Nation(s). BORN Ontario has a responsibility to ensure that the information it collects is managed in a culturally appropriate and respectful manner, and thus adheres to the principles of ownership, control, access and possession (OCAP®) and other similar Indigenous frameworks for conducting research pertaining to Indigenous people. The decision to suppress Indigenous data in BORN is based on guidance from Indigenous Stakeholders on the collection, interpretation and governance of data related to their community members and communities as a whole.[52] Resources are dedicated to facilitating data release to Indigenous stakeholders for program planning and delivery of maternal, newborn and early childhood services and does not otherwise release information without evidence of engagement and consent by a community stakeholder.

Data access fees

Costs associated with preparing aggregate data and record-level datasets for external requestors depend on the nature and complexity of the request. Following consultation and an assessment of the project needs, cost estimates can be provided for research funding applications, for funded research projects and other quality initiative and policy work. Data access fees include consultation, risk assessment and de-identification, data analyst time for file preparation and verification, and an administration fee.

Summary

BORN Ontario is a primary and authoritative resource for reproductive health information and data in Ontario, Canada. The BORN Information System is an accurate and trusted tool for evaluating care delivery and health outcomes of mothers and their newborns. It can further be used to support data-driven change management strategies in perinatal health care policy and programming. Importantly, BORN

Ontario data are accessible to local, national and international investigators looking to address research questions relevant to maternal, newborn and pediatric populations.

Ethics Approval

Ethics approval is not required for Data Resource Profiles.

Funding

Data availability

There are no new data associated with this article. Requirements for BORN Ontario data access are described within the body of this Data Resource Profile.

Acknowledgements

Conflicts of Interest

None declared.

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BORN Ontario data are submitted on a voluntary basis by health information custodians from across

Ontario servicing the maternal child population. Data are classified by the nature of the health care

encounter and are linked to create aggregate records for each woman and child. CARTR, Canadian

Assisted Reproductive Technologies Registry; MFM, maternal fetal medicine; NICU, neonatal intensive

care unit; NIPT, non-invasive prenatal testing; SCN, special care nursery; HBHC, Healthy Babies Healthy

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Figure 2. Better Outcomes Registry & Network (BORN) Ontario data quality framework. The data

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Figure 3. Accessing Better Outcomes Registry & Network (BORN) Ontario data. External parties

may submit requests for aggregate or record-level data can be initiated through submission of an online

form. Turn-around times and data access fees may vary depending on the nature and complexity of the

request. Requests to access record-level data from BORN Ontario data holdings may be subject to

additional approvals.

Table 1. Summary of data collected by the Better Outcomes Registry & Network (BORN)

Information System

Encounter type or Data holding	Description
Assisted reproductive technology (ART) [53,54]	Collects information on *in vitro* fertilization treatment cycles from fertility clinics across Canada collected into the Canadian Assisted Reproductive Technology Register (CARTR Plus). Also include record level details on any ART treatment cycles from Ontario fertility clinics that result in a pregnancy that is delivered at >20 weeks gestation are automatically linked with other records within the BORN Information System.
Antenatal General	Captures information relevant to the antenatal period (i.e. obstetrical history, exposures, complications, etc.)
Antenatal Specialty	Captures maternal, pregnancy, and fetal information for women who require specialized care management at a high risk maternal fetal medicine or prenatal genetic clinic
Prenatal Screening and follow-up[55,56]	Prenatal screening records for every pregnant individual who receives any form of prenatal screening in Ontario. Includes information from laboratory and ultrasound testing, clinical assessment, genetic counselling and diagnostic testing from prenatal screening, as well as screening and diagnostic results.
Non-invasive prenatal testing[19]	Information captured during non-invasive prenatal testing for fetal genetic disorders.
Cytogenetics	Information related to the clinical indications and results of maternal and child cytogenetic testing

Labour & Birth	Captures information relevant to the pregnant person's spontaneous or induced labour and birth experience through to the first hour postpartum whether this occurs in hospital, at home or in a birth centre. Midwifery-client specific data are also captured in the midwifery encounter
Birth-Child	Documents a child's birth experience through to the first hour postpartum.
Postpartum Mother	Documents the course of care experienced by the mother from one-hour post birth to discharge from hospital
Postpartum Child	Documents the course of care experienced by the child from one-hour post birth to discharge from hospital
Newborn Screening and Diagnostic Evaluations	Screening tests and results from the provincial newborn screening laboratory (including hearing and congenital heart disease). Information on short-term follow-up, clinical status, diagnostic information and treatment plans for infants who received a positive newborn screen are also available
Neonatal intensive care / Special care units	Information collected during infant stays in neonatal intensive care units and special care nurseries
Midwifery Practice Group Data	Data on prenatal and birth care (home, hospital and birth centre births) provided by midwives in Ontario
Well Baby Well Child visit information	Information obtained through regular assessments of a baby or child's development. Includes age, height, weight, vaccinations, and documentation of developmental milestones using the standardized

	measures (Rourke Baby Record Ontario, Nipissing District Developmental Screen)
Healthy Babies Healthy Children (HBHC) Program	Information collected from completion of the standardized HBHC Screening Tool. The tool facilitates identification of risk factors that may affect a child's healthy development and referral to community programs and services. Screening is voluntary and consent-based. BORN facilitates the transfer of this information from hospitals/homes to public health units who provide the follow-up

Citations are provided where data elements have been previously validated or described in detail.

Table 2. Available datasets at Better Outcomes Registry & Network (BORN) Ontario

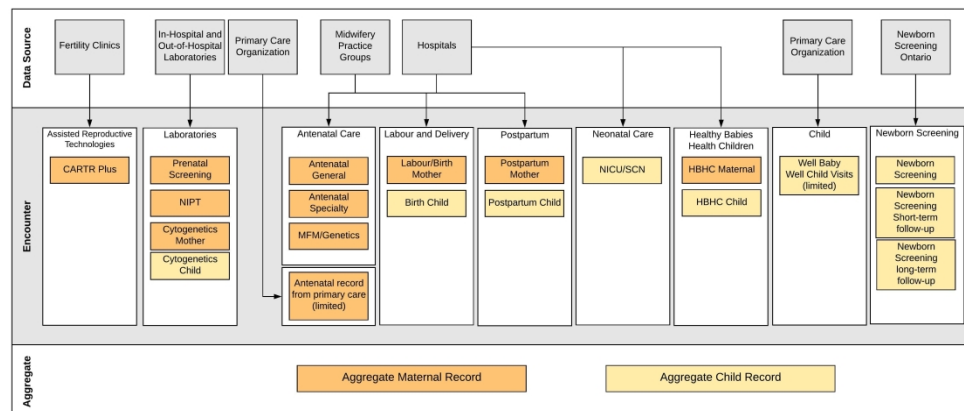|	**Legacy data holdings**	**BORN Information System**
Description	Includes record-level data from: • Niday Perinatal Database • the Ontario Midwifery Program, • Prenatal Screening Ontario and historical non-invasive prenatal testing and cytogenetic testing results • the Canadian Assisted Reproductive Technologies Register (CARTR)	Includes record-level data from birthing hospitals, midwifery practice groups, birthing centres, fertility clinics, prenatal and newborn screening laboratories, follow-up clinics, clinical programs, and primary care organizations
Timeframe	April 2006 – March 2012	April 2012 - Present
Data Dictionary	https://bit.ly/2whlSRu	https://bit.ly/2I55jec

Figure 1. Better Outcomes Registry & Network (BORN) Ontario data sources and architecture. BORN Ontario data are submitted on a voluntary basis by health information custodians from across Ontario servicing the maternal child population. Data are classified by the nature of the health care encounter and are linked to create aggregate records for each woman and child. CARTR, Canadian Assisted Reproductive Technologies Registry; MFM, maternal fetal medicine; NICU, neonatal intensive care unit; NIPT, non-invasive prenatal testing; SCN, special care nursery; HBHC, Healthy Babies Healthy Children.
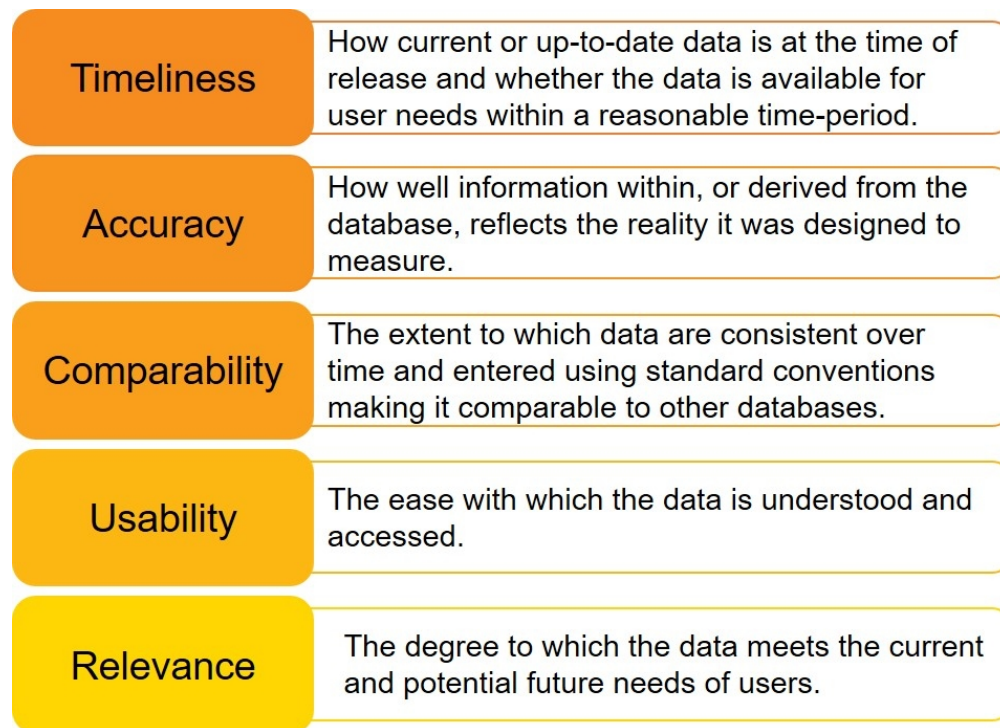
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Figure 2. Better Outcomes Registry & Network (BORN) Ontario data quality framework. The data quality framework is based on five dimensions to ensure that user decision-making is based on current, valid, reliable and relevant data.
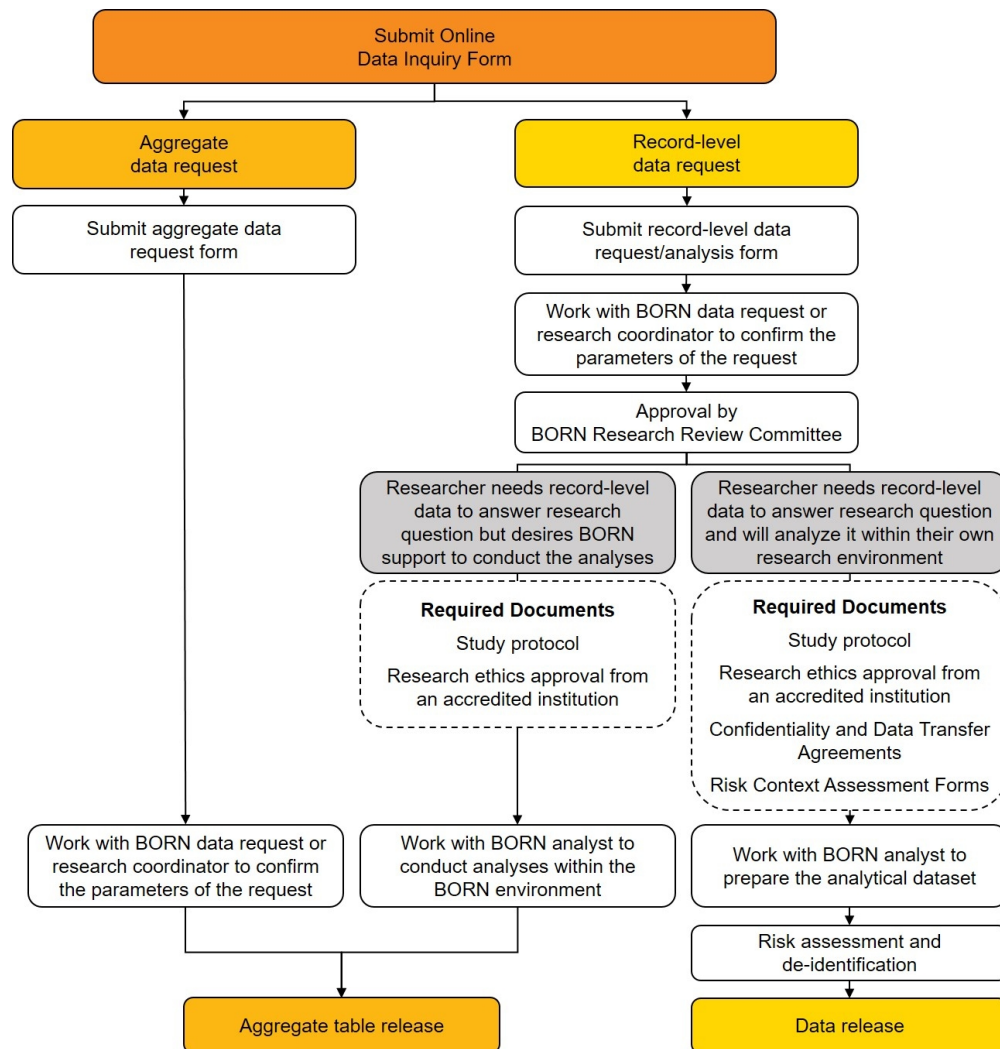
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Figure 3. Accessing Better Outcomes Registry & Network (BORN) Ontario data. External parties may submit requests for aggregate or record-level data can be initiated through submission of an online form. Turn-around times and data access fees may vary depending on the nature and complexity of the request. Requests to access record-level data from BORN Ontario data holdings may be subject to additional approvals.

218x228mm (150 x 150 DPI)

Pocket Profile

Title: Data Resource Profile: Better Outcomes Registry & Network (BORN) Ontario

Authors: Malia SQ Murphy[1], Deshayne B Fell[2], Ann E Sprague[3], Daniel J Corsi[2], Shelley Dougan[3], Sandra I Dunn[3], Vivian Holmberg[3], Tianhua Huang[3], Moya Johnson[3], Michael Kotuba[3] et al. The complete author list is available in the full version of the profile online.

Keywords: BORN Ontario, birth registry, perinatal research, perinatal epidemiology, obstetrics, maternal-child health

Corresponding author: Mark C Walker, mwalker@toh.ca

Cite this as: The full version of this profile is available at IJE online and should be used when citing this profile

Data Resource Basics: The Better Outcomes Registry & Network (BORN) Ontario is a provincial registry that maintains an ongoing collection of pregnancy, birth and newborn information and outcomes data to facilitate and improve maternal-newborn care in Ontario, Canada. BORN Ontario has achieved near-complete capture of all births in Ontario from 2012 to the present-day, and has captured over 1.3 million records to date (Figure 1). BORN Ontario also maintains historical birth registry data of predecessor organizations and programs (2006-2012).

[Pocket Profile Figure]

Data Collected: Data are submitted by over 250 hospitals, fertility clinics, birth centres, midwifery practice groups, primary care organizations and prenatal and newborn screening laboratory and treatment centres from across Ontario (Figure 1). Data are collected in real-time by several mechanisms, including manual data entry into a secure portal by staff in clinics and birthing units, HL7 feeds, or by automated extraction and uploads from electronic health record systems. Data include maternal demographics, health behaviours, use of assisted reproductive technologies, prenatal screening, pregnancy interventions and complications, intrapartum events, peripartum outcomes, intensive care and newborn screening information. They are classified by the nature of the clinical encounter with the health care system. Record-level data can be linked to a wide range of provincial administrative and clinical datasets to track individuals from conception to birth and across the lifespan.

Data Resource Use: Contributing hospitals, labs, clinics and birth centres have access to their own data within the BORN Information System reporting portal to facilitate practice audits and quality improvement initiatives. BORN Ontario data are available to external requestors to support program evaluation, policy development, surveillance and research. BORN Ontario data have been used to enhance the quality of maternal newborn care delivery in Ontario through data quality assessments, introduction and evaluation of new health services, programs, and technology-based interventions. The BORN Ontario

registry is also an invaluable research resource for addressing maternal and child health issues. It is extensively used to address research topics, including the developmental origins of health and disease, complications of pregnancy and childbirth, and evaluating short- and long-term maternal and child health outcomes.

Reasons to be cautious: Despite its scope and size, BORN Ontario data, as in other large information systems, may be incomplete and some misclassification and under-reporting can occur. There is a system of rigorous data checking to maintain high data quality. Some data are difficult to ascertain due to reliance of patient recall (e.g. pre-pregnancy weight) and self-reporting of socially sensitive information (e.g. substance use/abuse, congenital infections, intimate partner violence), but validation of key fields has shown agreement with other sources. Socioeconomic information is not available through BORN Ontario, but may be determined through data linkage to other provincial data resources.

Collaboration and data access: Aggregate and record-level BORN Ontario data may be accessed pending submission and approval of data requests to the BORN Data Access Request Team. BORN Ontario data dictionaries are openly available to browse online.

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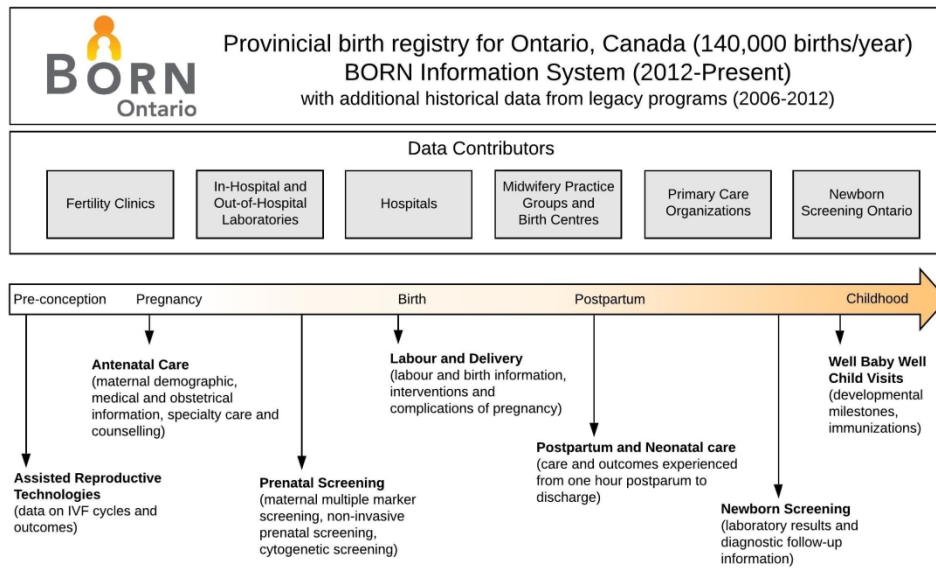
The Better Outcomes Registry & Network (BORN) Ontario is a provincial registry in Ontario, Canada. Comprehensive data collection from health information custodians servicing the maternal newborn population permits population-level evaluation of health services use, care delivery and maternal and newborn outcomes across the pregnancy continuum and into early childhood. Since 2012, over 1.3 million records have been captured.

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