## OVERVIEW

**The Challenge:**

Enable discussions on evidence-based privacy risk levels when sensitive data is requested by researchers, government agencies and other health organizations. Subsequently, enable the sharing of EMR and population-based birth data in order improve maternal health care.

**The Solution:**

Integrate a proven de-identification software system with BORN's Information System (BIS) that can assess the level of privacy risk and then de-identify the data using a globally accepted standards and guidelines.

**The Benefit:**

Researchers and health-care decision-makers now have access to high quality data that they can use to support performance measurement, quality improvement, answer policy questions, enable research and inform funding inquiries.

# Better Outcomes Registry & Network: Enabling Better Health Care Outcomes for Mothers and Infants

*Health researchers and decision-makers understand that comprehensive data is needed to help inform research, policy and funding questions to support pregnancy, birth and child health care. This can only be accomplished through access to patient information over multiple care systems. However, researchers and health care decision-makers alike need to feel confident in the level of risk in the data shared.*

## Identifying Risk and Enabling Sharing of Data on Pregnancy, Birth and Childhood

Established in 2009, the Better Outcomes Registry & Network (BORN) is one of Canada's largest registries integrating information on pregnancy, birth and newborn care, including screening tests. Approximately 140,000 maternal records are added to the system per year. Overall, BORN has 1 million records for Ontario births in the BORN Information System (BIS). As of March 31, 2014, data has come from 97 hospitals providing obstetrical services, 44 Neonatal Intensive Care Units (NICUs)/Special Care Nurseries (SCNs), 86 Midwifery Practice Groups (MPGs), 36 fertility centers (Canada), 12 Family Health Teams (FHTs) and 5 prenatal screening labs in Ontario, and Newborn Screening Ontario (NSO).

BORN provides health practitioners and researchers with useful, detailed health information in order to make a positive and lasting contribution to the health of mothers, newborns and children. In order to safely use the personal health information colledted in BIS, BORN needed a proven methodology to de-identify health information in order to protect patient privacy. By de-identifying information from primary care centers and hospital electronic medical records (EMRs) from across Ontario, researchers and health care decision-makers are able to use quality data to answer health care policy questions, guide health care funding needs, and support research to improve care.

While only a portion of the data requests require that the data be de-identified and used for research and analysis, the requests are increasing yearly.

This maternal, pregnancy and infant data can be extremely identifiable unless protections are put in place to de-identify the information. Right from the beginning, BORN sought Privacy Analytics' expertise to ensure best practices were in place to protect patient privacy. The greatest concern for BORN is to manage patient privacy through a systematic, quantitative method that could be shared with the entities requesting the sensitive health information. Utilizing Privacy Analytics software, methodologies and expertise enabled BORN to share evidence-based risk levels in order to discuss any concerns with researchers. Based on these conversations, BORN de-identifies the information so that it can be shared

they conduct a risk assessment and then de-identify the requested data based on the context of its intended use.

In order to enable access and analysis of high volumes of patient data from numerous settings, automation and scalability are essential. Privacy Analytics – the leading provider of software that safeguards and enables personal health data for secondary purposes – assisted BORN is devising methods and implementing the software needed to automate data sharing and scale with the number of records.

"Privacy Analytics software provides an objective measure," says Dr Ann Sprague, Scientific Manager at BORN. "It identifies what the risk is and I know there is a proven methodology to back it up. It's insurance that we are not going to inadvertently disclose information that we shouldn't."

## How It Works

BORN receives data from hospitals, clinics, labs and EMRs in primary care practices across Ontario. The health care organizations can either manually enter data into the BIS or they can upload data on regular basis. When BORN receives a record level data request, a BORN analyst works with the requesters to provide data that not only answer the policy, research and funding questions, but protects patient privacy. If the analyst determines that the data will need to be de-identified, the data is extracted from the BIS and a dataset is prepared by one of the trained BORN analysts who then upload the dataset into Privacy Analytics' software. Using the software,

> "Without this technology a lot of research we want to do would grind to a halt" - Dr Mark Walker.

## Real World Application: Inform Policy

Ontario Public Health Units and the Health Analytics Group within the Ontario Ministry of Health has periodically requested de-identified BORN data to inform heath care policies. These groups explain the intended use to inform a policy and provides BORN a list of data elements that they would like to receive. BORN runs a risk

assessment using Privacy Analytics software, which provides a quantitative measure of the level of risk for the intended use of that data. BORN is able to share this score and discuss exactly which data elements are increasing the risk of re-identification. The ability to have this conversation ensures that both BORN and the requestors have a clear understanding of re-identification risk and what appropriate de-identification methods can be conducted to ensure patient privacy.

De-identified data provided by BORN has been used to conduct public health surveillance, such as analyzing key newborn variables, such as low birth weight and feeding. The data will inform program planning and allocation of resources for reproductive and child health programs.

> "This method...helps us ensure we meet privacy standards, and it protects the researcher."

## Real World Application: Answer Research Questions

Research is a core function of improving health outcomes. Typically, researchers want the most detailed information possible in order to identify insights and trends for mothers, newborns and children health care. When a health researcher submits a request for BORN data, they provide the Research Ethics Board letter of approval and a research plan with the list of data elements that

they would like to receive in the de-identified dataset. BORN analysts identify all variables determined to be quasi-identifiers, such as geography or dates, and then run a risk assessment to determine the level of risk in the data and discuss the risk and potential de-identification options and scenarios to protect this information. Through this conversation, both BORN and the researcher are able to protect patient privacy, while ensure the data has the ability to answer the research questions.

Using de-identified data, BORN has helped researchers to develop strategies to reduce caesarean sections and improve health outcomes. Researchers are able to analyze data that includes risk factors for caesarean section and outcomes in order to determine if care can be improved.

BORN is involved with several ongoing projects in the Ontario community, including a maternity care communication project and a pilot project to integrate prenatal best practice clinical guidelines into EMR systems.

"This method and technology protects both us and the researcher requesting this data. It helps us ensure that we meet privacy standards, and it protects the researcher from any inadvertent disclosure or re-identification. Ultimately, it also protects the mothers and babies of Ontario," said

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Dr. Sprague.

For more than six years, BORN has utilized Privacy Analytics' software to have evidence-based discussions surrounding the level or risk in requested data. BORN is able to then provide policymakers, program managers and researchers with data that has the greatest level of utility for the lowest level of risk. De-identified data has been used for research and analysis that leads to improved care for mothers, newborns and children. Using de-identified data, organizations have informed program planning and allocation of resources for reproductive and child health programs, and developed strategies to reduce unnecessary caesarean section and improve healthcare outcomes.