



BORN ONTARIO:

- 140,000 babies born annually in Ontario
- Fall, 2011: integration of maternal child data including pregnancy, birth, newborn care, and screening data
- Future: BORN seeks additional data sources

“From the perspective of a researcher, I think it is BORN’s responsibility to educate people about our data – how it has to be kept secure, used and people’s privacy respected, and how we need to be careful about destruction. It’s part of our responsibility to educate the people using BORN data or requesting BORN data.”

Dr. Ann Sprague



CASE STUDY:

BETTER OUTCOMES REGISTRY AND NETWORK (BORN) ONTARIO

Recall a new mom and baby that you met at a park or lingered with over coffee.

Forget names. Discard unique health card numbers. Erase knowledge of a home address. If, like a nosy neighbour, you can obtain the baby’s date of birth, find out the mother’s age and know the mother’s postal code then you can be assured that the pair’s privacy is jeopardized.

Armed with those three seemingly harmless pieces of information, more than 95% of mothers and babies can potentially be identified in Canada’s most populous province.

Yet, powered by the Privacy Analytics Risk Assessment Tool (PARAT) to protect privacy while guaranteeing the optimal data release to answer important policy, quality or research questions, BORN (Better Outcomes Registry and Network) Ontario is about to become one of the largest registries in Canada. Healthcare providers, public health professionals, governments and researchers are eager to start using the registry to inform their work in policy development, quality assurance initiatives and health services utilization research.

Enabling Research

“Without this technology a lot of research we want to do would grind to a halt,” says Dr. Mark Walker, BORN’s Scientific Director.

Headquartered within secure offices inside the Children’s Hospital of Eastern Ontario with satellite offices at the Ottawa Hospital – General Campus and various other locations in Ontario, BORN integrates maternal-child data for all hospital and home births in Ontario - approximately 140,000 babies each year. The longitudinal records date back to 2004 (and earlier in some areas of the province) and the prescribed registry will eventually capture most encounters that mother and baby/child have with the healthcare system.

BORN’s “prescribed registry” status was granted under Ontario’s Privacy Legislation (PHIPA) and allows BORN to use and disclose personal health information for the purpose of facilitating or improving the provision of health care, and the information can also be used for secondary purposes, such as research. BORN’s leadership team is committed to meeting all industry best practices to protect against unauthorized accidental or intentional release of information.

The Privacy Analytics Risk Assessment Tool (PARAT) coupled with the close proximity of Dr. Khaled El Emam in the Electronic Health Information Laboratory at the Research Institute of the Children’s Hospital of Eastern Ontario, provide the objective risk assessments and de-identification capabilities to quantitatively respond to all research requests.

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“The public expects us to protect their privacy and we can do that and still get data that is useful for what researchers are doing. It is not either or, with PARAT you can actually have both.”

Dr. Khaled El Emam



Objectively Measuring Risk

“I like it (PARAT) because it’s an objective measure. It tells me what the risk is and I know that there’s a methodology and sound rationale to back it up,” says Dr. Ann Sprague, BORN’s Scientific Manager.

“It’s insurance that we’re not going to inadvertently do a disclosure that we shouldn’t.” Word has spread through the various communities that this rich data set is accessible and that PARAT’s risk assessments consider the security measures of data handlers and data recipients to set the appropriate release thresholds. The result has dramatically changed the interactions between Dr. Sprague and researchers, making the process more collaborative while streamlining decision making.

“It protects both us and the researcher. It protects us in helping to meet our requirements under PHIPA and it protects the researcher from any inadvertent disclosure or re-identification. Ultimately, it protects the mothers and babies of Ontario.”

Doctors Walker, Sprague and the other leaders of BORN Ontario are determined to take every possible step to establish a registry that meets and exceeds all current and future security and privacy requirements, making it worthy as “one of the world’s safest and largest” maternal-child registries. PARAT’s risk assessments and de-identification will continue to play an important part in this growth.



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