



BORN: Grow Into Child

BULLETIN

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The main focus of a health registry is to use the data collected to directly facilitate and improve care. To-date through linkages of perinatal data sets in the BORN registry, we've been able to fulfill this mandate by identifying missed care opportunities (e.g. newborn screening) and areas for improvement (e.g. the maternal newborn dashboard). In this edition of the Bulletin we are profiling two new innovations that we believe will greatly expand the power of the BORN Registry: 1) collecting data on young children, and 2) extracting this child data from primary care electronic medical records (EMRs).

This edition of the Bulletin highlights how we collect and use data from primary care including children's height and weight data, immunization data, cognitive development screening and nutrition information. We also highlight how the BORN registry can integrate with other data collection systems such as the Integrated Service for Children Information System from the Ministry of Children and Youth Services. Researchers can also benefit and we provide one example of a linkage between BORN data and the TARGET Kids to provide greater depth of information to a research team. Our growth into the child space has begun, but we realize there is a lot of potential. Like new parents, we are excited to see how the baby grows up!

ENHANCED 18 MONTH WELL BABY VISIT

BORN Ontario, Ministry of Child & Youth Services and eHealth Ontario partnered to build a repository of 18-month data that would track children who are receiving the Enhanced 18-month Well-Baby Visit. The objectives of this pilot project were to identify toddlers who are at risk or who have been identified with developmental delay and provide population-level understanding of the health of children at this important age. Ten Family Health Teams and 2 EMR vendors participated, generating 1,337 visits that were captured in the Born Information System (BIS), with 95.5% of those visits being matched to a BIS birth record.

The project concluded with a detailed survey of all stakeholders and participants to fully evaluate the pilot project. Key findings noted that 71% of respondents said that overall, the integration of the practice tools and new functionality positively impacted the visit.

This pilot project also concluded that data from integrated tools (Rourke Baby Record and NDDS) can successfully be collected, compared, stored and analyzed. This proves that registries can collect information directly from EMRs to support the facilitation of care and to collect health information in standardized formats. This centralized EMR data collection further supports the ability to evaluate tool use and build the necessary evidence to support data quality improvement initiatives across the province for children.

The positive evaluation, combined with an increased interest from the primary care community, has led to the expansion of this work under the BORN Kid eConnect Strategic Plan for EMR Integration.

KID eCONNECT: CHILD 0-5

The BORN Kid eConnect strategy, in partnership with the Ministry of Child and Youth Services and eHealth Ontario, aims to ensure that all children meet their full developmental and health potential. The early years are a critical time for child development, setting the patterns for lifelong health and well-being. Timely assessment of young children provides the opportunity to ensure they receive any additional support needed for the best possible start.

The Kid eConnect strategy expands on the Enhanced 18-Month Well-Baby Visit EMR Integration Project. These projects are expanding data transmission to and from the BORN registry while enhancing clinical workflow and helping providers to assess and monitor child health through the integration of standardized forms and the creation of summary reports.

EMR Integration Projects implemented through the Kid eConnect Strategy will be deployed through a series of projects and milestones required to reach the majority of children and providers, as well as support clinical adoption of EMRs in Ontario. This work will inform future methods of EMR data integration and patient information exchange between registries and providers that are crucial for better facilitation of care and managing patient outcomes.

The first project underway is called the Child 0-5 Project. This project further integrates with EMRs to provide enhanced EMR functionality and collection of data from Well-Baby visits,

improving clinical workflow, clinical use and data collection from standardized tools. A child development summary report that presents identified areas of concern for all visits from birth to age 5 will be integrated into the EMR solutions.

To learn more about other projects under the Kid eConnect Strategic Plan, please visit our website at:

<https://www.bornontario.ca/en/partnership-projects/kid-econnect-emr-integration-project/>

In November 2012, under Dr. Wilson's leadership, the ImmunizeON (Ontario) application was released. It all started with a conversation between Dr. Kumanan Wilson of The Ottawa Hospital and a fellow parent in their neighborhood park in Ottawa. As a busy mother, she was looking for an easy way to access reliable immunization information, and to record and store her family's immunization status: an all-in-one immunization tool.

With the success of ImmunizeON and the potential of empowering all Canadians with this tool, three organizations, the Canadian Public Health Association (CPHA), Immunize and the Public Health Agency of Canada (PHAC), joined Dr. Wilson. The goal was to create a free, bilingual tool that was available to as many Canadians as possible (via the App Store for iPhones and Google Play for Android devices). In 2014 ImmunizeCA was released. It is now bilingual and covers all of





Canada's provinces and territories. It also provides a channel for public health officers to communicate credible information about vaccinations, whether nationally or by province or municipality.

The Opportunity - ImmunizeCA and BORN

Public Health Units in Ontario are mandated to monitor adherence to immunization schedules for children in schools and daycare centres (Immunization of School Pupils Act & the Day Nurseries Act). There is a need to monitor and trend coverage rates and understand who in the population has been immunized, where they live and go to school. Prior to school-age (<5 years) the opportunities to collect records are few. Parents are a valid source of immunization data and when this data is held on their wireless devices, there is an opportunity to collect this accessible source of valuable data.

As a child health registry BORN plays a role in:

- Storing and sharing immunization data among providers
- Capturing adverse events
- Centralizing population data related to immunizations
- Identifying at-risk populations or individuals

As part of a pilot program with Ottawa Public Health (OPH), users of the ImmunizeCA App are provided with a mechanism to easily communicate their immunization information to the local public health unit, eliminating the need for paper requests and record transfers. This reduces the burden on parents of submitting records by phone, fax, Internet or in-

person. Use of the ImmunizeCA app includes a confidentially statement and requires the user to provide consent to send the data to OPH, who in turn discloses it to BORN. Users have the ability to withdraw consent from further data transmission to OPH at any time. However, all information previously collected based on prior consent is maintained.

Future Opportunities for ImmunizeCA and BORN

- Provide this feature to other Public Health jurisdictions in Ontario to improve record capture
- Leveraging our BORN Kid eConnect work with primary care EMRs to provide bi-directional sharing of immunization between families and providers via the app
- Create a store of immunization data of pre-school and non-day care children that can be shared with the Panorama Ontario program
- Provide this feature to other Canadian provinces to assist in their immunization programs

With this application we can see that when individuals provide just a little bit of information like their age and location of residence, ImmunizeCA can provide information back to them thus arming parents with a personalized immunization pathway and schedule.

NEWBORN SCREENING – ENSURING QUALITY OUTCOMES

Every week Newborn Screening Ontario (NSO) refers approximately 25 screen-positive infants to the five Regional treatment centres (RTCs) across Ontario. Clinical staff at these treatment centres are responsible for retrieving the infant for follow up diagnostic testing. The BORN Information System (BIS) plays a pivotal role in the communication and information sharing between NSO and the RTCs during this critical time period and is essential to ensuring continuous quality improvement at NSO.

Since November 2012, the Diagnostic Evaluation Report Forms (DERFs) have been integrated into the BIS so that the RTC clinicians can electronically confirm the timely retrieval of screen positive infants in real time. This allows NSO to confirm that the referral has been received and the family has been informed of the screen positive result. The DERF also records the short-term follow-up, including the clinical status of the infant, follow up investigations, definitive diagnosis, and treatment plan which are used as quality metrics at NSO to ensure timely, accurate and effective service.

Long term follow up indicators are essential for a screening program to understand the impact of screening and treatment. Collecting long-term follow up data is a challenge. NSO

HBHC (HEALTHY BABIES HEALTHY CHILDREN) SCREEN PROJECT

BORN and MCYS (Ministry of Children & Youth Services) are working with hospitals across the province to improve the quality of the HBHC screen and the timeliness of patient referrals for services. In addition, changes are being implemented to reduce duplicate data entry and remove the need for faxing personal health information.

In August 2013 a pilot project demonstrated that a significant portion of the HBHC Screen could be pre-populating with information already captured in the BORN Information System (BIS). In October 2014, Phase 1B of the pilot addressed some of the HBHC Screen completion issues. Fourteen hospitals and 13 of their corresponding Public Health Units (PHUs) are currently using the BIS to support HBHC data collection.

A key issue identified in this pilot was the need for hospitals to enter their data into the BIS in real time to take advantage of the pre-populated fields. HBHC screens were then printed and the rest of the screen was completed by hand. These print-outs of the screen still continue to be faxed to the health units.



has not instituted a formal long-term follow-up system but has rather focused on collaborating with relevant research studies in this area. As BORN grows into collecting early childhood data elements, it will now be possible to even better understand the long term health outcomes of children identified as being at higher risk for screened disorders.

For Phase 2, BORN and MCYS are exploring how the technology can be enhanced such that the HBHC Screen can be completed in its entirety in the BIS and transmitted directly into the data base that supports the HBHC Program (ISCIS-Integrated Services for Children Information System). Health units will then download their daily report of women in their catchment area from ISCIS. From a privacy perspective, the BIS is acting as the conduit and enabling hospitals to replace their current faxed disclosures to PHUs with the ability to disclose their HBHC data to ISCIS via the BIS.

In the Phase 2 pilot eight hospitals and their corresponding health units will be using the BIS to electronically complete and transmit their HBHC Screens. The sites have been preparing with process mapping activities and training to get themselves ready for the launch planned for late Fall 2015.

ON THE HORIZON – LINKING WITH TARGET KIDS!

TARGet Kids! (The Applied Research Group for Kids) network out of the Hospital for Sick Children is a research project focusing on healthy children aged 0-5 years in the Toronto area. Children are recruited through their primary care provider. The aim of the TARGet Kids! Registry is to link early life exposures to health problems including obesity, micronutrient deficiencies, and developmental problems. Imagine if data from this cohort of children could be combined with the prenatal and birth information held in the BORN

registry for this same child. What might we discover about childhood wellness and illness that could help improve and facilitate care? BORN and TARGet Kids are collaborating to determine if the data can be linked and then designing specific projects. One of our first endeavors is to look at children born late preterm (34-36 weeks) and evaluate the association between late preterm birth and cardio-metabolic outcomes in early childhood. Stay tuned for updates!

BEYOND BMI: INVESTIGATING THE FEASIBILITY OF USING ELECTRONIC MEDICAL RECORDS AND NUTRISTEP® FOR CHILDHOOD HEALTHY WEIGHT SURVEILLANCE

Roughly one-third (31.5%) of Canadian children and adolescents aged 5 to 17 years are overweight or obese (Roberts et al 2012). It is essential to intervene early in life, as weight-related behaviours established in early childhood persist into adolescence and beyond (OAHPP 2013a). Taking an ecological approach, family factors, peer influences and environmental factors all play a role in determining a child's weight (OAHPP 2013a).

In Ontario, estimating rates of overweight and obesity in children 5 years of age and younger has been identified as a critical information gap for public health (Healthy Kids Panel 2013, OAHPP 2013b). Electronic medical records (EMRs) are a potential source of data that could provide local level

estimates to inform the care and management of children and their families, as well as support local public health surveillance, program planning and evaluation.

NutriSTEP® is a tool used to assess the nutritional risk and protective factors in children (NutriSTEP® 2014) and has the potential to be integrated into EMRs. However, currently little is known about the use of NutriSTEP® in primary care practices.

BORN has been working with a research team, headed by Kathy Moran from the Durham Regional Health Department to understand the potential for building an EMR-based healthy weights surveillance system which includes risk and protective factors for overweight and obesity in Ontario children.

ON THE HORIZON: POINT OF CARE SCREENING

In the original Star Trek, set in the 23rd century, doctors had "tricorders" that could non-invasively scan a patient to collect vitals and detect disease. We may not be quite at the point of going "where no one has gone before", but the tricorder technology is no longer science fiction. There are a number of non-invasive technologies now being used in screening programs at the point of care, which have moved the paradigm of newborn and childhood screening into the future.

Unlike newborn blood spot screening which requires a sample to be sent to a laboratory for testing, point of care tests are administered and interpreted close to the bedside, to allow for immediate action on the screening result. For example, audiometric screening has occurred for many years in infant hearing screening: the screening results are available immediately and follow up testing can be arranged as necessary. Similarly, bilirubin screening has traditionally been done by measuring total serum bilirubin from a blood sample. But new technology called Transcutaneous Bilirubinometers can now measure the yellowness of subcutaneous tissue to provide a non-invasive and instantaneous screening result at the point of care.

Many jurisdictions around the world have been adding Critical Congenital Heart Disease (CCHD) to the newborn screening panel. While it is not a new technology, pulse oximetry (PO) is a simple, widely available, non-invasive, point of care test. Simply put, PO measures the level of oxygenation in the arterial blood and in the newborn screening environment

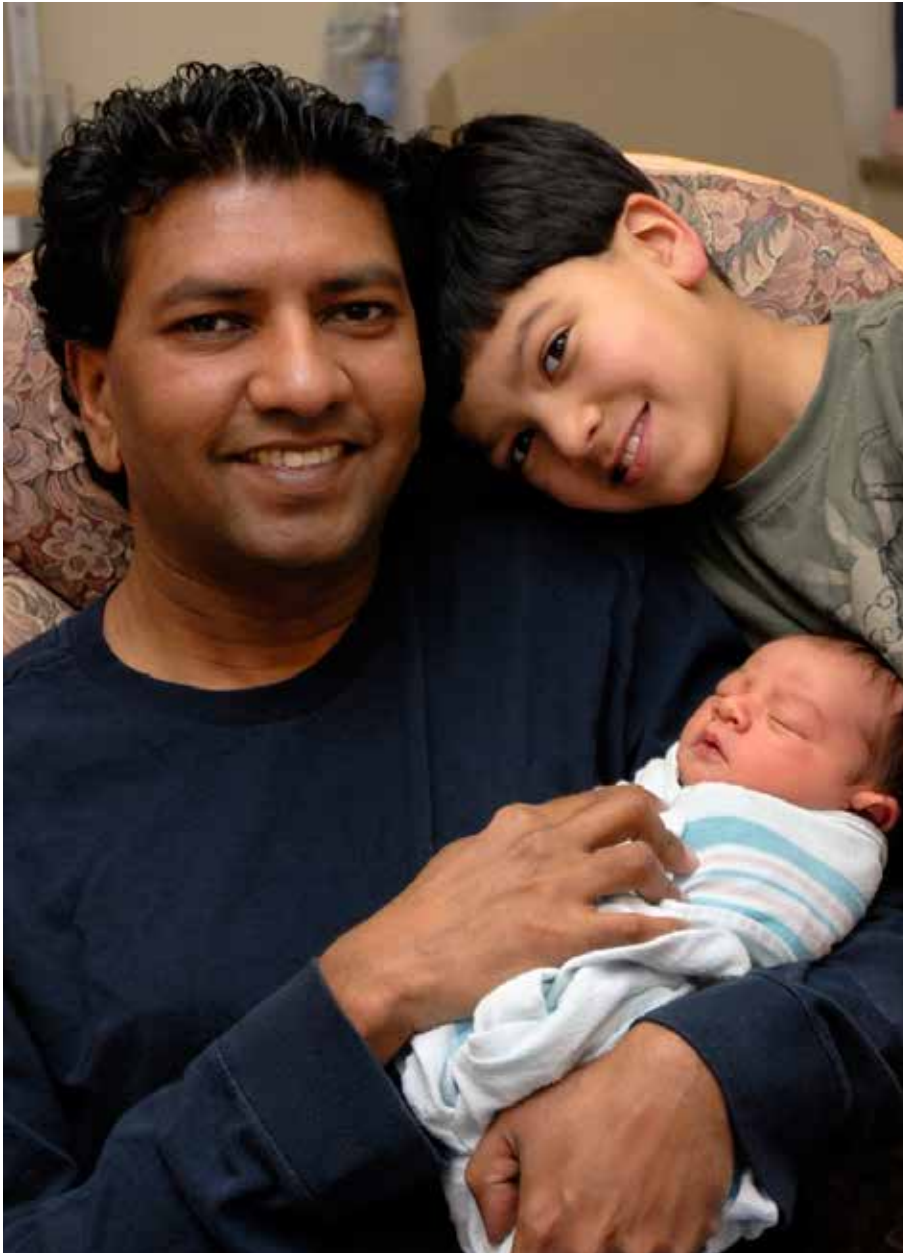


specific algorithms have been published that define normal, abnormal, and intermediate cases that require a repeat screen. As this is a point of care test, false positive results

will be addressed immediately at the bedside and babies with a positive screen can immediately receive a full physical examination by a Pediatrician as the first diagnostic follow up.

With the implementation of any screening policy, whether point of care or more traditional laboratory-based, it is essential that the screening is of high quality, as poor quality screening has the potential to do more harm than good.

BORN's registry status allows for collection of not only screening results, but also patient outcomes. As point of care screening becomes imbedded in our provincial protocols, these results can be linked with outcomes to create robust quality assurance metrics for review and analysis by the appropriate oversight body(ies), with the goal of ensuring improved care and overall outcomes.



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Have you been able to use BORN data to inform practice or improve outcomes?

We want to tell your story.

If you have a success story you would like to share please contact info@BORNOntario.ca with details so we can write your story.

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