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# A Message from the

# **EXECUTIVE DIRECTOR**

I'd like to start by thanking all the health-care professionals who tirelessly collect, submit, and validate the data to populate the BORN Information System (BIS). With over 1.4 million babies in the BIS, we truly have a world-class data set! We have great respect for our partners and know we can accomplish things together that we could never do alone.

2019 was a special year for BORN as we celebrated our 10th birthday! We've grown and changed significantly over the past 10 years. Our foundational pillars, however, remain the same; we're committed to data quality, privacy and security, innovation, and service excellence.

The aim of this report is to provide examples of BORN's impact over the past two fiscal years: 2018-2019 and 2019-2020. Events during this time period have underscored the need for and value of the Registry.



Cannabis, the most frequently used illicit drug during pregnancy,<sup>1</sup> became legal in Canada in October 2018. Legalization and social normalization brought issues of safety to the forefront. Ontario care providers and pregnant individuals needed answers to questions: "Is cannabis a good option for treating morning sickness?" "Is cannabis safe to use in pregnancy? What about breastfeeding?"

In response, BORN researchers and partners from the University of Ottawa, the Ottawa Hospital and CHEO conducted one of the largest studies to date on the effect of cannabis use during pregnancy. The results informed practice guidelines, position statements, and social media campaigns – these diverse communication channels helped spread an important message: avoid cannabis during pregnancy.

Most recently, the COVID-19 pandemic brought the need for high-quality data into laser sharp focus. In this unprecedented era of anxiety and uncertainty, Ontario health-care providers and policy makers need data to remain focused and effective and to guide rational decision-making. Pregnant individuals in Ontario need answers to questions: "What are the risks for my baby if I get COVID-19?" "Can I still get my ultrasound?" "Can I pass COVID-19 to my baby through birth or breastfeeding?"

BORN responded quickly by coordinating data collection for COVID-19-infected pregnant individuals in Ontario and consulting with other Canadian and international groups to ensure variable compatibility. We also served on rapid-response provincial COVID-19 task forces and assisted in the development of recommendations to the Ministry of Health regarding policy and funding changes to ensure pregnant individuals in Ontario have continued access to prenatal screening during the pandemic.

Cannabis legalization in Canada and the current COVID-19 pandemic put the importance of high-quality data in the spotlight, but many other examples of BORN data informing health care, policy, and research are included in this report as well.

I'd like to draw your attention to the narrative at the beginning of the report, featuring a fictional character named Amira. The narrative illustrates how BORN supports Amira and her care providers throughout her pregnancy journey. Although the characters are fictional, the scenarios are real and provide practical examples of BORN ensuring the best possible beginnings for life-long health for Ontarians.

I hope you enjoy the 2018-2020 BORN Impact Report and stay well.

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Dr. Lise Bisnaire

 $1 \ \ Clearing the Smoke on Cannabis, Canadian Centre for Substance Use and Addiction, 2018.$ 



rira's

# **PREGNANCY JOURNEY**

Walk through one woman's pregnancy experience to see how BORN makes a difference!



Dr. Neita loves her job as a family physician. She enjoys seeing a wide variety of patients with a broad range of health conditions. Keeping up-to-date with current medical information is challenging especially when it includes evolving prenatal screening options. But **Prenatal Screening Ontario (PSO)** recently launched their new website showcasing resources such as point-of-care tools, screening algorithms, and requisitions which help care providers stay abreast of new information and quickly find what they need. Dr. Neita uses counselling tips from PSO to guide her conversation with Amira about her prenatal screening options.

Amira asks Dr. Neita about using cannabis to help with morning sickness. She's heard it is natural and safe. Dr. Neita consults *Up-to-Date*<sup>2</sup>, an invaluable resource for medical knowledge at the point of care. *Up-to-Date* recommendations are based on critically-evaluated research and written by physician experts from around the world. Based on the *Up-to-Date* cannabis recommendation (which cites BORN research as well as other rigorous studies), Dr. Neita advises Amira against using cannabis during pregnancy and breastfeeding.

After the appointment with Dr. Neita, Amira and Akeem realize they have more questions about prenatal screening; they call the **toll-free information line** at PSO and speak to a genetic counsellor. With their questions answered, they feel confident to move ahead with their decision to have enhanced first trimester screening (eFTS). Dr. Neita completes the eFTS screening requisition after downloading it from the PSO site. She also consults the new **interactive map** on the PSO website to find the nuchal translucency (NT) imaging facility that is closest to Amira's house. Amira is scheduled for an NT ultrasound and a blood test.

At the imaging clinic, a NT-certified sonographer performs a nuchal translucency ultrasound. Amira's sonographer - Mya - is able to regularly check her personalized NT measurement performance by logging into the BORN Information System (BIS). PSO's Nuchal Translucency Quality Assurance program supports sonographers in their practice by assessing their NT measurement performance and providing them with actionable feedback to help them maintain and/or improve their skills (as needed). Measurement quality and screening quality are known to decrease over time if sonographers are not participating in a formal NTQA program.

Amira has the bloodwork portion of the eFTS drawn at her local blood lab. All the results (i.e. bloodwork, ultrasound information and various maternal factors - including Amira's age at delivery) provide information about the chances of trisomy 21 (Down syndrome) and trisomy 18 in her pregnancy. Dr. Neita receives the eFTS results a week later (the results also populate Amira's record in the BIS).

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Dr. Neita discusses the screen result with the couple which indicates an increased chance for Down syndrome in the pregnancy. Amira is visibly anxious and has many questions. Dr. Neita uses the PSO point-of-care tools and feels well prepared for their conversation. Amira is offered Ministry of Health-funded non-invasive prenatal testing (NIPT). When Amira learns that this screen involves a simple blood draw and will give them further information about the chances of trisomy 21, 18, and 13 in her pregnancy, she decides to go ahead. Dr. Neita downloads the appropriate requisition from the PSO website and Amira takes it to the lab for the blood draw. The sample is sent to a specialized lab whose technicians analyze the results. Ten days later Dr. Neita receives the results (which also populate Amira's record in the BIS).

Amira's results are reported as low-risk; she feels reassured and declines any further testing. If her results were high-risk, she would be referred to a Regional Genetics Centre to discuss further testing options. Amira may have pursued diagnostic testing such as chorionic villus sampling or amniocentesis and her results would have populated the Cytogenetic encounter in the BIS. The details of her genetics appointment would have been captured in the Genetics/Maternal Fetal Medicine encounter in the BIS.

Amira's pregnancy goes smoothly. At 36 weeks she starts getting irregular contractions and low-back pain and finds she needs more rest. Dr. Neita assures her this is normal and her body is getting ready for labour. Amira goes into labour early one Saturday morning when she is 38 weeks pregnant. Akeem re-checks the 'hospital bag' for the tenth time and times Amira's contractions on his phone. At 2pm, they head for the hospital. After what seems like forever – at 10:38pm - an exhausted but elated Amira gives birth to a little girl weighing 6 pounds 8 ounces. Shortly after birth, a small sample of blood is taken from the baby's heel for **newborn screening**. BORN cross-references newborn screening results with every birth in Ontario to ensure all families are offered screening.

Leslie - the nurse caring for Amira and her newborn - enters the birth details into the BIS. Leslie's day is hectic and she is happy she doesn't have to spend time entering demographic information into the BIS. BORN has been working on **automating more data entry** so demographic details (address, phone number, etc.) flow into the BIS in real time from the hospital information system.

Amira's baby requires assistance with breathing (oxygen and continuous positive airway pressure) at birth, but is stable otherwise. When Leslie examines the baby a short time later, she notes that her temperature and blood sugar are low. Feeding and bundling do not improve temperature or blood glucose levels so the baby is transferred to the Neonatal Intensive Care Unit (NICU) for further care and investigation.

Amira gets ready to be discharged; her baby remains in the NICU. As part of the discharge procedure, Leslie explains the Healthy Babies Healthy Children (HBHC) screening to Amira who consents to the HBHC screen. Using the BIS, Leslie completes and submits the electronic HBHC Encounter securely to her local public health unit (PHU) – a process that ensures Amira's personal health information is protected as it moves between the hospital and health unit. The PHU receives the screen immediately, and Amira is identified to be 'with risk' due to her baby being in the NICU and Leslie's concerns about Amira's anxiety and stress. Public health will follow up with Amira to offer support such as home visits and community referrals.

Amira's baby requires IV fluids to stabilize her blood sugar and some time in an incubator to keep her temperature stable. After 3 days in the NICU, she is stable and ready to be discharged home. The neonatal team enters her data into the BIS; her admitting temperature and the amount of oxygen she required in the first 30 mins of life are automatically reflected on the hospital's NICU Dashboard. The dashboard, developed by BORN, helps teams monitor their performance on these 2 key performance indicators.

Just prior to discharge, a second HBHC Encounter is completed with updated information on the family/baby and submitted to the local PHU. This provides additional information for the public health nurse to support the family. Amira is very happy to bring her daughter home. She feels fortunate to be in Ontario where her baby has the best possible beginning for lifelong health.



## Fighlights of FISCAL YEARS 2018-2020

## OMAMA UPDATES

In February 2020, BORN updated OMama - a website and app that connects pregnant individuals to trusted, evidence-informed pregnancy, birth, and early parenting information for Ontario.

#### New features:

Pictures of records/documents can be saved in the application:

- lab results (e.g. complete blood count, urine screen)
- Ontario Perinatal Record
- prenatal appointment details
- hospital packing list

A scroll-through-tool shows baby's growth each week and can be displayed as an ultrasound photo, illustration, or fruit/veggie.

Pregnant individuals can still take advantage of other helpful features that have been there all along:

- setting up a personal pregnancy profile
- using the journal to track mood, exercise, water intake, food, kick counts, etc.
- tracking pregnancy, birth, and early parenting weekby-week
- learning about programs, resources, and caregivers
- searching a glossary of terms relevant to their needs

In FY 2019-2020, 52,694 people used the OMama website.

#### PSO TOLL-FREE Information line

Prenatal Screening Ontario (PSO) launched a toll-free prenatal screening information line in 2018. A certified genetic counsellor is available 8am-4pm Monday to Friday to answer questions from patients, providers, and other stakeholders (e.g. lab personnel).

Examples of questions fielded by the team include:

- When does screening need to be done?
- I got a positive screen result now what?
- What are the funding criteria for Non-invasive Prenatal Testing (NIPT)?
- How does COVID-19 impact access to prenatal screening tests?

## PRENATAL SCREENING ONTARIO RESOURCES

In August 2019, Prenatal Screening Ontario launched its new website. The new content provides information for pregnant individuals, families, and health-care providers.

The website helps pregnant individuals and their families:

- find information on prenatal screening test options
- understand prenatal screening test results

The website helps health-care providers:

- find prenatal screening requisitionslearn about the Nuchal Translucency Quality
- learn about the Nuchai Translucency Quality
  Assurance Program
- find ways to become involved with Prenatal Screening Ontario
- discuss prenatal screening with patients/clients
- request on-site or virtual educational outreach sessions

In 2019-2020, 52,548 people used the PSO website. The number of users increased by 20% between Q2 and Q3 and by 64% between Q3 and Q4.

## **BORN CANNABIS RESEARCH**

Researchers from BORN, the Ottawa Hospital, CHEO, and the University of Ottawa conducted one of the largest studies to date on the effect of cannabis use during pregnancy; findings were published in JAMA in June 2019.

The research team analyzed BORN data from 2012 to 2017, prior to the legalization of recreational cannabis in Canada. They found that reported cannabis use during pregnancy was associated with an increased risk of preterm birth.

This publication was among the top 5% of research outputs ever tracked by Altmetric and gained international media attention from scientists and healthcare practitioners from many countries including the United Kingdom and Cote d'Ivoire.

#### NUCHAL TRANSLUCENCY Quality Assurance Program

Nuchal translucency (NT) ultrasound refers to the measurement of the fluid under the skin at the back of the fetal neck in the first trimester of pregnancy. Increased NT can be associated with chromosome abnormalities, structural abnormalities such as cardiac defects, and/or other genetic syndromes.

Health-care providers arrange for NT ultrasounds for their pregnant patients/clients between 11 weeks 2 days to 13 weeks 3 days gestation.

Since the incorporation of the NT measurement into the prenatal screening process, sonographers have played a huge role in providing the majority of pregnant individuals with risk prediction for Trisomy 21 (Down syndrome) and Trisomy 18 (Edwards syndrome).

International standards recommend that sonographers participate in a formal quality assurance program if taking NT measurements. Without participation in such a program, measurement and screening quality decrease over time.

Over the past two years, PSO has been educating the diagnostic imaging community on the status of nuchal translucency measurement performance in Ontario and increasing awareness of the Nuchal Translucency Quality Assurance (NTQA) Program. Program promotion occurred through webinars, conferences, social media, large-scale mail outs, promotion from Sonography Canada, and a quarterly newsletter.

At the end of fiscal year 2019-2020:

- 1397 sonographers were registered in the BIS
- 41 sonographers participated in one-onone remediation through the NTQA program.

## **NEWBORN SCREENING**

Newborn screening is performed shortly after birth to test for treatable diseases that usually show no symptoms in the newborn period. The diseases screened for can be life-threatening if not treated and every baby could be at risk. BORN and Newborn Screening Ontario (NSO) work in partnership to identify babies who have missed their newborn screen and may be at risk for serious health conditions as a result.

In October 2019, BORN improved one of the key reports used to identify babies in Ontario who may have missed newborn screening. A summary tab was added to facilitate trending of the number of alerts generated by BORN for follow-up by NSO. We also made it easier for NSO to review the total number of records included for each alert.

## **CYTOGENETIC DATA**

In 2018-2019, BORN developed the system architecture to collect, store, and analyze cytogenetic data from both prenatal and neonatal testing. In February 2019, we launched the new cytogenetic encounters in the BIS.

This data has been the missing piece in terms of linking prenatal screening results with outcomes on a populationlevel in Ontario. This allows PSO to understand precisely how well our system works in screening for Down syndrome, trisomy 18 and trisomy 13. Prior to this, our only references were from industry-funded statistics, literature from other jurisdictions or theoretical modelling for our own population.

We're now able to report NIPT and traditional multiple marker screening results in relation to diagnostic testing and birth outcomes, allowing us to assess the true population performance of prenatal screening in our province for the first time.

### **INTERACTIVE MAP**

In March of 2020, PSO launched a new interactive map on their website to help health-care providers and patients find facilities that offer nuchal translucency ultrasound in Ontario.

Users are able to 'zoom in' and find the name and street address of facilities located in their neighborhood. Clicking on a facility takes users to a webpage with more information about the facility (e.g. hours, services offered, etc.). This map is updated monthly as new site information comes in.





## **AUTOMATING DATA ENTRY**

BORN is continually looking for ways to make data entry easier for contributors; automating the transfer of patient information to the BIS is one of the ways we're accomplishing this. We are now able to accept demographic information from Admission, Discharge, Transfer (ADT) records as well as clinical information from hospital information systems.

#### Automating Demographic Information Transfer

When a pregnant individual is admitted to a hospital, key demographic information (name, date of birth, address, etc.) appears in the BIS in real time which:

- eliminates the need for manual data entry
- automates mother-child record linking
- allows public health nurses to complete the Healthy Babies Healthy Children (HBHC) encounter immediately (instead of waiting for the patient record to be manually added to the BIS).

At the end of 2019-2020, 43 birthing hospitals in Ontario were using data automation to feed demographic information into the BIS. These 43 hospitals are realizing the benefits: the patient record is automatically created in the BIS; demographic variables for the patient automatically populate the BIS; less time is spent correcting typographic errors etc. The time saved is returned to the world-class care being delivered in Ontario.

#### Automating Clinical Information Transfer

In addition to accepting automatic ADT feeds, we are also able to accept clinical data transfers to the BIS. At the end of 2019-2020, 5 hospital sites were submitting clinical data electronically in near real-time. This type of automation eliminates the need for manual entry of hundreds of data fields and improves data timeliness and quality. Grand River Hospital is one of the 5 hospitals currently automating the transfer of demographic and clinical data. Data flows directly from Cerner - their electronic health system - without any manual effort required from hospital staff. In addition to time savings, they see a huge impact on data timeliness since patient data is in BIS within 24 hours of discharge.



"Automating demographic and clinical data transfer will greatly decrease the amount of time our staff members spend manually creating encounters and entering data. The automated feed allows more time to be focused on direct patient care."

- Maggie Hilton RN, BScN, Health Informatician, Grand River Hospital



#### HEALTHY BABIES HEALTHY Children Screen

Healthy Babies Healthy Children (HBHC) is a Ministry of Child and Community Social Services (MCCSS) Provincial Program delivered by Ontario Public Health Units (PHUs). The program supports vulnerable women, children and their families from the prenatal period through to children's transition to school.

The HBHC Screen is a comprehensive tool that provides good predictive validity in identifying vulnerable families that may benefit from HBHC services. Screening is voluntary and consent-based. Eligible families are referred to community programs and services designed to support new parents.

From January 2018 to June 2019, BORN led the provincial roll-out of an initiative funded by MCCSS to improve the way maternal-child screening information moves between hospitals and public health-care providers. BORN built an electronic HBHC screen (eHBHC) to augment current data collection mechanisms and securely transfer Personal Health Information (PHI) to PHUs.

The eHBHC eliminates manual data capture, faxing, and re-keying of PHI. Since implementation of eHBHC, the number of missed screens has gone down by 6% – meaning that more Ontario children are being screened for risks.

## NICU/SCN DASHBOARD

One of the highlights of 2018-2019 was launching the Neonatal Intensive Care Unit/Special Care Nursery (NICU/SCN) Dashboard. Two key performance indicators were chosen for the dashboard: 1) newborn resuscitation and 2) body temperature on admission to the NICU/SCN.

Evidence shows that resuscitation with room air, as the first gas used, is associated with comparable or better outcomes than if high concentrations of oxygen (i.e., 80% or 100%) are used. The dashboard shows care providers how many babies (>35 weeks gestation) admitted to their NICU/SCN received room air as the initial gas during resuscitation (in the 1st 30 minutes of life). The target is >95%.

Body temperature on admission to NICU/SCN is a critically important metric to track as babies who are hypothermic or hyperthermic can become very sick or even die. The dashboard shows care providers how many babies (> 35 weeks' gestation) were admitted to their NICU/ SCN with a normal temperature (36.5-37.5 °C). The target is >85%.

The dashboard uses a simple green-yellow-red display to provide hospital staff with information on their performance at-a-glance. Green means they're in the target zone; yellow is the warning zone, and red is the alert zone. The dashboard is an important signal for care providers; a yellow or red display is a signal to examine how care is being provided and take the necessary steps to improve it.

## **BORN CONFERENCE**

On November 7th & 8th, 2019 BORN held its biennial conference in Ottawa. This year's theme - *Improving Care through World-Class Data and Innovation* - attracted a diverse crowd of health-care providers, administrators, policy makers, researchers, and students.

Presentations and discussions focused on:

- disruptive technology in health care
- perinatal risk and safety
- Ontario's maternal newborn data partnerships
- using data to support better care future trends

A favorite among the participants was Keynote speaker, Dr. Anthony Chang, (also known as 'Dr. Al') who spoke about artificial intelligence in health care.

"I'm just back to work after the BORN conference in Ottawa last week – that was the best conference I've been to and I'm really excited to bring the information and ideas back to Muskoka"

- conference participant from Bracebridge, Ontario



## COVID-19 RESPONSE

The end of Q4 was marked by efforts to address the COVID-19 crisis:

- helping pregnant individuals access prenatal screening amidst the COVID-19 pandemic;
- coordinating data collection on the clinical characteristics of COVID-19 infected pregnant individuals
- participating in COVID-19 provincial taskforces and a COVID-19 national project

#### **Accessing Prenatal Screening**

As a result of COVID-19, access to ultrasounds and blood collection services were reduced in some areas, causing understandable anxiety among pregnant individuals and care providers. In other cases, self-isolation requirements meant pregnant individuals couldn't leave the house to go to time-sensitive ultrasound appointments.

Prenatal Screening Ontario (PSO) responded quickly recommending changes to screening pathways and funding policies to ensure pregnant individuals would still receive high-quality prenatal screening despite COVID-19 related challenges. These recommendations were endorsed by the Ministry of Health (effective April 6 -July 6, 2020).

#### **Coordinating Data Collection**

In response to the urgent need to determine whether COVID-19 posed any threat to maternal, fetal, or infant heath, BORN began coordinating data collection for cases of COVID-19-infected pregnant individuals admitted to Ontario hospitals or cared for by a midwife.

To verify the number of cases and to assist public health, BORN also added 'COVID-19 status' to the electronic Healthy Babies Healthy Children (eHBHC) screening tool.

BORN received overwhelming support to spearhead data collection in Ontario; registry status allowed us to collect data quickly from individual hospitals and midwifery practice groups and to combine data at the provincial level.

In developing the Ontario data variables, BORN consulted with other Canadian and international groups to ensure variable compatibility (important for future reporting and collaboration once the pandemic has ended).

Because about 40% of all births in Canada each year occur in Ontario, information collected here can make an important contribution to national knowledge on this issue.

#### Serving at the Provincial and National Level

BORN was asked to sit on the Provincial Council for Maternal and Child Health (PCMCH) *Maternal-Neonatal COVID-19 Task Force* responsible for developing provincial recommendations to guide care. This rapidresponse group produced clinical practice guidelines approved by the Ministry of Health. Dissemination is starting in the new fiscal year.

At the national level, BORN is sitting on the CAN-COVID group and will provide de-identified provincial data and epidemiological expertise to help understand the Canadian prevalence rates in pregnancy and the associated outcomes for pregnant individuals and their newborns.

## PRIVACY

As a prescribed registry under Ontario's Personal Health Information Protection Act (2004), BORN is required to have rigorous policies to protect the privacy and security of all personal health information in its custody.

These policies are based on requirements from the Office of the Information and Privacy Commissioner of Ontario. They are reviewed by BORN annually, and they are also reviewed and approved by the Office of the Information and Privacy Commissioner ("IPC") every three years. The most recent review by the IPC commenced on October 31, 2019.

During the past two years, BORN privacy coordinators and privacy officers:

- oversaw 69 policies and procedures and 355 data sharing agreements that govern the collection, use, disclosure, and security related to personal health information
- revised BORN's Privacy and Security Management Plan to include more detailed governance processes
- conducted privacy impact assessments related to numerous projects and programs and made specific privacy-related recommendations

BORN's privacy approach is grounded in a Privacy and Security Governance Framework that includes industry best practices, physical and technical safeguards, access controls, audits, reporting tools, and most importantly, shared responsibility across the organization.

## FERTILITY DATA

Some families require in-vitro fertilization (IVF) treatment to help them build the family they desire. BORN works with the 19 IVF clinics across Ontario, as well as 17 additional IVF clinics across the rest of Canada, to report IVF-related data to BORN under the Canadian Assisted Reproductive Technologies Register (CARTR Plus).

BORN works with the Medical Directors of the IVF clinics to refine data elements, develop standard reports, and provide data for ground-breaking fertility research to improve practice and increase the chances of healthy, full-term babies after IVF treatments.

Since 2015, Ontario has provided funding (Ontario Fertility Program or OFP) for one IVF cycle per Ontario resident, should they require it, as well as egg/sperm freezing for cancer patients. Patients who access this funding agree to allow their de-identified data to be reported to BORN in order for the Ministry of Health to monitor outcomes of funded IVF treatment. BORN reports this OFP data to the Ministry on an annual basis. Since the beginning of the funding program, over 3700 babies have been born to families that might not otherwise have been able to have children.

Data has shown that singleton pregnancies are more likely to result in a full-term, healthy baby. Under the OFP, single-embryo transfer was mandated for patients undergoing a provincially-funded cycle. This data-driven practice change has resulted in a decrease in the multiple pregnancy rate in Ontario from 18.8% in 2013 to 5.8% in 2018.

In Canada, as a whole, the multiple pregnancy rate has decreased from 15.1% in 2013 to 7.4% in 2018. Even without a mandate, most clinics are following this 'bestpractice,' resulting in healthier babies born from pregnancies that were conceived via IVF treatment.





# Data Releases **FISCAL YEARS 2018-2020**







# FISCAL YEAR 2018-2019

Revenue Distribution FY2018-2019



#### Expenditure Distribution FY2018-2019



Professional Services

Perinatal Program Costs

- (Tech, Privacy, Legal)
- Technology Infrastructure
- Fertility Program
- Prenatal Screening Ontario
- Strategic Projects

BORN



# Finances FISCAL YEAR 2019-2020

#### Revenue Distribution FY2019-2020



#### Expenditure Distribution FY2019-2020



- Perinatal Program Costs
- Professional Services (Tech, Privacy, Legal)
- = Technology Infrastructure
- Fertility Program
- Prenatal Screening Ontario
- Strategic Projects

We'd like to hear from you... CONTACT US

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