



BORN & GROWING

Annual Report | 2012–2014
Two Years of Progress



Better Outcomes Registry & Network
Registre et Réseau des Bons Résultats dès la naissance

DISCLAIMER

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ONTARIO'S PREGNANCY, BIRTH AND CHILDHOOD REGISTRY & NETWORK



ONTARIO'S PREGNANCY, BIRTH AND CHILDHOOD REGISTRY & NETWORK

Established in 2009 to collect, share and rigorously protect critical data about each child born in the province, BORN Ontario manages an advanced registry that provides reliable, secure and comprehensive information on maternal and child care.

Because pregnancies and births in Ontario are thoroughly documented, and because the clinical data collected are complete, professionals in every discipline within the health sector gain vital knowledge they can apply to improve the system.

The result is change that contributes directly to the wellbeing of mothers, with positive and lasting effects on the health of newborns, children and the citizens of Ontario.

DIRECTOR'S MESSAGE

BORN experienced exciting growth during the two fiscal year periods included in this report (April 2012 to March 2013 and April 2013 to March 2014). The first babies entered into the BORN Information System (BIS) – from early 2012 – are now turning three, so it seemed fitting to find ways to better

facilitate and improve care for these growing children. We have great partnerships with eHealth Ontario, the Ministry of Child and Youth Services (MCYS), and primary care providers which now allow us to access data from the 18-month well-baby visit, and we have plans to further expand data

collection for all young child visits (from 0-5). We are also working on obtaining standardized data from autism treatment clinics in Ontario.

We want to sincerely thank all those individuals and groups who have been a key part of the growth and success of BORN. While we can't single out everyone, we are incredibly thankful for our principal funders, our vendor partners, our committee members, our host organization CHEO, our leadership and team members and other stakeholder groups across the province. Our biggest thanks, however, must go to those people across the province who prepare and enter data for the BIS. As evidenced by this report, the work you do allows Ontario to have a remarkable system to help facilitate and improve care as well as to have timely information to plan and deliver maternal child care.

Highlights of this report include news about:

- The addition of the CARTR Plus (Canadian Assisted Reproductive Technologies Register) dataset to the BIS
- Provincial progress on the maternal newborn dashboard
- Expansion into mobile health via smart phone apps
- Congenital anomaly surveillance in Ontario
- Enhancing our partners' ability to use data (i.e. providing self-service reports; processing more BORN-facilitated data requests; and adding new functionality to the website for data requests)



Ann Sprague
Acting Director, **BORN** Ontario



A newborn baby wrapped in a striped blanket, looking up at a healthcare professional in a blue cap and mask.

286,497

ONTARIO BIRTHS WERE
CAPTURED IN THE BORN
INFORMATION SYSTEM
IN 2012-2014

FOUNDATIONS OF BORN



BORN INFORMATION SYSTEM (BIS)

What it does, Who it connects

The BIS is the central web-enabled system developed and used by BORN to collect, store and exchange health information. The system links data contributors and care providers from birthing and neonatal intensive care sites, midwifery practices, newborn screening and prenatal screening laboratories, primary care and community care facilities, fertility treatment centres and public health units to improve access and interpretability of health information when and where it is appropriate.

The BIS securely maintains personal health data for women who are pregnant, have given birth or are seeking fertility treatment. Every year more than 145,000 new births and pregnancy records are added to the system. Over 100 reports are discretely and securely made available to health care organizations to provide care insight and manage their contribution of high quality data to BORN.

The Next Frontier: Getting data into the right hands at the right time

The flexibility of the BORN technology platform, the BIS, brings new opportunities to make health information available to the appropriate provider at the appropriate time. With our partners at eHealth Ontario, the Ministry of Children and Youth Services and the Ministry of Health and Long-Term Care, we are working on new BIS functionality for the future that will:

FOUNDATIONS OF BORN

- Make registry data available centrally to other health care providers using electronic medical records or hospital electronic health records
- Provide in-time screening alerts to providers for women at risk of developing long-term health problems due to type 2 diabetes or hypertension in pregnancy
- Provide benchmarked reports on child health indicators
- Monitor and support referrals to community programs for children at-risk of developmental delays
- Transmit data to another provincial database, the Ministry of Children and Youth Services' HCD-ISCIS database, to improve the timeliness and comprehensiveness of the Healthy Baby Healthy Children Program that promotes healthy child development

Table 1: BIS Activity in 2012-2013 and 2013-2014

GENERAL STATISTICS	2012-13	2013-14
Total Ontario Births Documented in the BIS**	140,590	138,798
Hospitals Submitting Data*	103	101
Newborn Screens	147,644	146,223
Neonatal Intensive Care Units Submitting Data	43	44
Midwifery Practice Groups Participating	84	86
Fertility Centres Submitting Data from across Canada	34	36
Family Health Teams Submitting Data	4	12
Prenatal Screening Labs Participating	5	5
Registered Users	5,072	6,754
Available Reports	76	108

* *Decrease due to obstetrical units closing.*

** *Includes live and stillbirths only.*

THE BORN TEAM & LEADERSHIP

BORN is comprised of a tight-knit group of individuals dedicated to our common goals. We have physical space in Ottawa and Toronto, but we are really a virtual team with about 1/3 of our group working in different locations across the province. We are subdivided into smaller teams for administration, screening, data analysis and research, technical work, coordination and business development. In March of 2014 BORN director Mari Teitelbaum left on a sabbatical to pursue an educational/business development opportunity and Dr. Ann Sprague took on the acting director role. Our senior leadership group of Susan Richardson, Dr. Pranesh Chakraborty and Dr. Mark Walker remain committed to the mission and vision of the organization.

PRIVACY

BORN is committed to protecting the privacy and security of the personal health information collected under its mandate of facilitating and improving the provision of health care to mothers, babies and children in Ontario. As a

DID YOU KNOW?

BORN received about 200 data requests in 2013–14, fifteen of which were for record level datasets for research.

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 every three years.

Privacy at BORN begins with training and is maintained through a strong internal culture of privacy in the workplace. Our privacy approach is fully supported by our privacy and security governance framework that includes industry best practices,

FOUNDATIONS OF BORN

physical and technical safeguards, access controls, audits, reporting tools and most importantly, shared responsibility across the organization.

FINANCE

BORN is primarily funded by the Ministry of Health and Long-Term Care through the Children's Hospital of Eastern Ontario. In addition, BORN partners with other organizations such as the Ministry of Children and Youth Services, eHealth Ontario, the Public Health Agency of Canada and various research organizations to support maternal child analysis, research and planning in Ontario.

COMMITTEES

Advice

BORN depends on expert advice from more than 60 scientific, technical and healthcare experts serving on our committees and subcommittees to inform strategic direction, key projects and scientific output. Each of the BORN committees meets two to three times per year with one face-to-face meeting. Our committee structure has changed slightly over this reporting period.

In 2014 we also added several committees to ensure all our stakeholder groups had a forum for discussion and advice.

CARTR Plus Steering Committee –

CARTR Plus is the data collection system for in vitro fertilization (IVF) clinics in Canada. This committee provides advice and direction on the collection, use and reporting of this data and is engaged in quality improvement initiatives for IVF clinics.

BORN Steering Committee –

This group has representatives from all the BORN committees, the Ministry of Health and Long-Term Care, the Ministry of Children and Youth Services, The Provincial Council for Maternal Child Health and BORN leadership. The committee assists BORN with strategic decisions and is tasked with ensuring that the BORN leadership team is aware of all opportunities for BORN data to be used to facilitate and improve care.

COMMITTEES WITH DUAL REPORTING

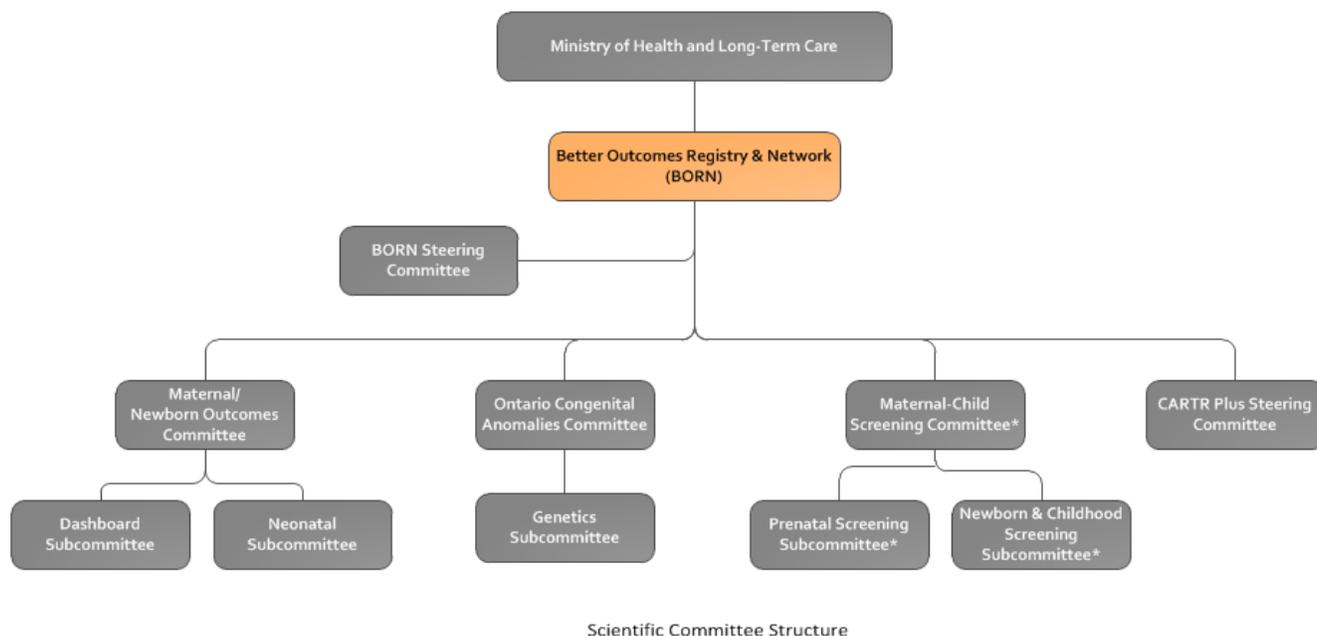
Ontario's Maternal Child Screening Committee (MCSC) was convened by BORN Ontario and the Provincial Council for Maternal and Child Health (PCMCH) in 2010. The MCSC had a dual reporting structure: to BORN for information and data issues and to PCMCH for policy recommendations. Supported by two subcommittees (the [Prenatal Screening Subcommittee](#) and the [Newborn-Child Screening Committee](#)), the MCSC has made some significant contributions to screening services in Ontario, with recommendations from these groups being endorsed by PCMCH and submitted to government.

In early 2014 the structure of MCSC evolved; MCSC is now reporting directly to PCMCH and will continue to advise regarding policy and the subcommittees have been dissolved. Work groups will be convened as required to take on the work generated by MCSC. To provide continued guidance for overall quality assurance activities for prenatal screening services in Ontario, BORN planned to convene a new Prenatal Screening Quality Assurance Committee in the fall of 2014.

DID YOU KNOW?

BIS users can customize their own reporting. Much of the data presented in this report is aggregated at the provincial level, but when you run a report for your own institution, you can customize your output (e.g. the date range). Some reports (profile reports, dashboard reports) automatically provide comparisons to same-level-of-care institutions, similar-birth-volume institutions, as well as the province. Give it a try – you'll be amazed at the information available to you with a few clicks of a mouse!

Figure 1: Committee Structure



* These committees also report to the Provincial Council for Maternal Child Health (PCMCH)

Committee Chairs

- BORN Steering Committee – Ms. Susan Richardson
- Maternal Newborn Outcomes Committee (MNOC) – Drs. Graeme Smith & JoAnn Harrold
- Ontario Congenital Anomalies Committee (OCAC) – Dr. Aideen Moore
- Maternal – Child Screening Committee (MCSC) – Dr. Pranesh Chakraborty
- Prenatal Screening Subcommittee (PSSC) – Dr. Nan Okun
- Newborn-Child Screening Subcommittee (NCSC) – Dr. Murray Potter
- CARTR Plus Steering Committee – Dr. Matt Gysler

DATA QUALITY

At BORN Ontario, we consider data quality to be one of our highest priorities. We recognize that the quality of data is directly related to use of the data and confidence in the results of any analysis. With the addition of benchmarking and comparators, the quality of the data across all organizations, practice groups and programs must be tracked and maintained. Our goal is to ensure that data entered into the BIS is timely, accurate, comparable, usable and relevant for our stakeholders.

BORN Data Quality Framework

The BORN Data Quality Framework (DQF) was implemented in 2013. BORN requires a comprehensive framework to promote data quality in all aspects of our data work: collection, analysis, use and disclosure of information. This framework assists with development of a data quality management plan (DQMP) and guides decisions on resource allocation to carry out the DQMP. It's also needed to align with criteria for data element additions, deletions and changes. The BORN DQF is based on 5 dimensions of data quality which in turn are divided into 19 elements and sub-

DID YOU KNOW?

School Boards request live birth data from **BORN** for enrolment planning.

elements and was modelled after and adapted from the Canadian Institute of Health Information.

Timeliness – Whether data is current at the time of release and whether the data is available for user needs within a reasonable time period.

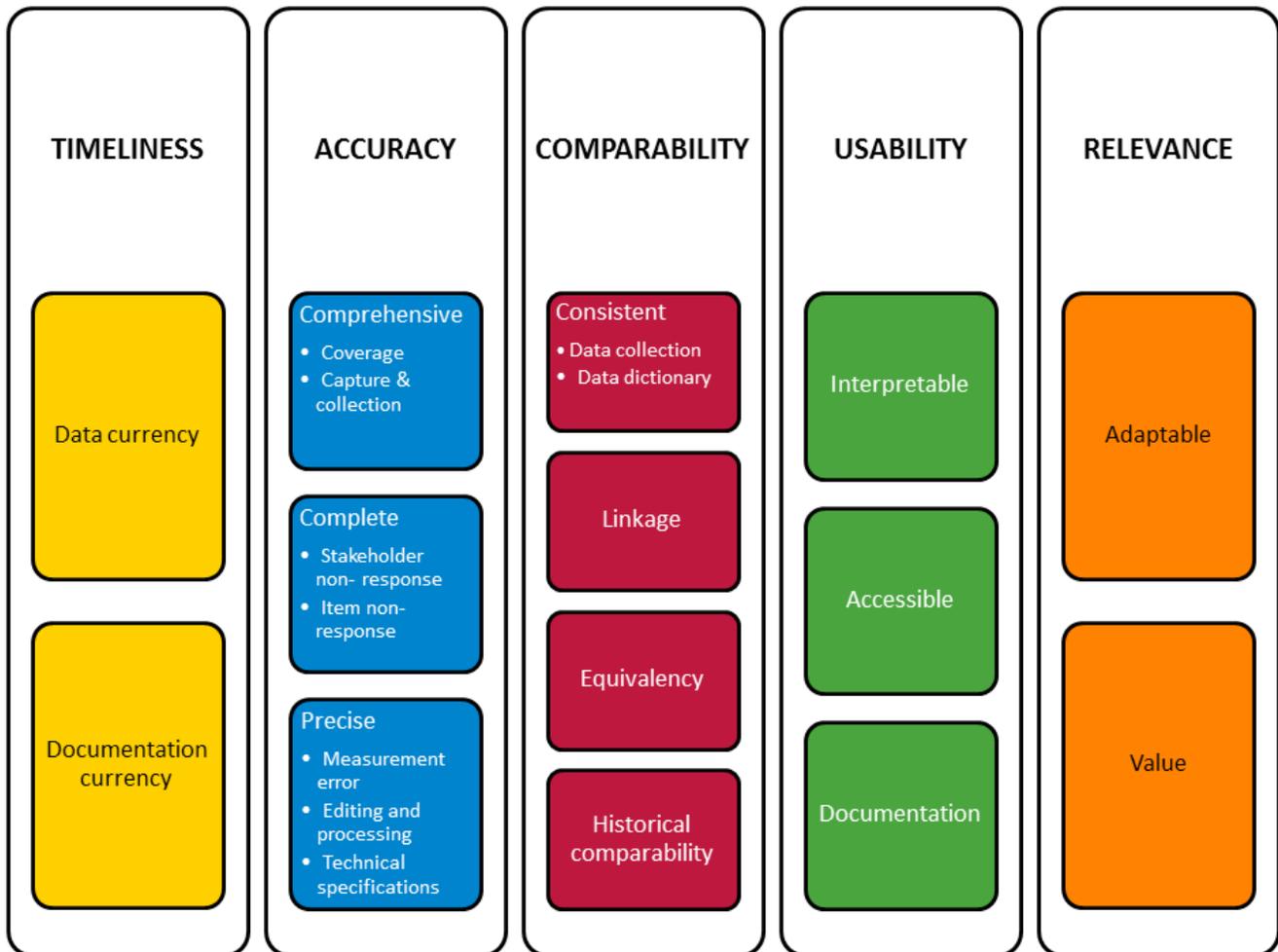
Accuracy (validity) – How well information within or derived from the database reflects the reality it was designed to measure.

Comparability (reliability) – The extent to which data is consistent over time and entered using standard conventions making it comparable to other databases.

Usability – The ease with which the data is understood and accessed.

Relevance – The degree to which the data meets the current and potential future needs of users.

Figure 2: BORN Data Quality Framework – Dimensions, Elements and Sub-Elements



Adapted from the CIHI Data Quality Framework, 2009

Data Quality Team

In 2014, BORN created a Data Quality Team (DQT), coordinated by our Quality Specialist. The purpose of the DQT is to facilitate and oversee implementation of the BORN Data Quality Priorities and Strategic Plan and to inform and provide advice on data quality issues. The DQT supports the BORN Leadership Team to further the vision and mission of BORN as an authoritative source of accurate, trusted and timely data to monitor, evaluate and plan for the best possible beginnings for lifelong health.

Other Data Quality Strategies

A number of other tools, processes and supports have been implemented to assure data quality:

- BIS Data Entry Guidelines
- Drop-Down Lists in the BIS in order to eliminate free text
- Mandatory Fields and Data Validation Rules
- Automated Algorithms
- Missing Data Reports
- BORN Coordinator Support
- BORN Committees

A chart re-abstraction of data in one of the BIS datasets was conducted in 2014 and more data quality assessments are planned for 2015.

A SNAPSHOT OF THE MATERNAL CHILD POPULATION IN ONTARIO – OUR METHODS

This report presents maternal-newborn data for births to Ontario women that occurred primarily during the fiscal years 2012–2013 and 2013–2014 (April 1, 2012 to March 31, 2014); however, some indicators are presented across additional fiscal years to allow for examination of temporal trends.

The data source for this report is the BORN Information System (BIS), which includes data from the Canadian Assisted Reproductive Technologies Register (CARTR Plus).

69.8%
OF PREGNANT WOMEN IN
ONTARIO HAD PRENATAL
SCREENING



PREGNANCY



SUCCESS STORY: REDUCING RISK FACTORS FOR GESTATIONAL WEIGHT GAIN

In 2012–2013 BORN started collecting data elements to calculate pre-pregnancy body mass index (BMI) and total weight gain during pregnancy. This data is incredibly important for clinicians, researchers and those developing policy recommendations related to healthy living and reducing maternal and childhood morbidity related to obesity.

Women who are overweight or obese at the start of pregnancy, or those who gain more than the recommended amount of weight in pregnancy, place themselves and their child at an increased risk for serious health complications. Fortunately, gestational weight gain (GWG) is modifiable and pregnancy is a time when many women are motivated to adopt positive lifestyle habits (e.g. physical activity, healthy eating, smoking cessation) to support a healthy baby.

The collection of GWG data is also important for clinicians who talk with women about subsequent pregnancies and for researchers looking at longer term health outcomes. Women who do not return to a healthy weight post-pregnancy may carry extra weight into subsequent pregnancies. The cycle of weight gain and weight-related complications persists and can be associated with chronic health issues such as Type 2 diabetes or hypertensive problems. By collecting and using BMI and GWG data, BORN can contribute to better preventative health care and evidence-informed public health policy.

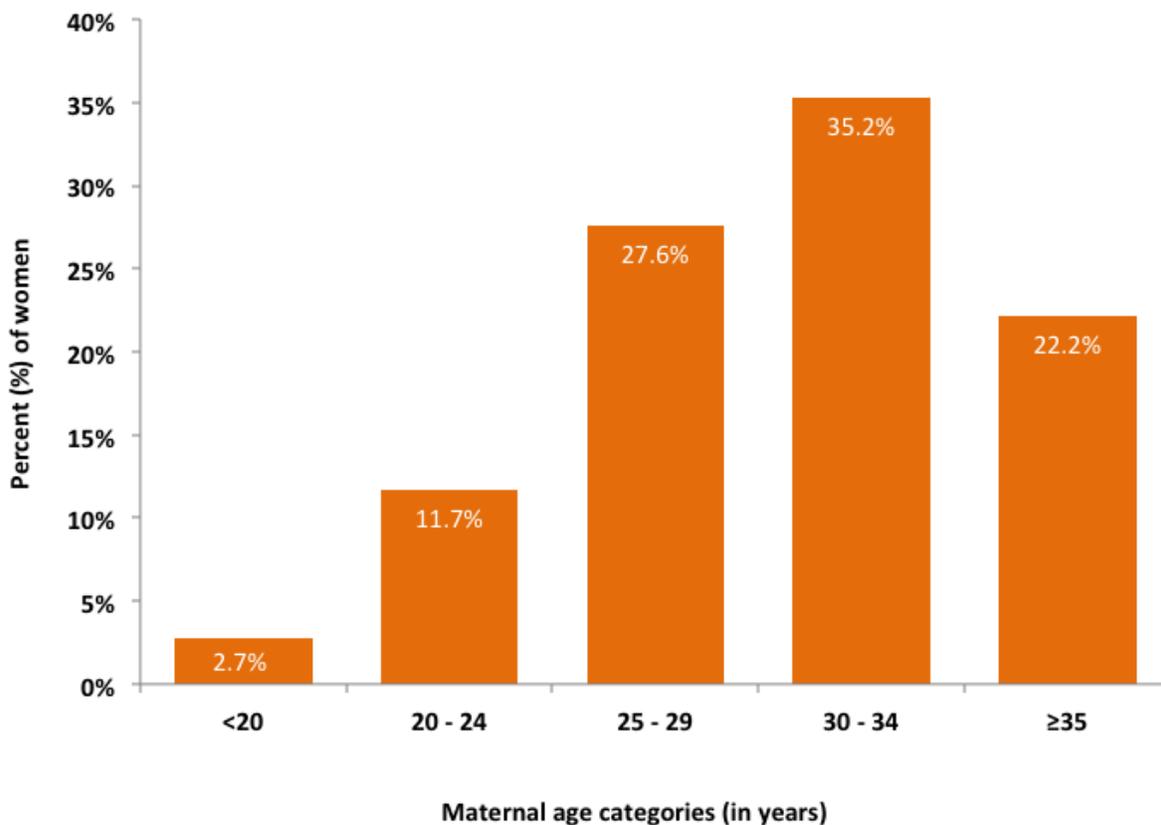
PREGNANCY

MATERNAL AGE

The highest proportion of births in the period 2012–2013 through 2013–2014 (35.2%) was to women 30–34 years of age. During the same time period, 2.7% of births were to teenage women and 22.2% were to women 35 years of age or older¹.

Over the past 5 years the average maternal age at birth has increased slightly from 29.9 to 30.4 years of age.

Figure 3: Distribution of Maternal Age
(Ontario, 2012–2013 to 2013–2014)



¹0.8% of records were excluded for missing data.

Data source

BORN Ontario, 2012–2013 to 2013–2014

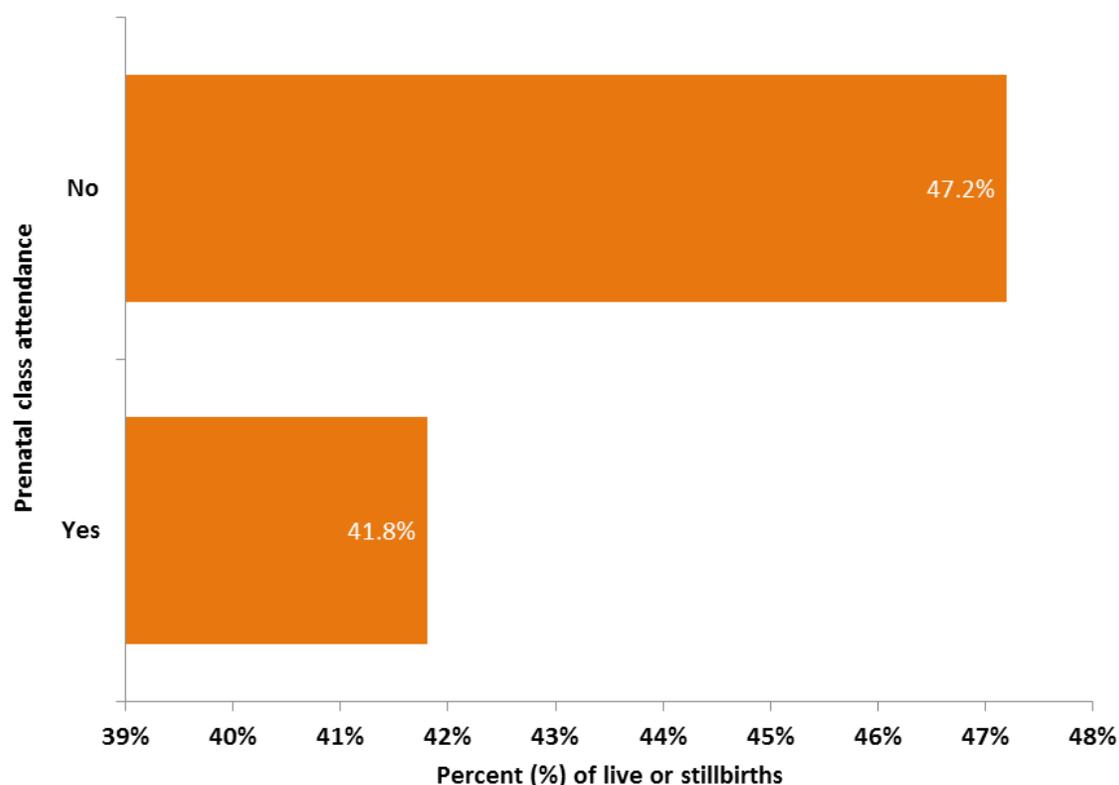
Definition of indicator

Distribution of categories of maternal age in years at the time of birth, expressed as a percentage of the total number of women who had a live birth or stillbirth.

PRENATAL CLASSES

Among all women who gave birth in 2012–2013 and 2013–2014, 25.7% of women reported attending prenatal classes²; however, among women having their first baby, the proportion was 41.8%.

Figure 4: Proportion of Nulliparous Women Who Attended Prenatal Classes
(Ontario, 2012–2013 to 2013–2014)



²9.8% of records were excluded for missing data.

Data source

BORN Ontario, 2012–2013 to 2013–2014

Definition of indicator

The number of nulliparous women who attended/did not attend prenatal classes during the current pregnancy (including online classes requiring enrollment or in-person classes), expressed as a percentage of the total number of nulliparous women who had a live birth or stillbirth.

PREGNANCY

PRENATAL SCREENING

The proportion of pregnant women in Ontario who had prenatal screening for their current pregnancy, and gave birth to a live or stillborn infant has increased slightly from 2009–2010 (66.9%) to 2013–2014 (69.8%). Access to prenatal screening in Ontario varies by geography, ranging from 27.0% in the North West LHIN to 82.0% in the Toronto Central LHIN for fiscal year 2013-2014.

Ontario's prenatal screening resources include laboratory and ultrasound testing, clinical assessment, genetic counselling and diagnostic testing. More than 95,000 pregnant women are screened annually. The related pregnancy and outcome data are captured in the BIS. This dataset is then used for the quality assurance of prenatal screening services. The data has also been used to support BORN's and PCMCH's prenatal screening committees and working groups. Starting later in 2014, BORN's new Prenatal Screening Quality Assurance Committee will advise on QA measures and reporting for prenatal screening performance in Ontario.

Table 2: Prenatal Screening by LHIN of Residence in Ontario* (Ontario, 2009–2010 to 2013–2014)

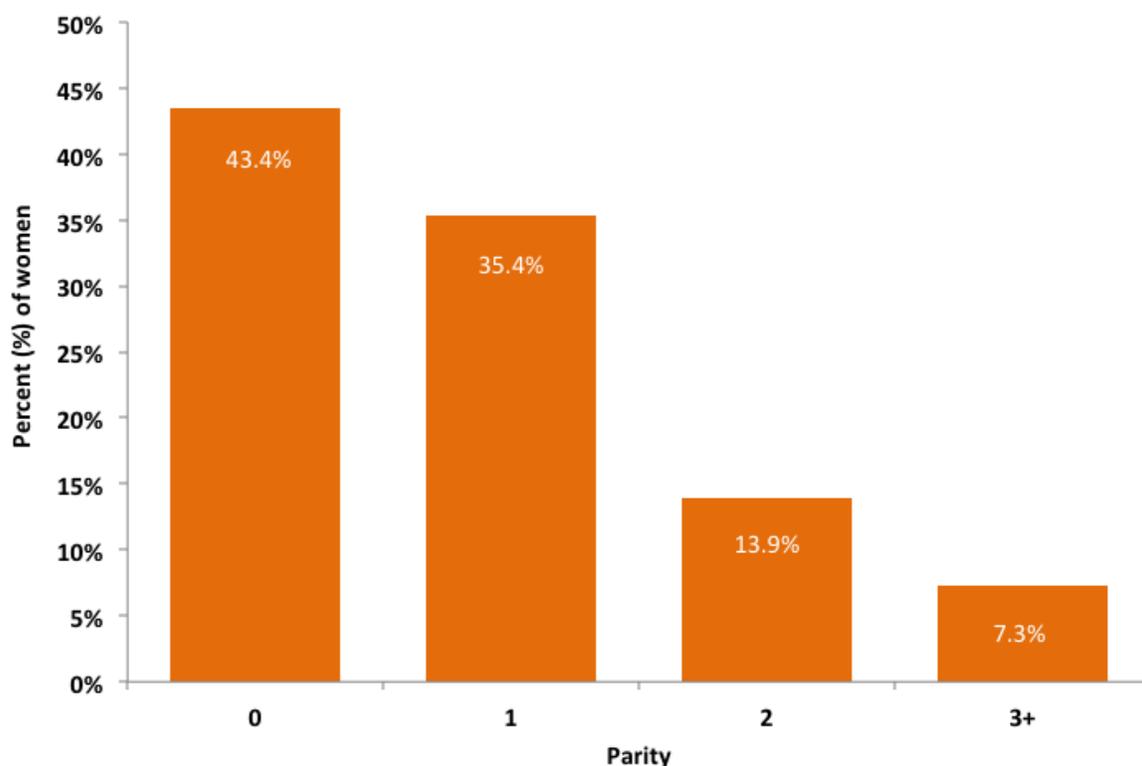
LHIN OF RESIDENCE	2012-2013	2013-2014
Erie St. Clair	40.4%	41.9%
South West	50.0%	50.4%
Waterloo Wellington	48.1%	49.2%
Hamilton Niagara Haldimand Brant (HNHB)	46.5%	50.3%
Central West	61.9%	71.8%
Mississauga Halton	61.7%	72.8%
Toronto Central	81.2%	82.0%
Central	81.3%	80.3%
Central East	71.5%	71.4%
South East	54.7%	55.5%
Champlain	64.3%	66.0%
North Simcoe Muskoka	46.5%	46.8%
North East	32.5%	35.5%
North West	27.3%	27.0%

**Prenatal screening rates are calculated using all available live births, still births, termination and pregnancy loss data in the BIS. However, not all terminations or pregnancy losses are captured completely in this data*

Number of Previous Births (Parity)

In 2012–2013 and 2013–2014 combined, 43.4% of women who gave birth in Ontario were first-time mothers (i.e. parity was 0)³. This proportion has been stable since 2011–2012.

Figure 5: Distribution of Parity
(Ontario, 2012–2013 to 2013–2014)



³1.7% of records were excluded for missing data

Data source

BORN Ontario, 2012–2013
to 2013–2014

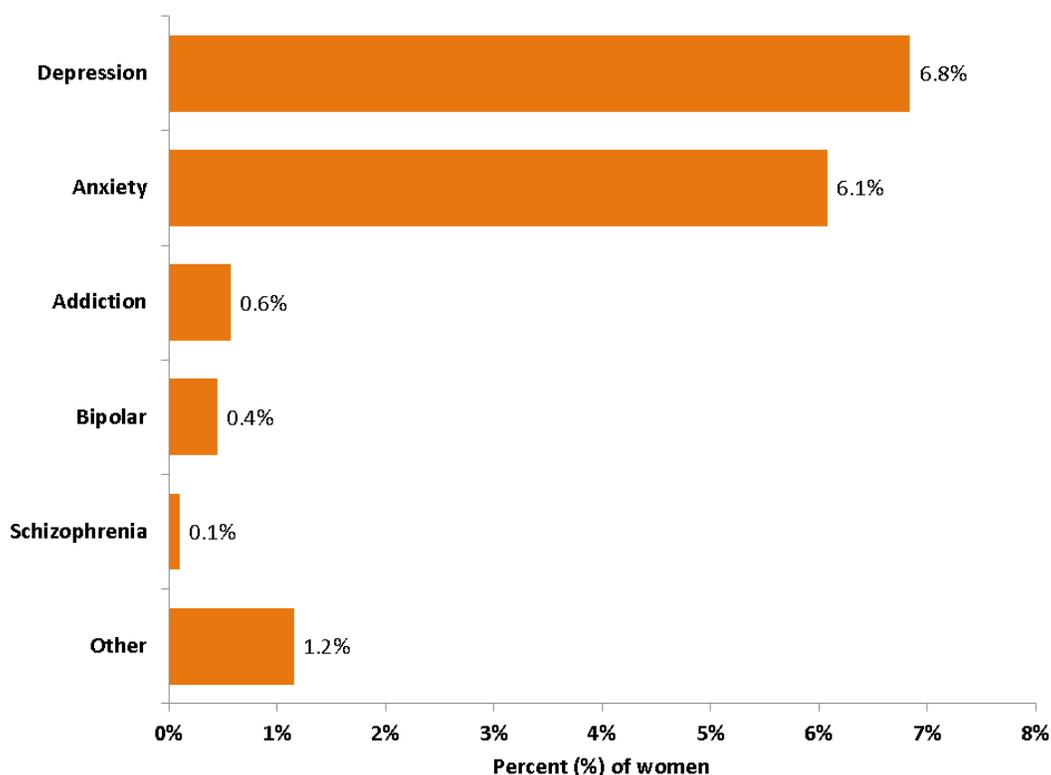
Definition of indicator

Distribution of parity, expressed as a percentage of the total number of women who had a live birth or stillbirth greater than or equal to 20 weeks' gestation. Parity is defined as the number of previous live births or stillbirths (0, 1, 2, 3+), excluding the current pregnancy.

MENTAL HEALTH CONCERNS

The proportion of women who gave birth in Ontario and reported mental health issues in the period 2012–2013 through 2013–2014 was 14.1%⁴. This included current disorders or a history of disorders such as anxiety or depression. Of women who reported mental health issues during their pregnancies in this time period, depression and anxiety were the most prevalent.

Figure 6: Rate of Mental Health Conditions Reported During Pregnancy
(Ontario, 2012–2013 to 2013–2014)



⁴6.5% of records were excluded for missing data.

Data source

BORN Ontario, 2012–2013 to 2013–2014

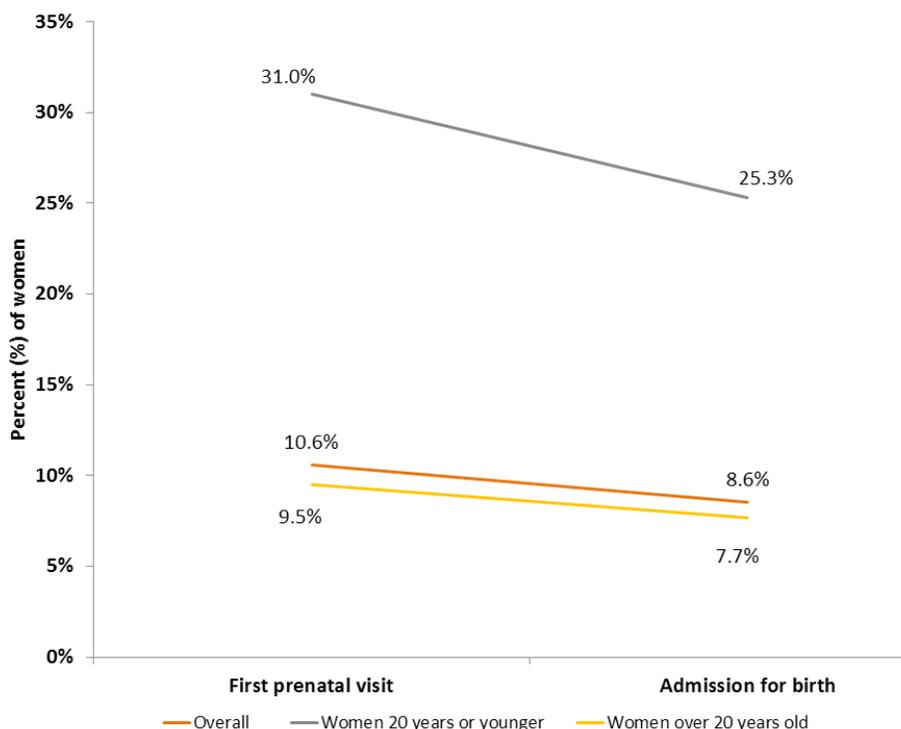
Definition of indicator

Rates of types of mental health conditions, expressed as a percentage of women who reported one or more mental health concerns during pregnancy. These categories are not mutually exclusive.

SMOKING DURING PREGNANCY

Overall, 10.6% of women in Ontario who gave birth in the interval 2012–2013 to 2013–2014 reported smoking at the time of their first prenatal visit⁵. However, almost a third of women under 20 (31.0%) reported smoking at the time of their first prenatal visit. By the time of admission for birth, however, this had decreased to 8.6% of women overall and 25.3% for women under 20⁶. While the total number of women who reported smoking during pregnancy decreased, the number of cigarettes reported by women who reported smoking at each point remained fairly constant.

Figure 7: Proportion of Women who Reported Smoking
(Ontario, 2012–2013 to 2013–2014)



⁵5.6% of records were excluded for missing data.

⁶2.8% of records were excluded for missing data.

Data source

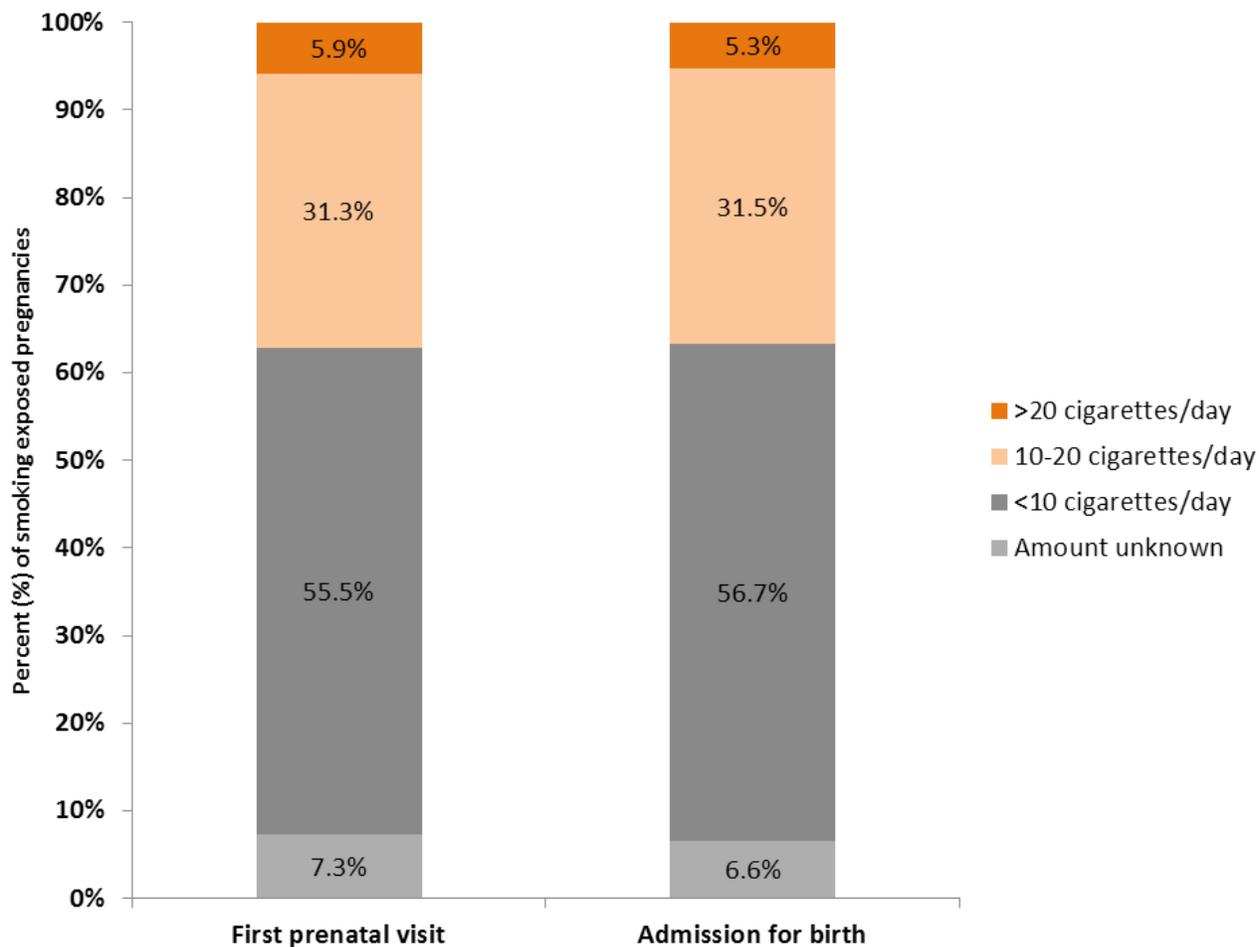
BORN Ontario, 2012–2013 to 2013–2014

Definition of indicator

Number of women who reported smoking at the first prenatal visit and at admission for birth, expressed as a percentage of the total number of women who had a live birth or stillbirth.

PREGNANCY

Figure 8: Distribution of Amount Smoked by Women who Self-Reported Smoking During Pregnancy (Ontario, 2012–2013 to 2013–2014)



Data source

BORN Ontario, 2012–2013 to 2013–2014

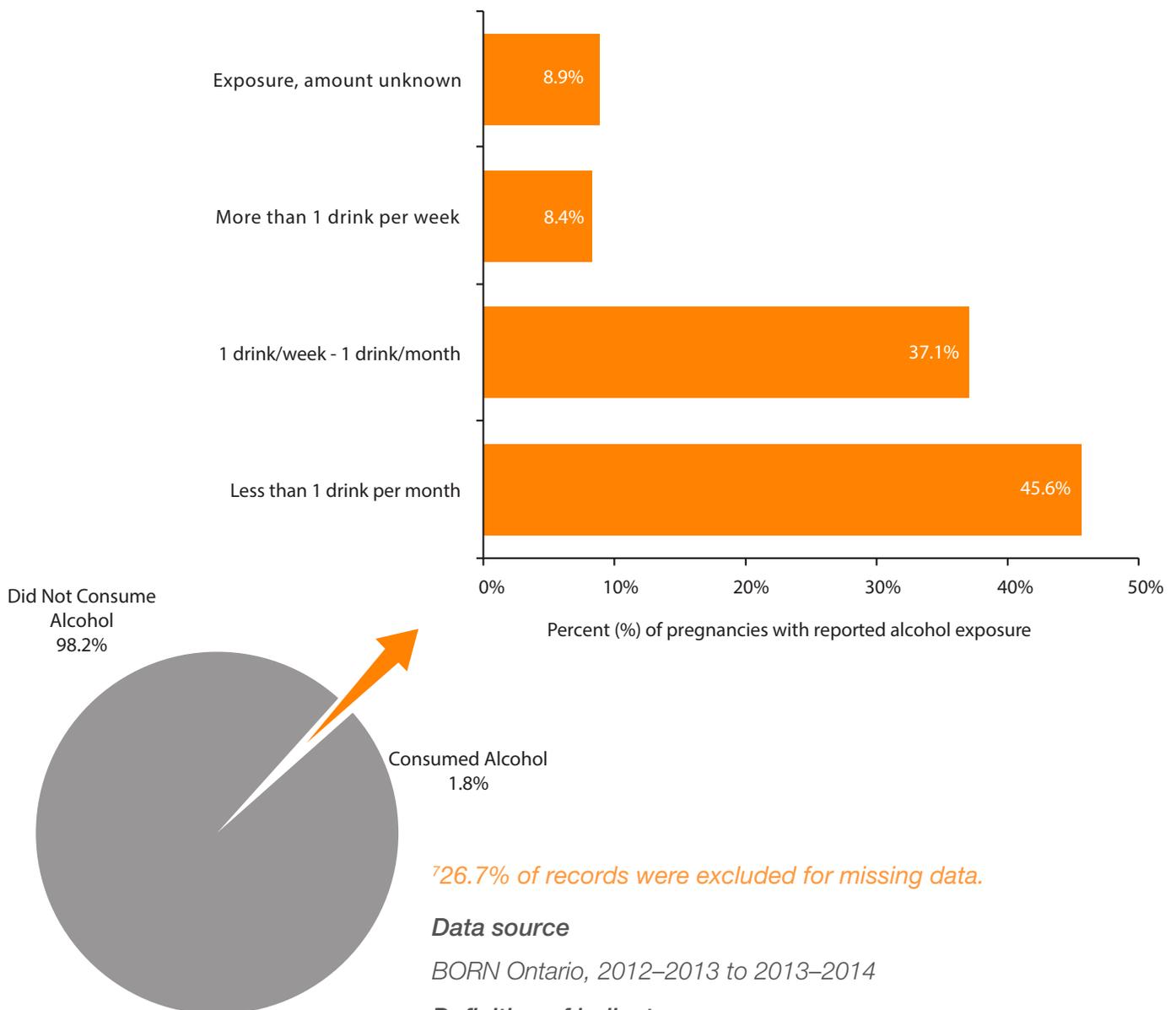
Definition of indicator

Distribution of amount smoked, expressed as a percentage of women who self-reported smoking during pregnancy.

ALCOHOL CONSUMPTION DURING PREGNANCY

The proportion of women in Ontario who reported consuming alcohol while pregnant was 1.8% in 2012–2013 and 2013–2014, combined⁷. Of these women, almost half (45.6%) reported having less than 1 drink per month.

Figure 9: Distribution of Amount of Alcohol Consumed by Women who Self-Reported Alcohol Consumption During Pregnancy (Ontario, 2012–2013 to 2013–2014)



⁷26.7% of records were excluded for missing data.

Data source

BORN Ontario, 2012–2013 to 2013–2014

Definition of indicator

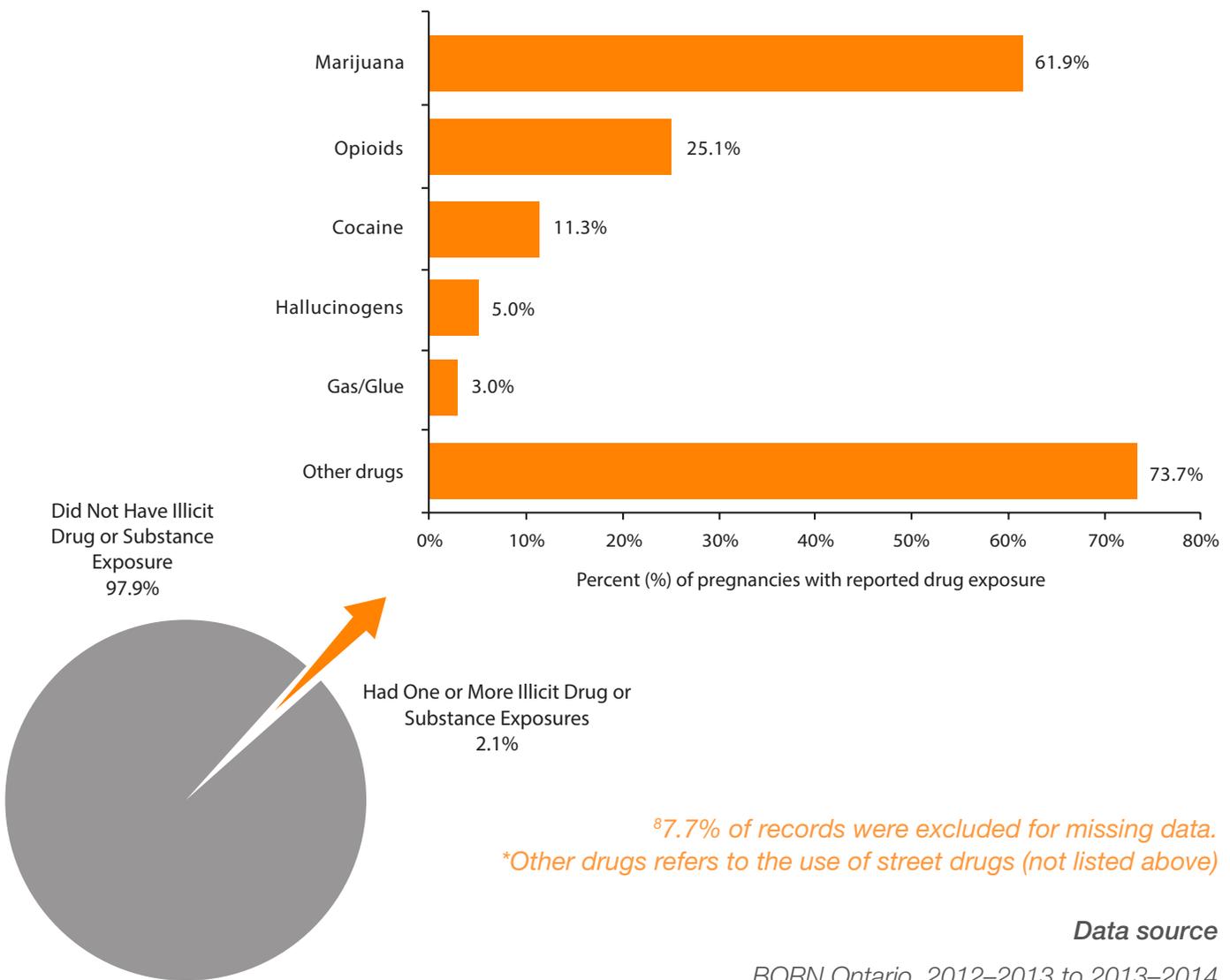
Distribution of amount of alcohol consumed, expressed as a percentage of women who reported consuming alcohol during their pregnancy.

PREGNANCY

Drugs and Substance Exposure

During 2012–2013 and 2013–2014 in Ontario, 2.1% of women reported having one or more illicit drug or substance exposure during their pregnancy⁸. Of these, 59.0% used only a single type of drug during their pregnancy, with the most common being marijuana (90.8% of women who reported using a single drug during pregnancy).

Figure 10: Distribution of Type of Illicit Drug and Substance Exposure by Women who Self-Reported Use* (Ontario, 2012–2013 to 2013–2014)



⁸7.7% of records were excluded for missing data.
 *Other drugs refers to the use of street drugs (not listed above)

Data source

BORN Ontario, 2012–2013 to 2013–2014

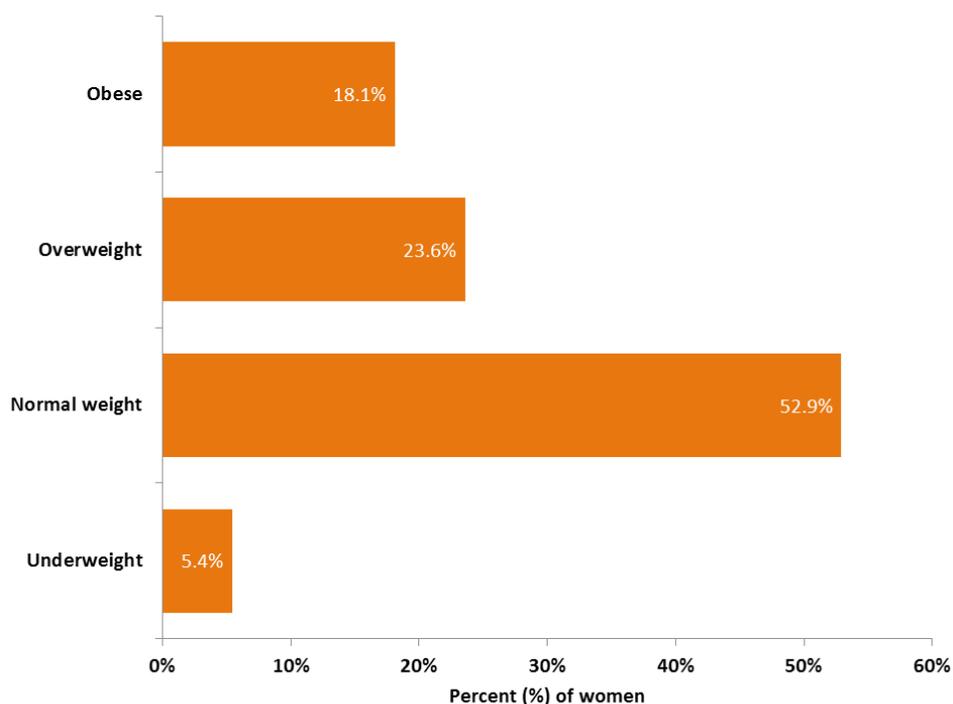
Definition of indicator

Distribution of type of drug or substance used, expressed as a percentage of women who reported using one or more drugs during their pregnancy.

Body Mass Index (BMI)

In 2012–2013 and 2013–2014 combined, just over half of women who gave birth had a normal body mass index (BMI) (18.5-24.9kg/m²) prior to pregnancy (52.9%)⁹. Over the same timeframe 41.7% of women were considered overweight or obese based on their pre-pregnancy BMI. The effects of obesity in pregnancy were described at the beginning of the ‘Pregnancy’ section. Additionally, rates of caesarean section are higher in obese women as described later in the ‘Birth’ section.

Figure 11: Distribution of Maternal Body Mass Index (BMI)
(Ontario, 2012–2013 to 2013–2014)



⁹26.7% of records were excluded for missing data.

Data source

BORN Ontario, 2012–2013 to 2013–2014

Definition of indicator

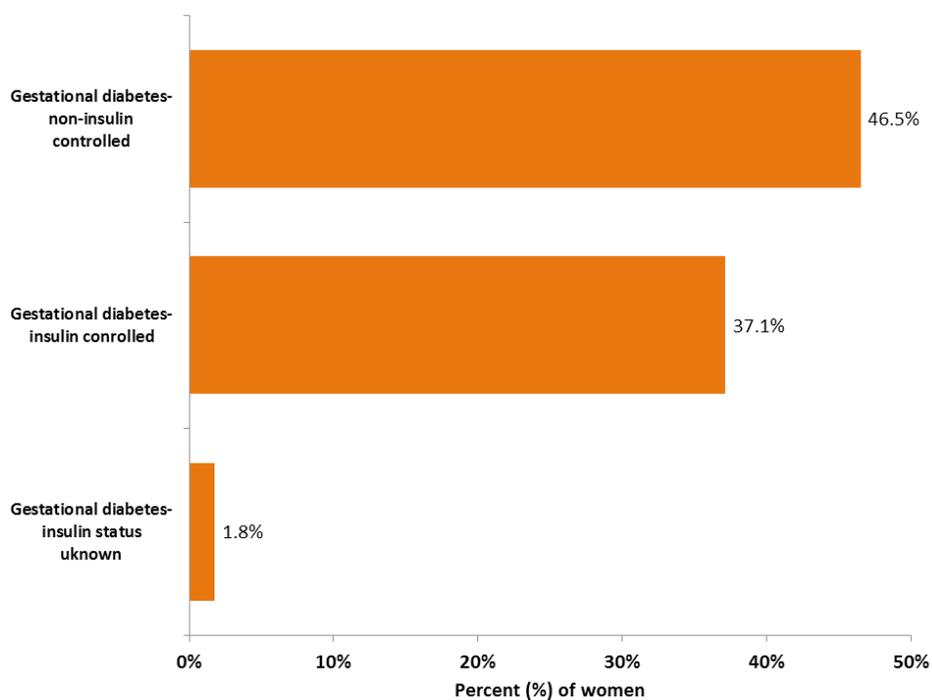
Distribution of Body Mass Index (BMI), expressed as a percentage of the total number of women who had a live birth or stillbirth. BMI categories were defined according to the World Health Organization (WHO) Guidelines as: underweight (<18.5 kg/m²), normal weight (18.5–24.9 kg/m²), overweight (25.0–29.9 kg/m²), and obese (30.0+ kg/m²)¹².

DIABETES AND PREGNANCY

During 2012–2013 and 2013–2014, 6.3% (16,906) of all Ontario women who gave birth had diabetes during their pregnancy. Almost 2/3 of women (63.0%) who reported diabetes during their pregnancy were overweight or obese prior to becoming pregnant. This rate was 4.0% in women with an underweight or normal weight BMI before pregnancy and 9.4% in women with an overweight or obese BMI before pregnancy.

Of the women who reported diabetes during their pregnancy, 85.9% (7,405) reported gestational diabetes, 9.1% (1,527) had type 2 diabetes and 5.0% (852) had type 1 diabetes. For the women with gestational diabetes, 46.5% controlled it without insulin, 37.1% used insulin to manage their diabetes and 1.8% reported unknown insulin status.

Figure 12: Distribution of Method of Insulin Control for Gestational Diabetes (Ontario, 2012–2013 to 2013–2014)



Data source

BORN Ontario, 2012–2013 to 2013–2014

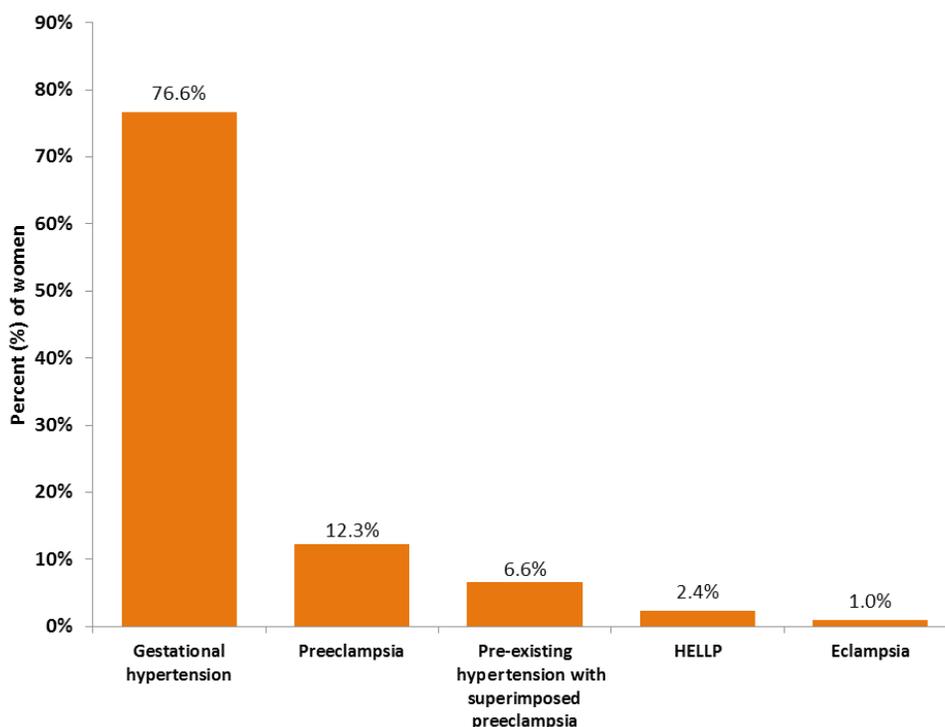
Definition of indicator

Method of insulin control for gestational diabetes, expressed as a percentage of the total number of women who had gestational diabetes.

HYPERTENSIVE DISORDERS OF PREGNANCY

In 2012–2013 to 2013–2014, 4.7% (12,961) of women who gave birth had some type of hypertensive disorder during pregnancy. Of these women, 76.6% (10,051) developed gestational hypertension, 12.3% (1,611) had preeclampsia, 6.6% (861) had pre-existing hypertension with super-imposed preeclampsia, 2.4% (309) had HELLP syndrome (hemolysis, elevated liver enzymes and low platelet counts), and 1.0% (129) had eclampsia.

Figure 13: Distribution of Type of Hypertension in Women with Diagnosed Hypertension during Pregnancy*
(Ontario, 2012–2013 to 2013–2014)



*Women could be diagnosed with more than one hypertensive disorder during their pregnancy

Data source

BORN Ontario, 2012–2013 to 2013–2014

Definition of indicator

Distribution of type of pregnancy hypertensive disorders, expressed as a percentage of the total number of women who reported having gestational hypertensive disorders.

DID YOU KNOW?

Our data quality assessments help to identify areas for improvement. For example up to 27% of women in Ontario are **NOT** asked about domestic violence despite recommendations by professional associations. To check how well your organization collects this information, log into the BIS and run the report entitled Encounter List – Birth Mother. If you see room for improvement, use this report to plan a quality improvement/monitoring initiative to address the issue.

CARTR

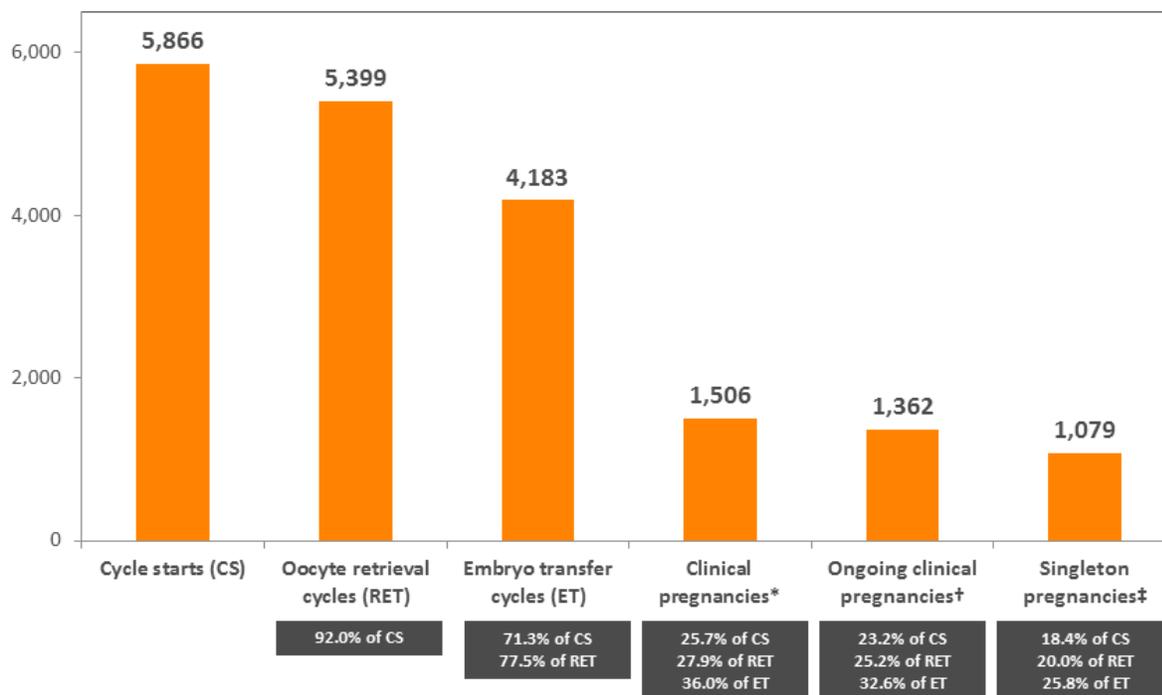
PLUS  Canadian Assisted Reproductive Technologies Register

In 2012, the medical directors of Canada's fertility clinics entered into an agreement with BORN Ontario to collect, analyze and report their clinics' in vitro fertilization cycles (IVF) data. Up until this point, the data was housed in the Canadian Assisted Reproductive Technologies Register (CARTR), which originated in 2001. Transitioning to BORN involved updating the registry to include additional data elements and to permit tracking of individual patients across IVF treatment cycles and pregnancies. Non-Ontario clinics manually enter their birth outcome data once it becomes available via the patient or provincial birth record.

Stage of Treatment and Treatment Outcomes – Fresh IVF with Own Oocytes

In 2013, there were 5,866 IVF treatment cycles started in Ontario. These treatment cycles resulted in 1,506 clinical pregnancies and 1,362 ongoing clinical pregnancies. Figures 14 and 15 demonstrate the progression from cycle start to pregnancy with fresh and frozen IVF cycles and the different outcomes along the continuum.

Figure 14: Stage of Treatment and Treatment Outcomes, Fresh IVF Cycles (Ontario, 2013)



Data source

CARTR Plus, 2013 (calendar year)

Definition of indicator

Distribution of treatment stage and outcomes for assisted reproductive technology (ART) cycles using fresh IVF with own oocytes.

Notes:

- * Documentation of a clinical intrauterine or ectopic pregnancy
- † Ongoing clinical pregnancy was defined as a clinical pregnancy with documentation of at least one fetal heart beat on ultrasound
- ‡ Singleton clinical pregnancy was defined as an ongoing clinical pregnancy with documentation of only one fetal heart beat on ultrasound

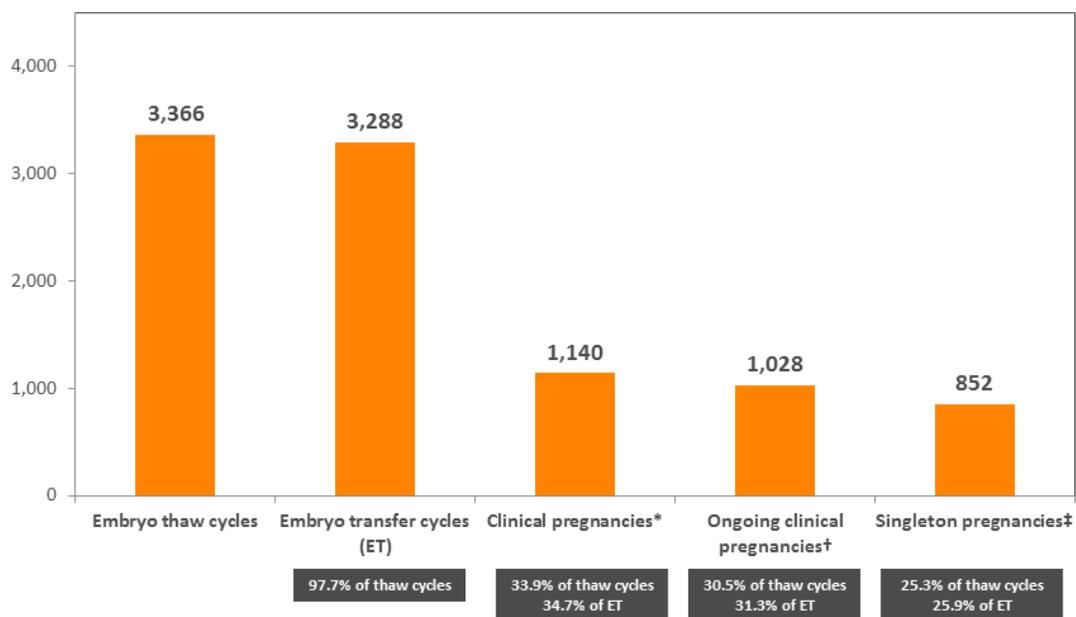
CS: cycle start; RET: cycle in which one or more oocytes was retrieved; ET: treatment cycle in which one or more embryos was transferred

PREGNANCY

Stage of Treatment and Treatment Outcomes – FET with Own Oocytes

In 2013, there were 3,366 Frozen Embryo Transfer (FET) cycles started with a patient's own oocytes. Only 78 cycles resulted in no embryo transfer cycle. These FET treatment cycles resulted in a 30.5% success rate for ongoing clinical pregnancies. Starting in the 2014–2015 fiscal year we will be able to report on live births.

Figure 15: Stage of Treatment and Treatment Outcomes, FET Cycles (Ontario, 2013)



Data source

CARTR Plus, 2013 (calendar year)

Definition of indicator

Distribution of treatment stage and outcomes for assisted reproductive technology (ART) cycles using frozen embryo transfer with own oocytes.

Notes:

- * Clinical pregnancy was defined as documentation of a clinical intrauterine or ectopic pregnancy
- † Ongoing clinical pregnancy was defined as a clinical pregnancy with documentation of at least one fetal heart beat on ultrasound
- ‡ Singleton clinical pregnancy was defined as an ongoing clinical pregnancy with documentation of only one fetal heart beat on ultrasound

Thaw cycle: a treatment cycle in which one of more previously frozen embryos were thawed with the intention to transfer; ET: treatment cycle in which one or more embryos was transferred

PRENATAL CARE – WHAT'S ON THE HORIZON?

ONTARIO ANTENATAL RECORD REVISION

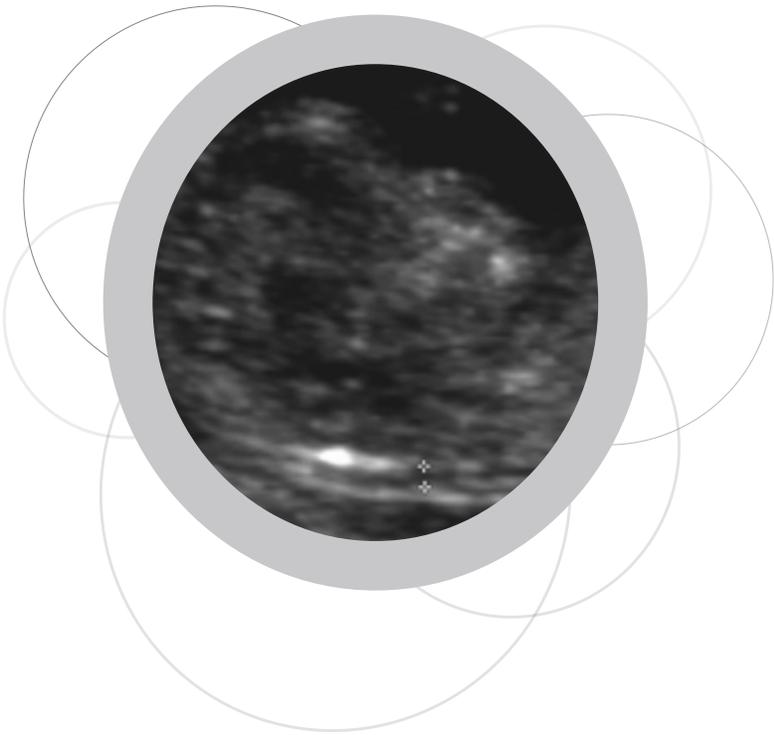
The Ontario Antenatal Record (OAR) is designed to provide vital information about the care provided in pregnancy, facilitate communication and highlight areas for follow-up. The current OAR was developed by the Ontario Medical Association (OMA) in conjunction with the Ministry of Health and Long-Term Care (MOHLTC) and has been in use since 1979 (last updated in 2005).

In 2012, BORN Ontario and eHealth Ontario identified an opportunity to improve care by enhancing the usability and functionality of the OAR. In this pilot project, the current paper forms were migrated into an electronic format using the OSCAR electronic platform and evidence links. Decision support pathways and reminders were added, thereby enhancing the OAR for clinicians. While the electronic enhancements were very positive, there was overwhelming feedback from care providers that the content of the forms also required revisions to

reflect current practice and evidence. Subsequently, BORN Ontario and the Provincial Council for Maternal and Child Health (PCMCH), in conjunction with the Ontario Medical Association (OMA) and the Association of Ontario Midwives (AOM) established a work group for this task.

The Enhanced Ontario Antenatal Record Work Group is comprised of a provincial panel of experts. The group is reviewing the current OAR, antenatal clinical pathways from other jurisdictions as well as evidence on prenatal care and will recommend specific evidence-informed content revisions. Once the content is determined, the Work Group will consult with experts in form development to implement changes for an updated OAR (both paper and electronic formats). Stay tuned for progress!

PREGNANCY



DID YOU KNOW?

In fiscal year 2012–2013 1,832 infants (1.3% of total live births) were born at less than 32 weeks gestation and needed intensive care services. In 2013–2014 this was similar at 1,610 infants (1.2% of total live births) born at less than 32 weeks' gestation.

NUCHAL TRANSLUCENCY QUALITY ASSURANCE

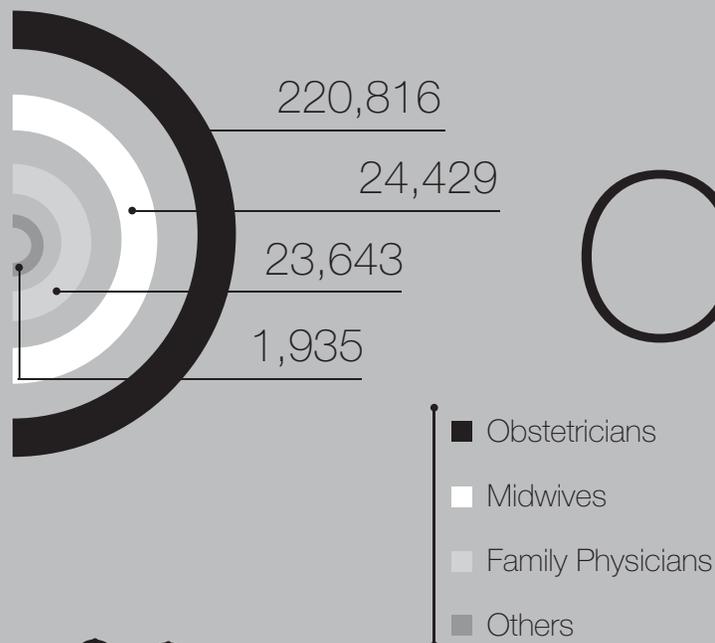
In 2013, BORN launched the Nuchal Translucency Quality Assurance (NTQA) report. Nuchal translucency (NT) is a fetal ultrasound measurement used in prenatal screening to help calculate the risk for Down syndrome. Regular self-monitoring and audit are essential to maintaining quality performance by sonographers and other providers conducting NT measurements.

Imaging professionals who have registered with BORN have access to their own individual NTQA report, which provides information on three quality metrics (bias, spread and trend). These metrics indicate how closely the plotted data approximate the expected Fetal Medicine Foundation curve.

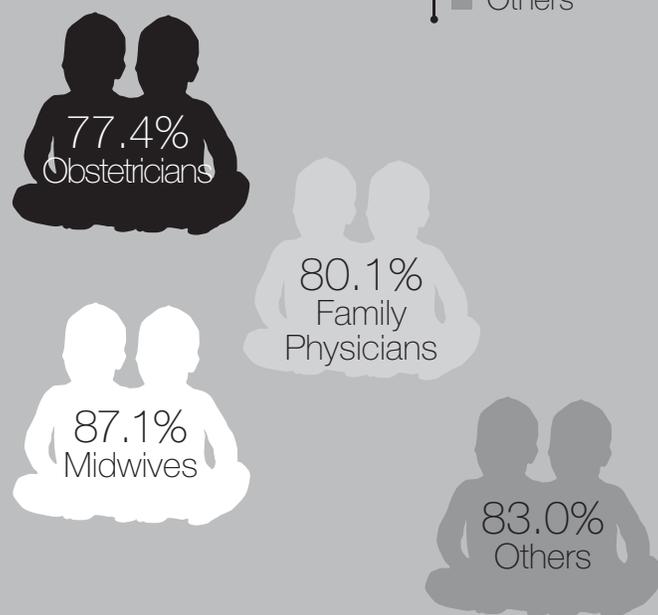
BORN is working with interested stakeholders to encourage widespread adoption of this report to inform related quality assurance activities.

Births in Ontario

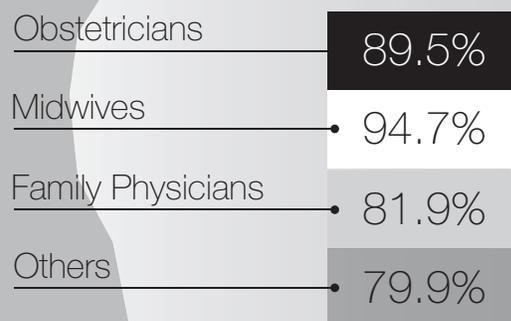
Birth numbers by type of health care provider



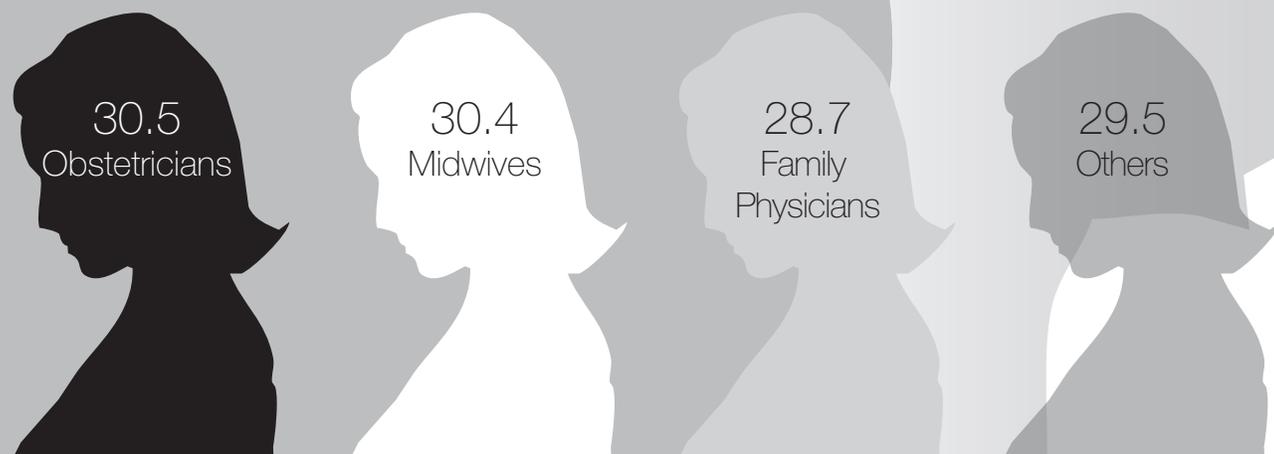
Proportion of women with a first trimester visit by type of care provider



Proportion of women who did not smoke during pregnancy



Average maternal age by type of care provider



BIRTH



SUCCESS STORY: USING THE MATERNAL NEWBORN DASHBOARD TO FACILITATE CHANGE

The BORN Maternal Newborn Dashboard (MND) was implemented in November 2012 in all Ontario hospitals providing maternal newborn services. The MND interface allows hospitals to view their performance in relation to the established Key Performance Indicator (KPI) benchmarks and make comparisons with hospitals of similar birth volume and level of care. Since implementation, many hospitals are using the MND regularly to support quality improvement activities related to the KPIs. In the sixteen months following implementation (December 2012–March 2014), measurable improvements have been noted in many of the KPIs, however, the gap between current provincial performance and established benchmarks for some of the KPIs remains large. Given the relatively recent introduction of the MND and the longer timeframe expected to see systematic change across the province, we expect to see continued improvement as we continue to monitor these indicators.

At the beginning, many sites were green for various KPIs. However, it is worth mentioning the hard work by some sites across the province to address their practice gaps. Of note: since the launch of the MND, forty-four hospitals (45.4%) improved their rates for at least one KPI moving from a red or yellow signal to green. Twelve hospitals (12.4%) moved from red or yellow to green on two KPIs. Five hospitals achieved green status for three KPIs and one site implemented improvements and achieved a green signal across four of the KPIs.

The most improved KPIs based on number of sites moving from red or yellow to green are:

- KPI 1 Proportion of newborn screening samples that were unsatisfactory for testing (20 sites)
- KPI 5 Proportion of women who delivered at term and had Group B Streptococcus (GBS) screening at 35-37 weeks' gestation (19 sites)
- KPI 6 Proportion of women who were induced with any indication of post-dates and were less than 41 weeks' gestation at delivery (16 sites)
- KPI 3 Rate of formula supplementation from birth to discharge in term infants whose mothers intended to exclusively breastfeed (13 sites)
- KPI 4 Proportion of women with a caesarean section performed from ≥ 37 to < 39 weeks' gestation among low-risk women having a repeat caesarean section at term (11 sites)
- KPI 2 Rate of episiotomy in women who had a spontaneous vaginal birth (10 sites)

Further exploration of these KPIs and feedback from users has revealed particular challenges and persisting barriers to change. While audit and feedback does not guarantee individuals or institutions will make practice changes to support quality improvement, it is an important first step since practice change will not occur without an awareness of the issues. With the development and implementation of the Ontario MND now complete, a formal evaluation of factors that are predictive of effective use of the MND to improve practice is underway (funded through a CIHR Operating Grant and MOHLTC Health Services Research Fund Capacity Award).

BIRTH

BIRTHS IN ONTARIO

Total number and location of births to Ontario residents, 2012–2013 and 2013–2014

Table 3: Total Number of Births to Ontario Residents

LOCATION OF BIRTH	2012-2013		2013-2014	
HOME	3563	2.5%	3,705	2.6%
HOSPITAL	137,206	97.0%	135,871	97.1%
BIRTH CENTRE*	N/A		42	0.0%
OTHER†	681	0.5%	336	0.2%
MISSING	11	0.0%	15	0.0%
TOTAL ONTARIO BIRTHS	141,461		139,969	

Data source

BORN Ontario, 2012–2013 to 2013–2014

Definition of indicator

Total number of live and stillbirths in Ontario by location of birth recorded on the birth record.

Notes:

* Birth Centres opened in Ontario in February 2014

† The 'Other' category includes unexpected out of hospital births, including those occurring at a nursing station

LHIN OF BIRTH

In 2012–2013 to 2013–2014, 81.0% of Ontario mothers gave birth in a hospital in the Local Health Integration Network (LHIN) in which they resided.

Table 4: Total Number of Births (Live Births and Stillbirths) to Ontario Residents, by LHIN of Birth 2012-1013 and 2013-2014

LHIN OF BIRTH	NUMBER OF BIRTHS			
	2012-2013		2013-2014	
1 ERIE ST. CLAIR	6,130	4.3%	6,010	4.3%
2 SOUTH WEST	9,844	7.0%	9,907	7.1%
3 WATERLOO WELLINGTON	8,438	6.0%	8,469	6.1%
4 HAMILTON NIAGARA HALDIMAND BRANT	13,362	9.4%	13,422	9.6%
5 CENTRAL WEST	11,068	7.8%	10,716	7.7%
6 MISSISSAUGA HALTON	11,746	8.3%	11,603	8.3%
7 TORONTO CENTRAL	13,594	9.6%	13,530	9.7%
8 CENTRAL	19,309	13.6%	18,347	13.1%
9 CENTRAL EAST	15,916	11.3%	15,489	11.1%
10 SOUTH EAST	4,341	3.1%	4,447	3.2%
11 CHAMPLAIN	13,358	9.4%	13,433	9.6%
12 NORTH SIMCOE MUSKOKA	4,086	2.9%	4,018	2.9%
13 NORTH EAST	5,348	3.8%	5,422	3.9%
14 NORTH WEST	2,538	1.8%	2,501	1.8%
MISSING DATA	2,383	2.5%	2,654	1.9%
ONTARIO	141,461		139,969	

Data source

BORN Ontario, 2012–2013 to 2013–2014

Definition of indicator

Total number of live and stillbirths in Ontario by LHIN of residence, based on the postal code of the mother at the time of delivery.

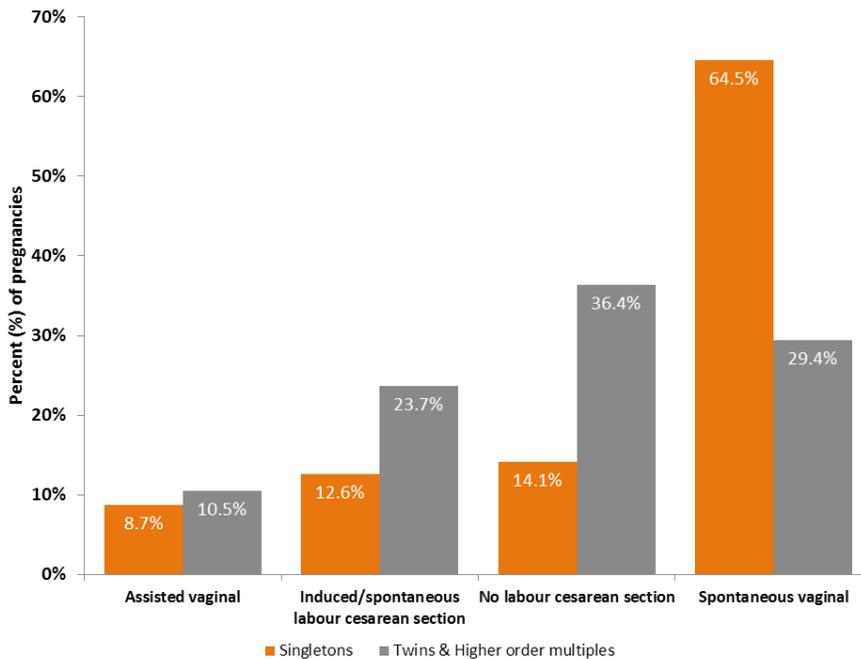
DELIVERY TYPE BY PLURALITY

In 2012–2013 to 2013–2014, 3.7% of infants born in Ontario were twins or higher-order multiples. The average gestational age for a multiple pregnancy was 35 weeks, compared to 38 weeks for singleton pregnancies. In addition to being born earlier, the distribution of birth type differs between multiples and singletons with 64.5% of singleton pregnancies being delivered vaginally while only 29.4% of multiples are delivered this way.

DID YOU KNOW?

Provincially in fiscal year 2012–2013 62.9% of infants were exclusively breastfed at discharge from hospital. In fiscal year 2013–2014 this rate was similar at 63.5%.

Figure 16: Distribution of Delivery Type for Twins and Singletons (Ontario, 2012-2013 to 2013-2014)



Data source

BORN Ontario, 2012–2013 to 2013–2014

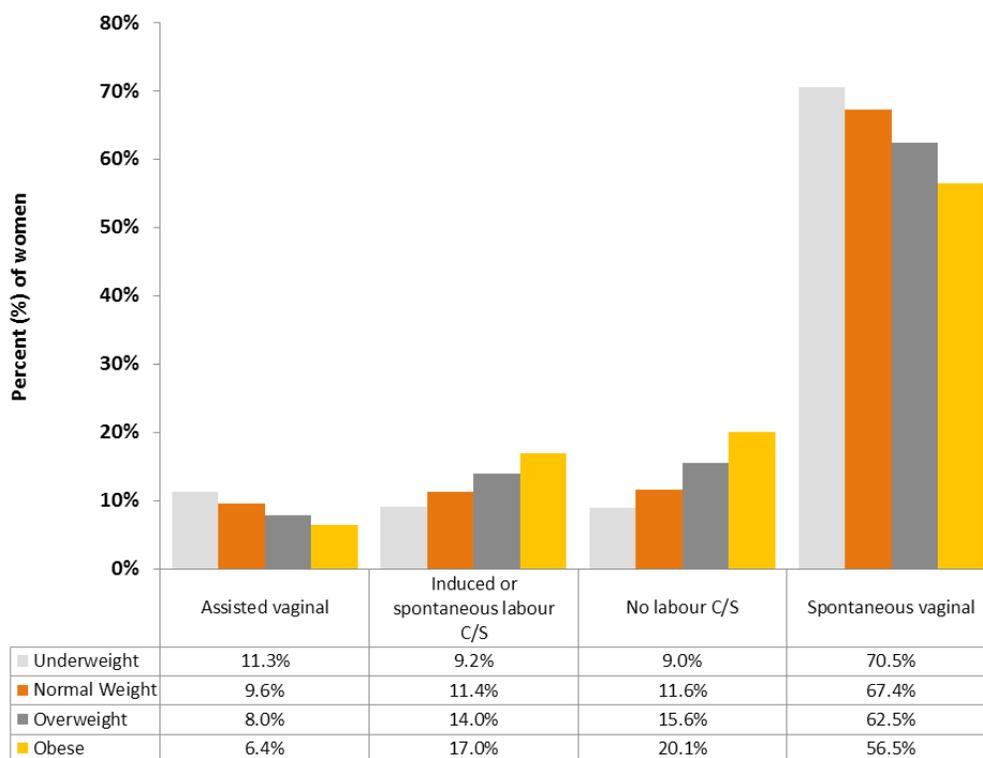
Definition of indicator

Distribution of mode of delivery for multifetal pregnancies, expressed as a percentage of the total number of live and still births.

DELIVERY TYPE BY BMI

In addition to varying by plurality of the pregnancy, delivery type also varies by BMI. Women with the lowest BMIs (underweight or normal weight) have the highest rates of spontaneous and assisted vaginal births, and have lower rates of cesarean delivery than women with higher pre-pregnancy BMIs. Conversely, obese women have almost twice the rate of cesarean delivery compared to their normal weight peers.

Figure 17: Distribution of Delivery Type by Maternal BMI Categories
(Ontario, 2012-2013 to 2013-2014)



Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

Distribution of mode of delivery by maternal BMI category, expressed as a percentage of the total number of women in each BMI category. BMI categories were defined according to the World Health Organization (WHO) Guidelines as: underweight (<18.5 kg/m²), normal weight (18.5–24.9 kg/m²), overweight (25.0–29.9 kg/m²), and obese (30.0+ kg/m²)¹⁰.

¹⁰Physical Status: The Use and Interpretation of Anthropometry. WHO Technical Report Series: 854. World Health Organization, Geneva, 1995.

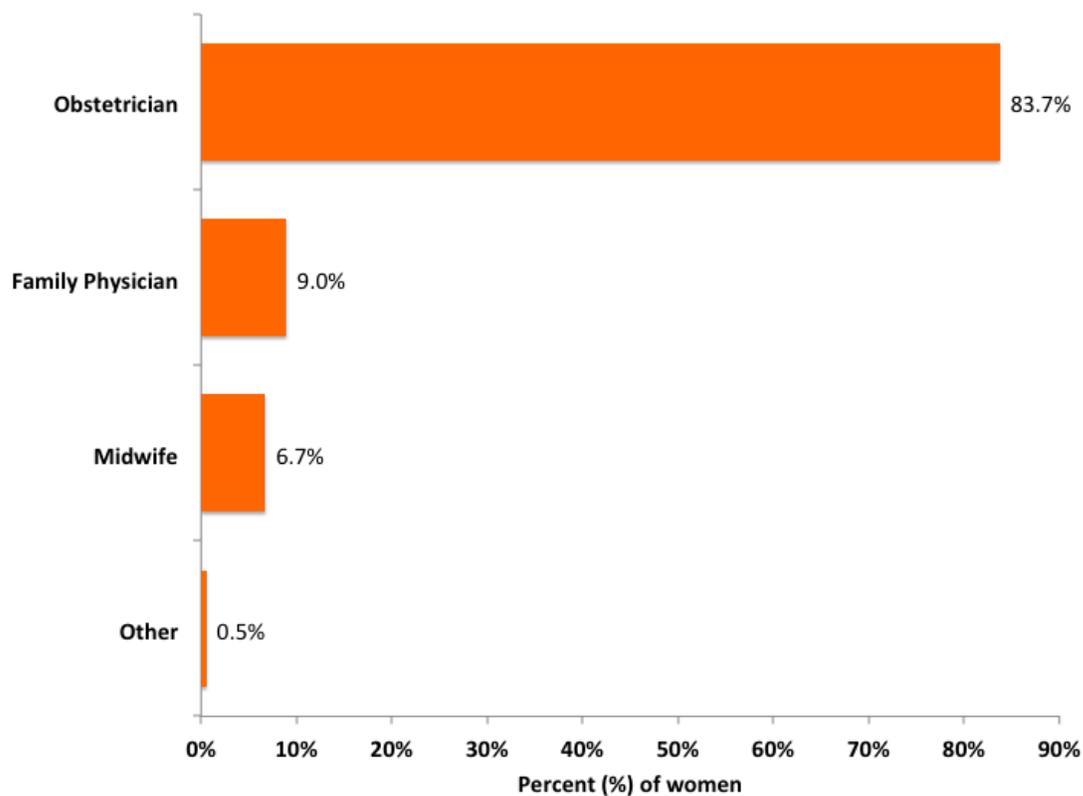
BIRTH

Attending Healthcare Provider

In the interval from 2012–2013 to 2013–2014, obstetricians attended the births of 83.3% of Ontario women¹¹. This figure remained relatively unchanged between 2007–2008 and 2013–2014, ranging between 83.3% and 85.8%.

The proportion of births attended by a midwife has increased steadily since 2011–2012. Midwife-attended births shown in Figure 19 include both hospital and home births.

Figure 18: Distribution of Type of Health Care Provider who Attended the Hospital Birth (Ontario, 2012-2013 to 2013-2014)



¹¹2.9% of records were excluded for missing records.

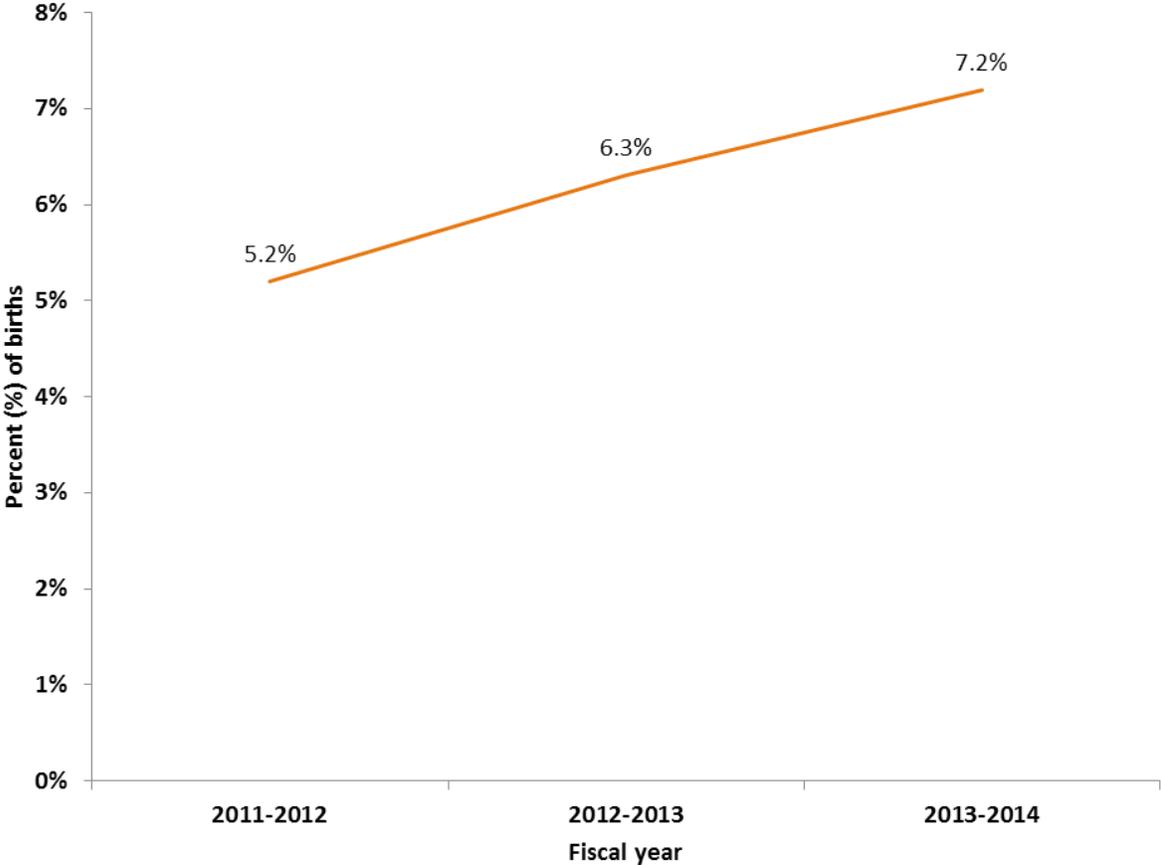
Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

Distribution of type of health care provider who attended the birth, expressed as a percentage of the total number of women who gave birth in hospital.

Figure 19: Percentage of Midwifery-Attended Hospital Births
(Ontario, 2012-2013 to 2013-2014)



Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

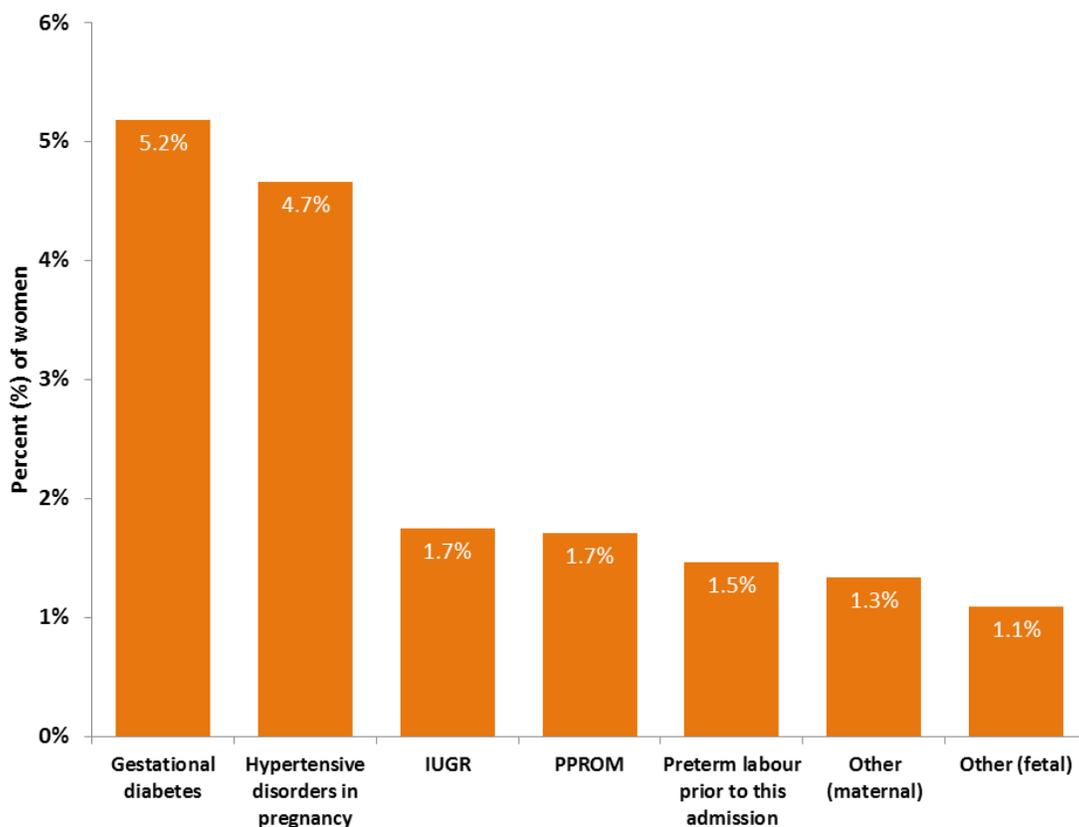
The number of hospital births attended by one or more midwives, expressed as a percentage of the total number of women who gave birth in hospital.

BIRTH

Obstetrical Complications

In 2012–2013 to 2013–2014, 20.1% of women in Ontario had one or more obstetrical complications. The most common obstetrical complications were gestational diabetes (5.2%), hypertensive disorders of pregnancy (4.7%), fetal intrauterine growth restriction (IUGR) (1.7%), preterm prelabour rupture of membranes (PPROM) (1.7%) and preterm labour prior to admission (1.5%)¹².

Figure 20: Distribution of Obstetrical Complications in Pregnancy
(Ontario, 2012-2013 to 2013-2014)



¹²4.4% of records had missing values for obstetrical complications

Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

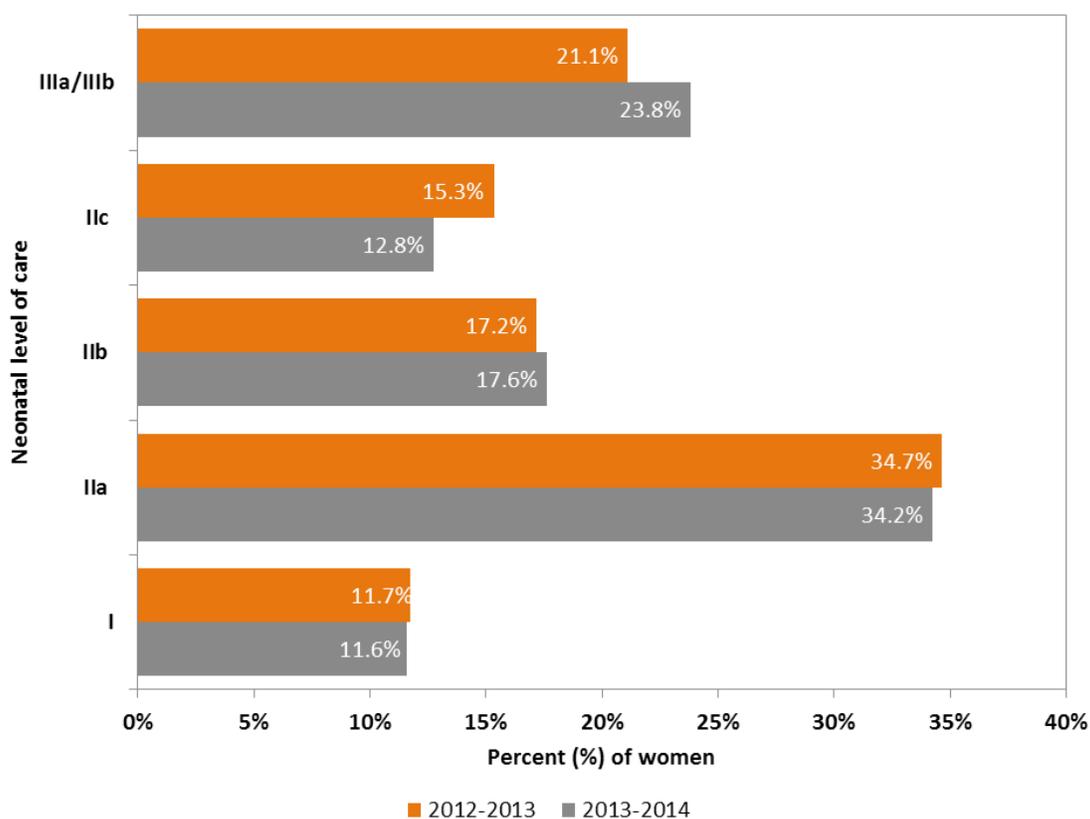
Distribution of obstetrical complications, expressed as a percentage of the total number of women who had a live or stillbirth

Level of Care

As of April 1, 2012 an updated hospital level of care classification system was introduced in Ontario by the Provincial Council for Maternal and Child Health (PCMCH). Subdivisions of the traditional levels (1, 2 & 3) were created.

Across Ontario, the largest volume of live births took place in Level II hospitals (67.2% in 2012–2013 and 64.6% in 2013–2014), followed by Level III hospitals (21.1% in 2012–2013 and 23.8% in 2013–2014) and then Level I hospitals (11.6% in 2012–2013 and 11.7% in 2013–2014).

Figure 21: Distribution of Hospital Live Births by Level of Care
(Ontario, 2012-2013 to 2013-2014)



Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

Distribution of hospital live births at each level of care, expressed as a percentage of the total number of live births.

DID YOU KNOW?

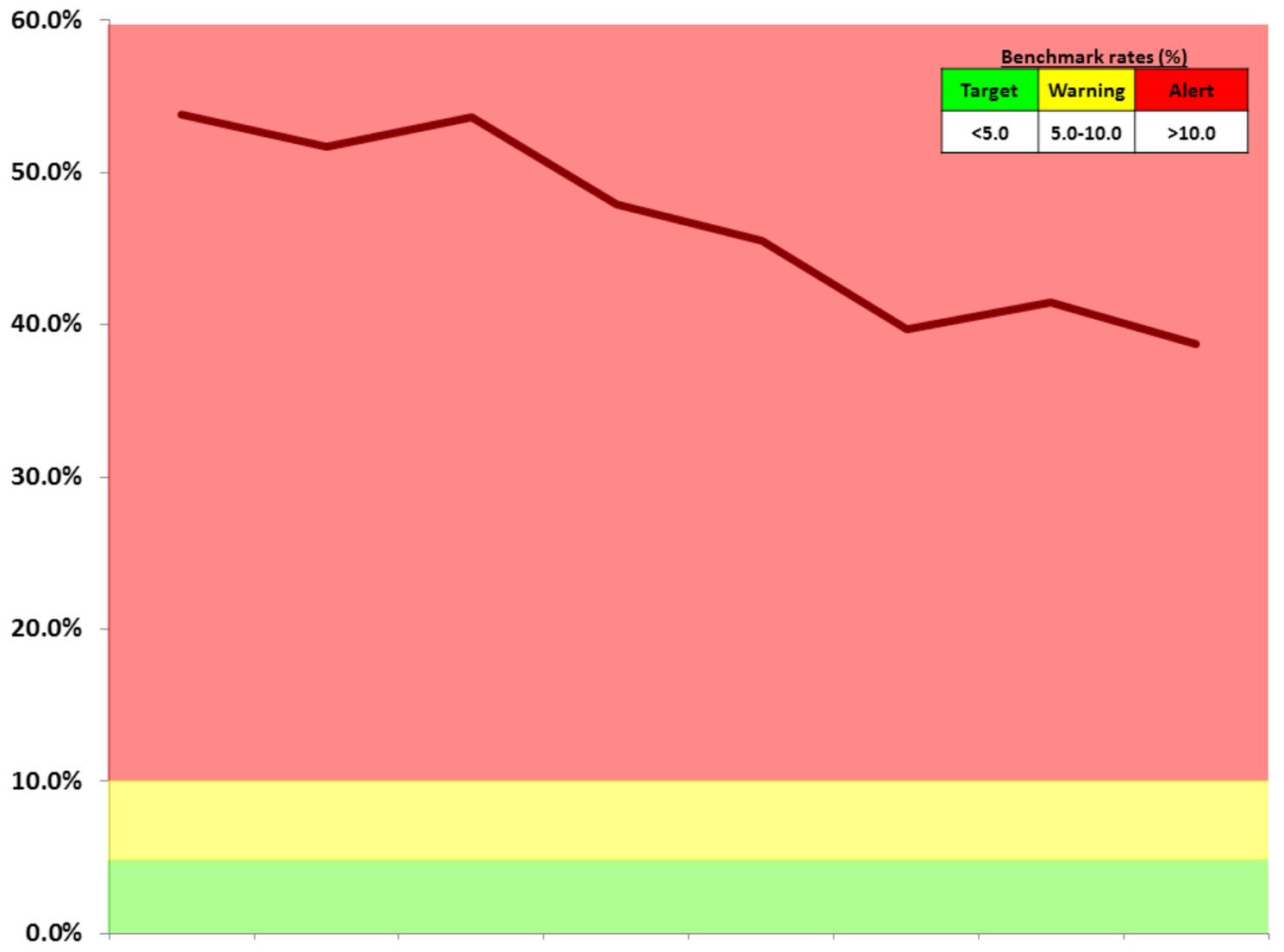
Ontario midwives provided care to 17,673 women in fiscal year 2012–2013 and 18.8% of midwifery clients gave birth at home. This increased in fiscal year 2013–2014 with midwives providing care to 19,417 women but with a consistent proportion of their clients giving birth at home (17.9%). This has been stable since fiscal year 2003–2004.

EVALUATION OF ONTARIO'S BIRTH CENTRE DEMONSTRATION PROJECT

In November of 2012, BORN Ontario established a multi-disciplinary working group to develop (and subsequently conduct) a mixed methods evaluation of the Ministry of Health and Long-Term Care's (MOHLTC) Birth Centre Demonstration Project. This project, part of Ontario's Action Plan for Health Care, funded two midwifery-led out-of-hospital birth centres in Ottawa and Toronto, in support of providing the "Right Care at the Right Time in the Right Place."

The Evaluation Working Group established the evaluation framework focusing on quality indicators, client experience, integration with the wider maternal child health community and economic analysis. Data collection began on opening day, February 4, 2014, and was to continue for one year.

To supplement data from the BORN Information System, the BORN-led working group designed a client-experience tool for completion by women in midwifery care during the pilot year – those planning a birth-centre birth as well as those intending to give birth with midwives at home or in hospital. The group also planned to carry out focus groups in hospitals that accepted transfers from each birth centre. Once analysis is complete, BORN will deliver a full evaluation report to the MOHLTC.



KPI 4:

The proportion of women in Ontario with a caesarean section performed from ≥ 37 to < 39 weeks' gestation among low-risk women having a repeat caesarean section at term

April 2012 to March 2014, by quarter.

CHILDREN



SUCCESS STORY: REDUCING RISK FACTORS FOR GESTATIONAL WEIGHT GAIN

BORN, eHealth Ontario and the Ministry of Children and Youth Services, have been working together to collect and integrate information directly from primary care electronic medical records (EMRs), namely from Family Health Teams (FHTs). Working with two EMR vendors (OSCAR EMR and QHR Technologies in the pilot phase), BORN was able to successfully collect health information on children receiving their 18-month enhanced well-baby check-up. Information included attainment of developmental milestones, exposure to environmental and nutritional risk factors as well as vaccination status. All of this was done with little change in the workflow of the primary care provider.

This project was also an important indicator of BORN's ability to create a longitudinal record for the Ontario-born children whose births were entered into the BORN Information system (BIS). Between October 2013 and December 2014 more than 1,000 records of children aged 16-24 months who had an 18-month well-baby visit were collected by BORN via FHT EMRs. Of those records, 95.5% matched an existing BORN-held birth record. This is a positive indication of the system's ability to link records for the same child despite a significant time lapse and the possibility of demographic information like name or address changing during that period.

Looking to the future, in 2015 with the help of our partners, two important expansions of the pilot will take place. Firstly, the eHealth Ontario Health Information Access Layer (HIAL) will be used to transmit the data from the EMR to BORN. This provincially-standardized method of exchanging health information will improve our ability to scale up data collection across the province. Secondly, the project scope will expand to more FHTs and more provider visits - all well-baby visits from age 0-5. It is anticipated that in fiscal year 15-16, more than 4,000 records from these visits will be captured via the HIAL.

GROWTH AT 18-MONTHS

As part of the 18-month well-baby checkup, physicians collect height and weight measurements for children. Data from our pilot project allowed us to bring these data into the BIS and link them to weight and gestational age measurements at birth. This data is from a small sample of children in the province and not necessarily generalizable to all Ontario children.

For this analysis, size at birth according to gestational age and sex was classified as being in the top or bottom 10 percent,

DID YOU KNOW?

As part of its direct-to-consumer mobile health strategy, BORN launched the OMama Project in early 2014. A two-year project supported by eHealth Ontario, OMama is building a website and mobile phone app. OMama will scope the necessary components of a personal health record to enable women to engage with trusted maternal and newborn health information/resources. For more information, contact

omama@bornontario.ca

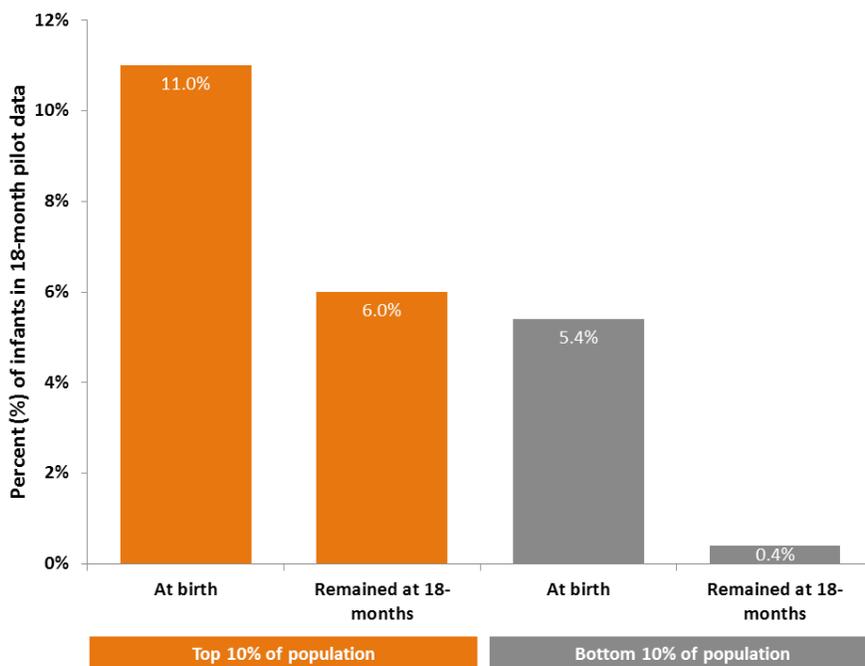


CHILDREN

using a Canadian reference standard¹³, while size at 18-months was classified similarly, using the World Health Organization's sex-specific Child Growth Curves¹⁴.

Interestingly, approximately half of the infants who weighed above the 90th percentile for their gestational age and sex at birth remained in the top 10% for size at 18-months, while among the infants classified in the lowest 10% for size at birth, only 7% remained in the lowest 10% for size by 18 months. While we would need a larger sample of 18-month weight data to draw conclusions about infant growth patterns for the province, many of the infants born large are remaining large through their first 18 months. Having more of this data in future will allow us to monitor trends in childhood weight as they grow up.

Figure 22: Infant Weight from Birth to 18-Months
(Ontario, 2012-2013 to 2013-2014)



Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

Proportion of children in the 18-month well baby visit pilot data who were in the top and bottom 10% standardized for their age and sex at birth and remained in the top 10% at 18 months, expressed as a percentage of the total number of children in the 18-month well baby visit pilot who linked to a birth record in the BIS.

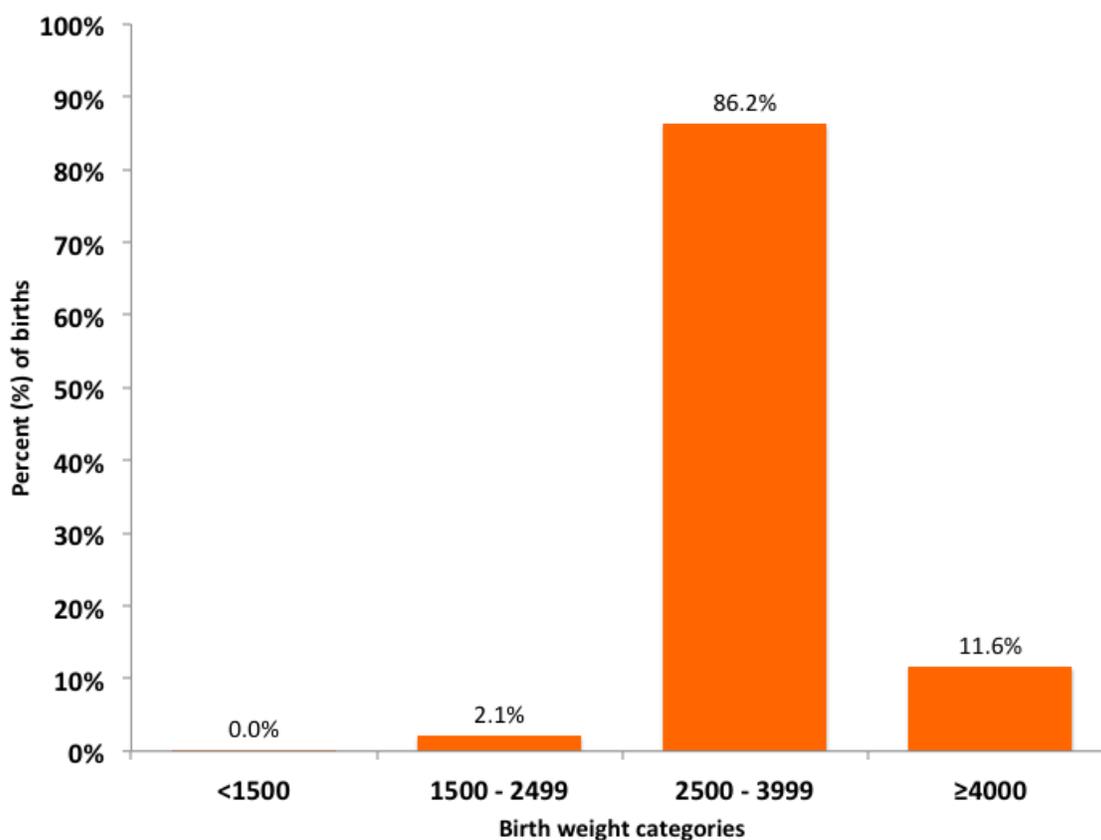
¹³Kramer, MS, et al. A New and Improved Population-Based Canadian Reference for Birth Weight for Gestational Age. *Pediatrics*. 108(2): 2001. 35-42.

¹⁴Dietitians of Canada. WHO Growth Charts. <http://www.dietitians.ca/Dietitians-Views/Prenatal-and-Infant/WHO-Growth-Charts.aspx> [Accessed: 5 June 2015].

BIRTH WEIGHT

In 2012–2013 to 2013–2014, the majority of live born infants (86.2%) weighed between 2,500 and 3,999 grams, which is consistent with data from 2011–2012 (82.6%).

Figure 23: Distribution of Birth Weight
(Ontario, 2012-2013 to 2013-2014)



Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

Distribution of birth weight in grams, expressed as a percentage of the total number of hospital live births.

GESTATIONAL AGE AT BIRTH

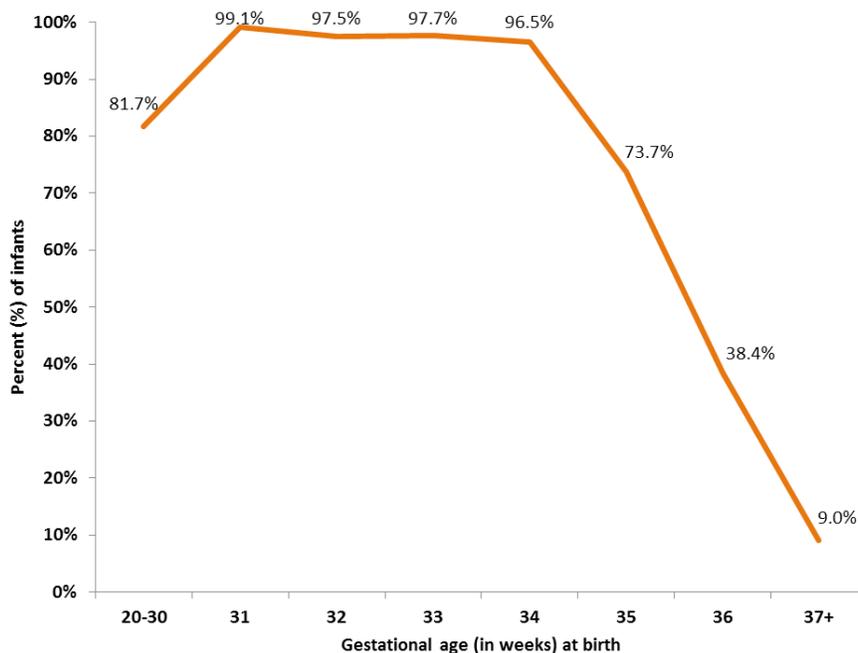
In 2012–2013 to 2013–2014, 91.6% of live births in Ontario occurred at ≥ 37 weeks' of gestation. This was unchanged from 2011–2012 (91.6%).

1.6% of live born infants were born very preterm (<32 weeks' gestation). These infants would have required tertiary level care. The majority of preterm infants (5.9%) were born between 34–36 weeks' gestation. These trends are consistent with data from 2011–2012.

GESTATIONAL AGE AT NICU ADMISSION

Between 2012–2013 and 2013–2014, 99.1% of infants born at 31 weeks of gestation or less were admitted to a NICU. For infants born at 37 weeks of gestation or higher, the rate of NICU admission was 9.0%.

Figure 24: NICU Admission by Gestational Age for Live Births
(Ontario, 2012–2013 to 2013–2014)



Data source

BORN Ontario, 2011–2012 to 2013–2014

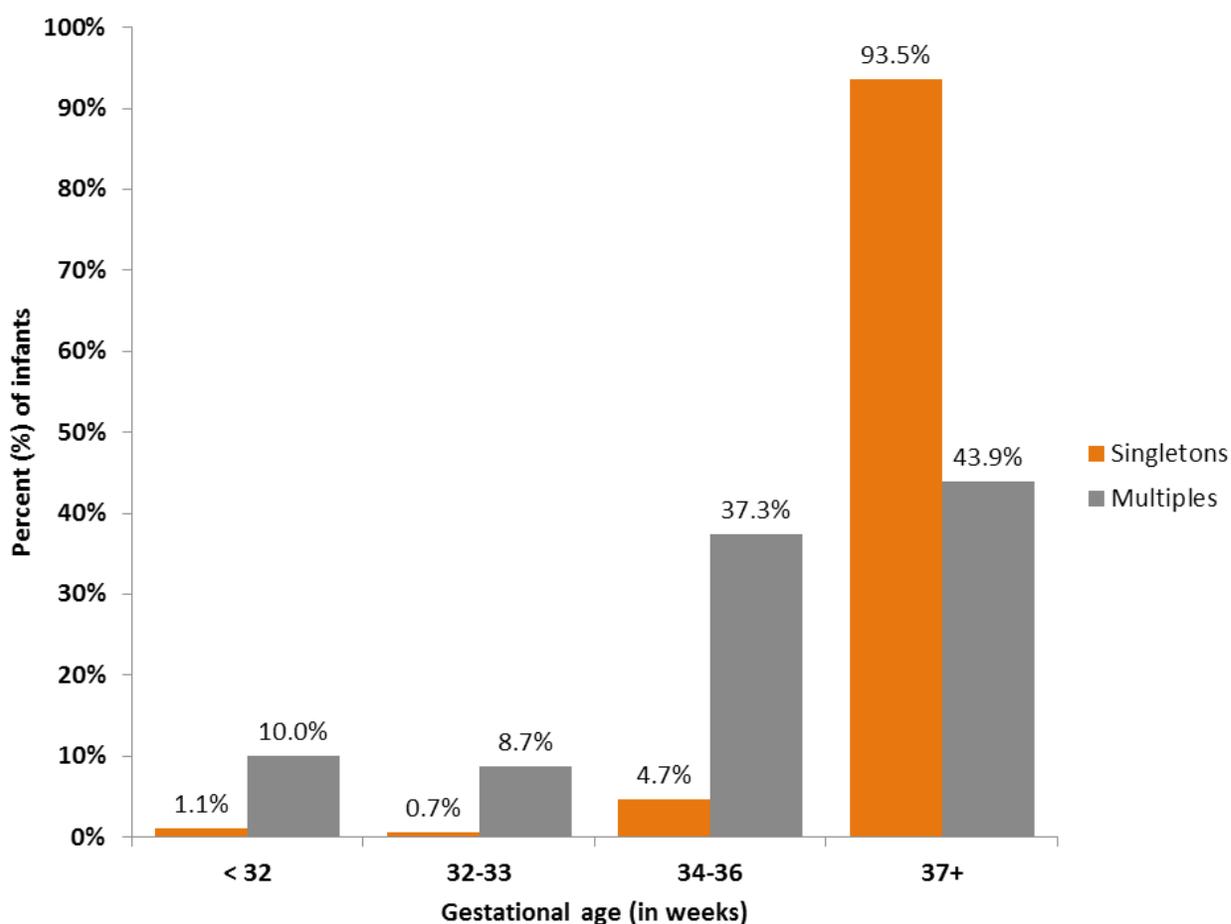
Definition of indicator

The percentage of live born infants at each gestational age who were admitted to NICU (level 2 or 3) in Ontario, expressed as a percentage of the total number of infants born at each gestational age and excluding infants who died in the neonatal period.

MULTIPLE BIRTH

At 3.7%, the multiple birth rate in Ontario has been stable since 2007–2008. The number of infants born in the province following a multiple gestation pregnancy remained constant at 5,009 in 2011–2012, 5,274 in 2012–2013 and 5,199 in 2013–2014.

Figure 25: Gestational Age at Birth for Singleton and Multiple Gestation Pregnancies
(Ontario, 2012–2013 to 2013–2014)



Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

Distribution of gestational age at birth in weeks, expressed separately for singletons and multiple gestation pregnancies as a percentage of the total number of hospital live births for each.

CONGENITAL ANOMALIES

In 2012–2013 BORN began reporting preliminary rates of sentinel congenital anomalies, as defined by the International Clearing House on Birth Defects (ICHBD) for comparison to other Canadian jurisdictions and internationally. To ensure the best possible capture of anomalies, BORN data from both the antenatal and newborn period was used in conjunction with administrative data from the Discharge Abstract Database (DAD) from the Canadian Institute for Health Information (CIHI) to produce the rates reported here.

When these two data sources are combined and duplicates removed, the estimates reported below are higher than those reported by the Public Health Agency of Canada (PHAC) from CIHI data alone. The difference between these estimates and those reported by PHAC are similar in pattern to those reported by the Alberta Congenital Anomalies Surveillance System, which, due to active and passive surveillance, has some of the most complete data in Canada.

Table 5: Selected Sentinel Congenital Anomalies (Ontario, 2012-2013 to 2013-2014)

	TOTAL CASES †	PREVALENCE RATE PER 10,000 BIRTHS
NEURAL TUBE DEFECTS (NTD) (ALL)	193	6.51
CLEFT LIP +/- CLEFT PALATE	265	8.94
CLEFT PALATE ONLY	271	9.15
LIMB DEFICIENCY DEFECTS (LDD)	93	3.14
GASTROSCHISIS (GS)	133	4.49
DOWN SYNDROME (DS)	545	18.39
TETRALOGY OF FALLOT (TOF)	100	3.37
HYPOPLASTIC LEFT HEART SYNDROME (HLHS)	66	2.23
TRANSPOSITION OF GREAT VESSELS (TGA)	76	2.56

Data source

BORN Ontario, 2011–2012 to 2013–2014

Definition of indicator

Prevalence rate of selected sentinel congenital anomalies per 10,000 births (including live births, stillbirths and terminations) in Ontario as defined by the ICHBD for two years of pooled Ontario data.

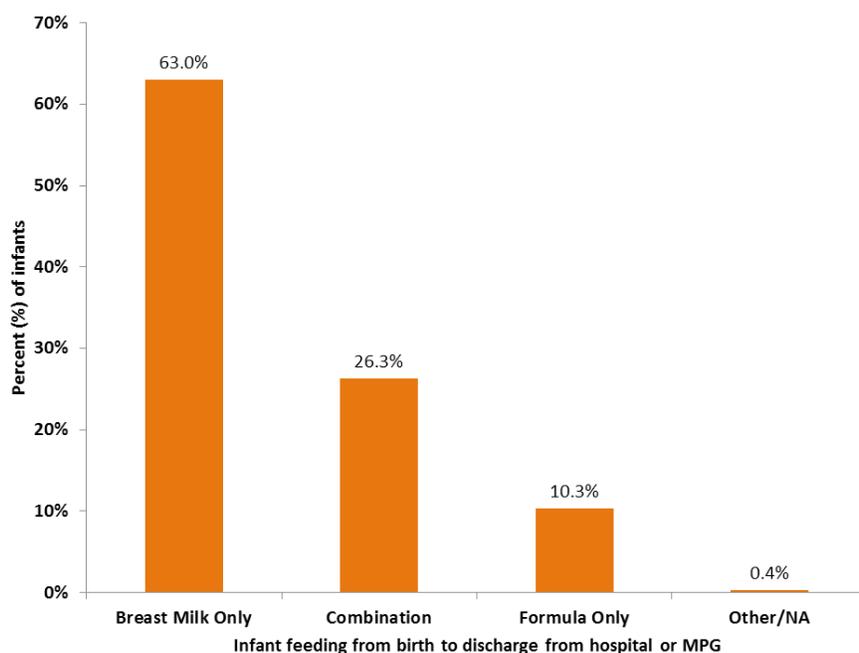
Congenital Anomalies Data Quality

To validate the quality of the fetal and congenital anomaly information collected in the BIS, comparisons were made to similar data collected in the DAD. When infant records were matched across the two databases the overlap in collected anomalies was found to be lower than expected. Work is continuing to understand the source of these discrepancies and to understand how to improve surveillance of anomalies in Ontario.

Supporting The Baby Friendly Initiative (BFI) Breastfeeding

A Baby-Friendly Initiative (BFI) Strategy for Ontario was initiated by the MOHLTC to enhance breastfeeding support across the province. The BFI Strategy will provide hospitals and community health organizations with training, tools, guidance and educational resources to help achieve the WHO's BFI designation and adopt best practices that meet BFI requirements. In consultation with the BFI Strategy Implementation Committee, BORN reviewed the breastfeeding data elements in the BIS and is implementing changes to better align the data collected with best practice guidelines and the BFI indicator definitions. Future work is also underway to develop standard reports to provide organizations with easy access to data to facilitate performance monitoring.

Figure 26: Rate of Exclusive Breastfeeding at Discharge Among Term Live Births
(Ontario, 2012-2013 to 2013-2014)



Data source

BORN Ontario, 2012-2013 to 2013-2014

Definition of indicator

Distribution of rate of feeding method from birth to discharge from hospital or MPG among term (≥ 37 weeks' gestation) live births, expressed as a percentage of the total number of live births in Ontario

NEWBORN SCREENING

Newborn Screening Ontario (NSO) tests all babies in the province to assess their risk of having any of 29 rare but treatable diseases, including SCID (Severe Combined Immunodeficiency) which was added in 2013. In 2012–2013 and 2013–2014 combined, an estimated 286,687 infants received newborn screening (143,277 infants in 2012–2013 and 143,410 infants in 2013–2014), and 2,770 infants (1.0%) received a positive screen result.

The BIS has helped to identify babies who may have missed having this test. In 2012–2013, 627 potential missed screens, or 0.4% of infants, were identified. In 2013–2014, BORN highlighted 542 potential missed screens to Newborn Screening Ontario, who confirmed 217 of these 542 cases as true misses. NSO contacts the care providers to report the potential missed screen and ensure that appropriate follow-up with parents occurs. This is a perfect example of how the data are used to facilitate care! Timely entry of birth data allows NSO to detect missed opportunities for care.

HEALTHY BABIES HEALTHY CHILDREN PROJECT

The BORN Information System (BIS) enables the collection of and access to data on every birth in Ontario with the goal of facilitating or improving the care of women and children in the province. The purpose of Ontario's Healthy Babies Healthy Children (HBHC) Program is to ensure children get a healthy start in life. Post birth, each woman is screened to identify at-risk families who may benefit from the HBHC home visiting and referral program.

BORN and the Ministry of Children & Youth Services (MCYS) developed a partnership to explore opportunities around the postpartum HBHC screen. Given that the BIS already collects a significant amount of the same information as the HBHC Screen, we developed a pre-populated BIS-HBHC Screen Report and deployed it to six real-time data-entry pilot sites in the summer of 2013. Once hospital staff enter the clinical and demographic information from the birth in the BIS, the applicable fields pre-populate the necessary areas on an HBHC Screen Report. The form is

printed, and the hospital nurse, midwife or public health nurse verifies the information and completes the rest of screen with the woman at the hospital bedside.

The scope of the pilot project included:

- Developing and testing an electronic report in the BIS to support the HBHC Screen completion
- Evaluation (methods included: surveys, follow-up phone calls, feedback)
- Pilot development and implementation with hospitals and public health units
- Considerations for future steps

The evaluation allowed participants to provide feedback and suggestions to enhance the process. Some of the identified benefits of participation included increased accuracy, legibility and quality of the screens. BORN coordinators provided support as needed, collected informal feedback and helped troubleshoot issues. Feedback to date has been very positive and there are plans for expansion to 8 additional sites in the 2014–2015 fiscal year.

What's next? BORN and MCYS will initiate Phase 2 which involves creating a completely automated business process around the HBHC Screens. We will collaborate to develop a privacy-sensitive electronic highway between the BIS and the MCYS Healthy Child Development - Integrated Services for Children Information System (HCD-ISICIS) which is accessed by the thirty-six health units throughout the province. Completing the HBHC Screen Encounter within the BIS and electronically transmitting consented screens to the appropriate health unit will be more efficient, eliminate the faxing process and improve timeliness of follow-up to women in the province. This process highlights the importance of timely data entry in the BIS to support every-day health care activities.

35.0%
OF INFANTS BORN LESS
THAN 32 WEEKS GESTATION IN
ONTARIO WERE BORN OUTSIDE
OF A LEVEL 3 FACILITY



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