

DATA SOURCES

There are several different sources of data related to reproductive health indicators in Ontario, including birth registrations (Vital Statistics), in-patient hospital discharges, the Better Outcomes Registry and Network (BORN) and the Integrated Services for Children Information System (ISCIS). This report focused on data from two sources only (birth registration data and BORN). The in-patient hospital discharge data do not have a sufficient degree of detail to be useful for these analyses and some variables of interest have been included only in recent years. ISCIS data are collected for the purposes of program delivery and planning and are not intended for population health assessment.

Birth Registration Data

The Office of the Registrar General (ORG) provides data on all live births and stillbirths registered in Ontario which may be used by public health units for population health assessment. For this report, these data were retrieved from the IntelliHEALTH Ontario system for the years 1986 to 2006 for Peel, the non-Peel Greater Toronto Area (GTA) health units (Durham, York, Toronto and Halton), and all of Ontario. For the stillbirth data, the most recent year available was 2005.

The information within the birth registration dataset is provided by both the parents (birth registration form) and the birth attendant (Notice of Live Birth or Stillbirth form). Both forms must be received by the ORG for the birth to be registered. Although live birth registration is required by law, changes in registration practices and the institution of registration fees have decreased the proportion of births which are registered. In the period of 1991 through 1997, approximately 1% of live births were unregistered. Unregistered births were more likely within urban populations and among younger mothers and infants with lower birth weight.

Known data quality issues exist within the live birth and stillbirth registration data. The 2008 Canadian Perinatal Health Report excludes Ontario live birth data from all perinatal surveillance due to these data concerns and provides an excellent summary of the nature of the concerns over time.¹ For example, until 1990 the Notice of Live Birth or Stillbirth form completed by the birth attendant was used as the gold standard for the determination of gestational age. From 1990 to 1998, the registration form submitted by the parents was used. In 1998, the Notice of Live Birth or Stillbirth form again became the gold standard, as a significant increase in preterm birth rates was observed. Additionally, projects aimed at linking infant death records with birth registrations have revealed that a large proportion of linkages were unsuccessful for Ontario (despite successful linkages in other provinces) as many infant death records could not be linked to their corresponding live birth registration.¹ Lastly, the number of stillbirths registered in 1991 and 1992 are inconsistent with other years and appear to be incorrect. Despite these known issues, the birth registration data are considered to be useful and serves as the main source of data for reproductive health analysis for Peel.

Variables of interest for analysis within the dataset include: infant sex, birth weight in grams, gestational age in completed weeks, maternal age, mother's marital status, father's age, country of birth of mother, country of birth of father, number of live births to mother, number of stillbirths to mother, type of birth (e.g., single, twin, triplet) and geographic information for the mother (e.g., postal code, public health unit, municipality). For stillbirths, additional variables

related to the cause of deaths are also included (e.g., ICD-10 code). Not all variables listed have been collected completely for all years. For example, maternal and paternal country of birth was complete for most live birth records from 2002 through 2006 but was recorded as “Unknown/not available from province” for previous years. Whereas, for the stillbirth data, the country of birth variables are relatively complete for 2005 only. There are also known data quality issues with the variables related to gestational age (see above). The effect that these issues may have had on the analysis presented in this report were discussed within the previous sections where appropriate.

Better Outcomes Registry and Network (BORN)

Beginning in April 2003, the Child Health Network for the Greater Toronto Area (CHN) implemented a standardized perinatal database (Niday GTA Perinatal Database) which provided access to real-time population based perinatal data on live births and stillbirths which occur in GTA hospitals (not all home births are captured in the database). Hospitals and midwives entered their own data into the database, which collected detailed information on maternal, newborn and perinatal care characteristics. Public health units were able to download record-level data regarding the births which occurred within their region for analysis through a web-based system. Niday data completeness and quality improved over time. Prior to 2007, Headwaters Health Care Centre- Dufferin in Orangeville was not participating in Niday and Peel mothers from Caledon who delivered there were not captured. Therefore the number of births to Peel mothers prior to 2007 may have been an underestimate of the true number of births. Starting in 2009, this database captured data from all hospitals in Ontario.

In 2010, the former Ontario Perinatal Surveillance System was granted registry status and was renamed the Better Outcomes Registry and Network (BORN). The five founding members of BORN (Ontario Maternal Multiple Marker Screening, Fetal Alert Network, Ontario Midwifery Program, Niday Perinatal Database and Ontario Newborn Screening) are integrating their data into one maternal-child registry.

With the Niday Perinatal Database becoming part of the BORN registry, there was a change in the manner in which the perinatal data were accessed. A two-year dataset was released by request for the period of January 1, 2007 to December 31, 2008. This dataset is considered to be more accurate than the previous annual datasets available through the web-based system, as additional data cleaning and assignment of correct geographical information were conducted by BORN. Compared to the previous datasets there are some notable changes in the availability of data. The new BORN-PHU dataset did not provide 6-digit postal code, exact birth weight in grams or mother’s age in years in order to address privacy concerns and to avoid the possible identification of individuals. Given the difference in the dataset used for analysis, the BORN data included in this report should not be compared to previous Niday Perinatal Database data which may have been reported elsewhere.