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Data Linkage and Data Quality Assessment for Congenital Anomalies Surveillance in Ontario

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Introduction

BORN Ontario is collaborating with the Public Health Agency of Canada (PHAC) to enhance the surveillance of congenital anomalies (CA) in Ontario and participate in the national CA Surveillance Enhancement Initiative. Since 2013, BORN has provided Ontario CA cases and the birth population data to the PHAC annually.

Objectives and Approach

The objectives include a description of CA data linkage methodology and a data quality assessment. Suspected and confirmed fetal anomalies were ascertained from regional sites entering data in the BORN Information System's (BIS) Antenatal Specialty (AS) and the Prenatal Screening Follow-up (PSFU) encounters. Newborn anomalies are identified from aggregate infant data ascertained from the Birth Child, Postpartum Child and Neonatal Care encounters. Both fetal and newborn anomalies are collected in the BIS using an extensive pick list, allowing for precise and accurate ascertainment. Once entered, pick list values are converted to ICD-10-CA codes or ranges using a lookup table.

Results

A few pick list values for minor congenital anomalies are not mapped to ICD-10-CA codes in the BIS. In this year's cohort (CY 2016), 13 pick list values did not map to ICD-10-CA codes. This impacted 127 of 5,346 records (2.4%, one infant may have multiple records). In these cases, the CA chosen from the pick list did not have a corresponding ICD-10-CA code. Among 447 PSFU fetal anomaly records for singletons (one fetus may have multiple records), 16 records did not have a corresponding ICD-10 code. Of the AS fetal anomaly records for singletons, 109 of 3,302 records (3.3%, one fetus may have multiple records) had fetal anomalies identified in the pick list that did not have a corresponding ICD-10-CA code.

Conclusion/Implications

BORN's CA pick list values were developed and enhanced by clinical experts. There is a discrepancy between clinical diagnosis and the ICD-10-CA classification for certain sub-types of CA posing a challenge for mapping. To enhance data quality, BORN will continue to improve matching of pick list values with ICD-10-CA classification.

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