The use of health care databases for surveillance of congenital anomalies: A EUROlinkCAT study

5.G. Pitch presentations: Data, assessments, impact

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The use of health care databases for surveillance of congenital anomalies: A EUROlinkCAT study

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Background:
Although health care databases were not designed for research or surveillance, they are increasingly used by researchers to investigate the epidemiology of congenital anomalies (CAs). Identifying specific CAs that can be accurately identified in hospital databases and those that are poorly recorded will enable surveillance of CAs. We evaluated the accuracy and the quality of the coding of CAs in hospital databases compared to EUROCAT data.
Methods:
The EUROlinkCAT project linked data from eleven EUROCAT registries I eight countries to electronic hospital databases. The coding of specific CAs in hospital databases was compared to the codes in the EUROCAT registries (gold standard). For birth years 2010-2014 all linked live birth CA cases and all children identified in the hospital databases with a CA code were analysed. Registries calculated sensitivity and Positive Predictive Value (PPV) for 17 selected CAs. Pooled estimates for sensitivity and PPV were then calculated for each anomaly using random effects meta-analyses.
Results:
Most registries linked more than 85% of their cases to hospital data. Gastroschisis, cleft lip with or without cleft palate and Down syndrome were recorded in hospital databases with high accuracy (sensitivity and PPV >85%). Hypoplastic left heart syndrome, spina bifida, Hirschsprung's disease, omphalocele and cleft palate showed high sensitivity (>85%), but low or heterogeneous PPV, indicating that hospital data were complete but may contain false positives. The remaining anomaly subgroups showed low or heterogeneous sensitivity and PPV, indicating that the information in the hospital database was incomplete and of variable validity.
Conclusions:
Electronic health care databases cannot replace CA registries, although they can be used as an additional ascertainment source for CA registries. CA registries are still the most appropriate data source to study the epidemiology of CAs.
Key messages:
- European hospital databases can accurately record a limited number of anomalies that are visible at birth, diagnosed prenatally and/or require hospitalisation or surgery in the first year of life.
- Additional data sources are needed to capture all children with CAs as hospital databases have limited information or codes to identify pregnancies that result in termination for fetal anomaly.