VALIDATION OF INFORMATION ON BIRTH DEFECTS REGISTRY WITH VITAL RECORDS

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ABSTRACT

The Connecticut Birth Defects Registry is in its second year of collecting information on all birth defects occurred statewide. Records submitted from birth hospitals to the Connecticut Department of Public Health through the Electronic Newborn Screening Program are a major data source for the Registry. Information on Electronic Vital Records (EVR), which is deemed as gold standard, is used to validate records submitted by hospitals before being incorporated into the Registry. In this study, we compared the birth defects data submitted by the University of Connecticut Health Center (UCHC) with EVR for information on demographic, geographic, and birth defects diagnoses.

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We linked the birth defects records submitted by UCHC for the years of 2002-2003 to EVR by unique Accession Number in the first step and by other identifying information in the second step. Results of this linkage were stratified by child's sex, race, care unit, and referral status, along with 95% confidence intervals to illustrate the precision of the estimates. Information examined included child's demographic and birth weight, mother's demographic and geographic, and birth defects diagnoses. Sensitivity and positive predictive value are used to ascertain the birth defects diagnoses on EVR.

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There were 227 birth defects records submitted by UCHC for this time period, among which, 169 records could be linked to EVR by unique Accession Number, another 44 records by the combination of Soundex, sex, initial, and date of birth, which resulted in a total of 213 (93.8%, 90.7%-96.9%) linked records. Despite the variations existed by gender, race, care unit, and referral status, the statistically significant difference can only be found for gender, in which females (99.0%, 97.0%-100.0%) had higher percent of records linked than males (90.8%, 85.8%-95.8%). The agreement on child's demographic and birth weight, and mother's demographic and residence were high with few cases that information on EVR is thought to be more reliable. The sensitivity and positive predictive value for birth defects diagnoses on EVR were 75% and 100% for Down syndrome respectively, and were both 100% for cleft lip/cleft palate. These are birth defects evident at birth and should be recorded on EVR.

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EVR can be a good source to supplement information to birth defects registry on child and mother's demographics, as well as birth defects diagnoses that are evident at birth. However, caution should be exercised before this information is used to enhance the birth defects surveillance system for planning, resource allocation, and epidemiological studies, as the quality of other information may be questionable.

INTRODUCTION

- Birth defects are one of the leading causes of infant mortality in Connecticut as they are in the United States
- The Connecticut Birth Defects Registry (CTBDR) was established and became operational in October 2002 to capture birth defects occurring statewide
- Birth records from hospitals are matched to the Electronic Vital Records (EVR) and diagnostic information is reconciled before a record is consolidated in the Registry
- Records from the University of Connecticut Health Center (UCHC) were matched to the EVR as an example in this study

MATERIALS AND METHODS

- Data were provided by the UCHC for the period between Dec 2002 and Oct 2003 and included newborn and mothers' biographics, and birth defects diagnoses
- UCHC records were matched to EVR by unique Accession Number through the deterministic approach in the step 1 and by the entry error allowance on the birth date, gender, initial, Soundex in the step 2 (Figure 1). Birth defect diagnoses were compared in step 3 for matched records
- Results of the record linkage were examined by gender, race, care unit, and referral status; sensitivity and positive predictive values were used as measurement for the comparison on diagnoses

RESULTS

- 169 out of 227 records could be linked to EVR in step 1, another 44 records in step 2, which resulted in a total of 213 (93.8%, 90.7%-96.9%) linked records (Table 1) (Figure 2).
- Females had statistically significantly higher percentage of records linked than males (99.0% vs 90.8%, P<0.01), among variations in race, care unit, and referral status.
- The sensitivity and positive predictive value for birth defects diagnoses on EVR were 75% and 100% for Down syndrome respectively, and were both 100% for cleft lip/cleft palate (Table 2).

DISCUSSIONS

- Birth defects registry data should be evaluated in terms of completeness, accuracy, and timeliness, before using in surveillance and epidemiological research
- The birth defects registries should use multiple data sources to register cases and to supplement diagnostic information
- Birth certificates can be a good source to supplement information collected by birth defects registries on biographics and birth defects diagnoses evident at birth, but quality of other information may be questionable