



Keeping Connecticut Healthy

# The Connecticut Birth Defects Registry

## Completeness of Case Reporting

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### INTRODUCTION:

- Birth defects are a leading cause of infant mortality in Connecticut and the nation. The existence of birth defects registries provides the opportunity of surveillance and prevention of birth defects through the use of registry data. However, the quality of registry data should be evaluated, in terms of completeness, timeliness, and accuracy, before they can be used for such purposes.
- Connecticut Birth Defects Registry (CTBDR) was established in October 2002 to actively capture birth defects occurring statewide, a transition from the retrospective mechanism in the past.
- Records submitted from birth facilities to the CT Department of Public Health through the electronic Newborn Screening System (NSS) are a major data source for the CTBDR.
- Three (3) components of the NSS - laboratory testing, hearing testing, and birth defects registry - share the biographic information of a child. Component information is completed and record submitted to NSS.
- Percentage of birth records in the NSS with missing birth defects registry information is used to monitor compliance of reporting among birth facilities in CT, and this information is used as proxy for estimating registry completeness.
- In this study, hospital discharge data, as an external source, were used to examine validity of this monitoring system as completeness estimate for CTBDR and to identify possible discrepancies.

### MATERIALS & METHODS:

- Data from the CTBDR for the years of 2002-2004 were used; cases diagnosed with 740.0-759.9 of ICD-9 codes were included in analysis and grouped by town.
- Children up to 19 years old diagnosed with congenital anomalies (740.0-759.9) in hospital discharge data were identified and grouped by town.
- Estimates of Registry completeness based on reporting compliance from birth facilities for January-September 2004 were compared to indices derived by using hospital discharge data.
- Geographic Information System (GIS) was used to examine the cases reported from birth facilities in relation to registry completeness estimated by reporting compliance, while considering cases identified in hospital discharge data.

### RESULTS:

- The overall completeness of CTBDR estimated by NSS system, based on reporting compliance is 79.3% (64.0%-94.6%)
- In general, facilities with poor compliance on reporting birth defects information to CTBDR are located in towns where indices derived by hospital discharge data were lower.
- However, facilities with better compliance are not necessarily located in towns where indices derived by hospital discharge data were higher.

### DISCUSSIONS:

- Birth defects occurred earlier in life before babies discharged from birth facilities are more likely to be captured in the CTBDR through NSS mechanism rather than by hospital discharge data, this may partially explain the discrepancies observed.
- All the birth defects diagnoses were included as a group for analysis to increase sample size, the variations of registration completeness among specific birth defects were not examined.
- The CTBDR started to collect birth defects information since October 2002 and the reporting compliance only improved greatly since the mid 2004, when Yale-New Haven began to report and data from UCONN Health Center were incorporated into registry
- The hospital discharge data used in the study were for years of 1996-1999, which is not corresponding to the years of CTBDR data used in the analysis. However, the number of birth defects diagnoses identified in the hospital discharge data should be consistent over the years, unless there are external factors.

### CONCLUSIONS:

- The completeness of registration should be assessed before data in the birth defects registries can be used for surveillance, prevention, and research.
- The completeness of CTBDR data estimated by reporting from birth facilities may not reflect the true picture of coverage for the target population.
- Information from multiple sources should be used to supplement the case registration in the birth defects registries, including information from hospital discharge file, emergency service file, birth certificates file, insurance claims, etc.

TABLE 3. TRACKING OF BIRTH DEFECTS REPORTING FROM HOSPITALS  
Connecticut Birth Defects Registry, Connecticut Department of Public Health, Jan. Sept. 2004

Town	Number of Births	Number of Births with Birth Defects Registry Information	Number of Births with Hospital Discharge Data	Number of Births with Both Sources	Compliance %	Compliance %
Bridgeport	100	100	100	100	100	100
...	...	...	...	...	...	...
Total	2042	1608	1927	1608	79.2	79.2

