

Texas Birth Defects Registry

(Used for Measure S1)

Brief description of the data set	Since 1994, the Texas Birth Defects Epidemiology and Surveillance Branch has maintained the Texas Birth Defects Registry, a population-based birth defects surveillance system. Through multiple sources of information, the Registry monitors all births in Texas (approximately 380,000 each year) and identifies cases of birth defects. The Texas Registry staff routinely visit all hospitals and birthing centers where affected babies are delivered or treated. There they review logs and discharge lists to find potential cases, and then review medical records of the potential cases to identify actual cases with birth defects.
Who provides the data set?	Texas Department of State Health Services.
How are the data gathered?	<p>The Texas Birth Defects Registry uses active surveillance:</p> <ul style="list-style-type: none"> ▪ Does not require reporting by hospitals or medical professionals. ▪ Trained program staff regularly visit medical facilities. <ul style="list-style-type: none"> ▪ Have legislative authority to review all relevant records. ▪ Review log books, hospital discharge lists, and other records to identify potential cases. ▪ Review medical charts for potential cases to identify those with birth defects. ▪ Program staff use medical charts for each potential birth defect identified. <p>Records in the birth defect registry are matched to birth certificates and fetal death certificates filed with the Vital Statistics Unit of Texas DSHS to gather demographic data.</p>
What documentation is available describing data collection procedures?	<p>Methods report available at:</p> <p>http://www.dshs.state.tx.us/birthdefects/Data/99-04_Methods.pdf.</p>
What types of data relevant for children’s environmental health indicators are available from this database?	Relevant data include the following birth defects: central nervous system defects; ear and eye defects; cardiac and circulatory defects; respiratory defects; oral clefts; gastrointestinal defects; genitourinary defects, including hypospadias; musculoskeletal defects; and chromosomal defects.
What is the spatial representation of the database (national or other)?	Prior to 1999: selected health service regions of Texas. 1999 onward: entire state of Texas.
Are raw data (individual measurements or survey responses) available?	Raw data for 1996-2007 are available through special request.
How are database files obtained?	<p>Routinely published tabulations of data for 1995-2007 (by birth defect, overall and broken down by selected demographic factors) can be accessed at: http://www.dshs.state.tx.us/birthdefects/Data/reports.shtm.</p> <p>A queryable database of data for 1999-2006, where users can design their own tabulations, can be found at: http://soupfin.tdh.state.tx.us/bdefdoc.htm.</p> <p>Other tabulations or raw data are also available through 2007, by written request. Go to http://www.dshs.state.tx.us/birthdefects/Data/reports.shtm and click on “Birth Defects Data Request and Access Policy.”</p>

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Are there any known data quality or data analysis concerns?	<p>Registry only includes birth defects diagnosed within one year of delivery (with the exception of fetal alcohol syndrome). Secondly, diagnoses made outside Texas or in Texas facilities that staff members do not have access to are excluded.</p> <p>Due to flooding during June 2001, several hospitals in Houston lost medical records. An estimated 50 fetuses and infants were born during this time with diagnosed birth defects at the affected hospitals.</p> <p>Data collected from medical records are subject to differences in clinical practice.</p>
What documentation is available describing quality assurance procedures?	<p>An article in <i>Birth Defects Research Part A: Clinical and Molecular Teratology</i> highlights quality issues:</p> <p>Miller, E. 2006. Evaluation of the Texas Birth Defects Registry: An active surveillance system. <i>Birth Defects Research Part A: Clinical and Molecular Teratology</i>. 76(11): 787-792.</p> <p>See: http://www3.interscience.wiley.com/journal/113455770/abstract.</p>
For what years are data available?	1996-2007.
What is the frequency of data collection?	Ongoing.
What is the frequency of data release?	Annual.
Are the data comparable across time and space?	Yes, generally. However, data from different locations may not be comparable due to differences in clinical practice. Identification of some birth defects may change over time as more sensitive examinations and technologies lead to more accurate recording of birth defects and/or better diagnosis of subtle defects. Prior to 1999, only certain regions were included in the registry.
Can the data be stratified by race/ethnicity, income, and location (region, state, county or other geographic unit)?	Using the interactive data query system (http://soupfin.tdh.state.tx.us/bdefdoc.htm), data can be stratified by mother's race/ethnicity, mother's age group, infant's sex, and geographical unit (statewide, public health region, county, and border residence status.)