

Tennessee

Tennessee Birth Defects Surveillance System (TNBDSS)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services

Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Early Childhood Prevention Programs, Legislators

Program status: Currently collecting data

Start year: 2000

Earliest year of available data: 1999

Organizational location: Department of Health (Maternal and Child Health)

Population covered annually: 80,864

Statewide: Yes

Current legislation or rule: TCA 68-5-506

Legislation year enacted: 2000

Case Definition

Outcomes covered: 47 major structural birth defects

Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (Prior to July 1st 2010: 500 grams or more, or in the absence of weight, 22 completed weeks of gestation or more; July 1st 2010 and later: 350 grams or more, or in the absence of weight, 20 completed weeks of gestation or more)

Age: Up to 5 years old

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation, Passive case-finding without case confirmation

Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program, Hospital Discharge Data System

Delivery hospitals: Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), Regular nursery logs, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Pediatric logs, Specialty outpatient clinics

Other sources: Midwifery Facilities

Case Ascertainment

Conditions warranting chart review in newborn period: ICD-10 codes from 26 specific birth defects

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), Cardiovascular condition, Ocular conditions

Coding: ICD-9-CM/ICD-10-CM

Data Collected

Infant/fetus: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Birth measurements (weight, gestation, Apgars, etc.), Tests and procedures, Infant complications, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.), Gravidity/parity, Illnesses/conditions, Prenatal care, Prenatal diagnostic information, Pregnancy/delivery complications, Family history

Father: Identification information (name, address, date-of-birth, etc.), Demographic information (race/ethnicity, sex, etc.)

Data Collection Methods and Storage

Data collection: Electronic file/report filled out by staff at facility (laptop, web-based, etc.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: SAS, REDCap, Birth defects internet case management system (iCMS)

Data Analysis

Data analysis software: SAS, Arc-GIS

Quality assurance: Validity checks, Double-checking of assigned codes, Comparison/verification between multiple data sources, Clinical review

Data use and analysis: Routine statistical monitoring, Public health program evaluation, Baseline rates, Rates by demographic and other variables, Time trends, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Referral, Grant proposals, Education/public awareness

System Integration

System links: Link to other state registries/databases, Link case finding data to final birth file

Funding

Funding source: 10% MCH funds, 90% CDC grant

Other

Web site: www.tn.gov/health

Surveillance reports on file: Tennessee Birth Defects Registry Report 2014-2018

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