

Nebraska

Nebraska Birth Defect Registry (NBDR)

Purpose: Surveillance, Research

Partner: Hospitals, Universities, Early Childhood Prevention Programs, Vital Statistics, Maternal Child Health

Program status: Currently collecting data

Start year: 1972

Earliest year of available data: 1973

Organizational location: Department of Health (Vital Statistics)

Population covered annually: 26,000

Statewide: Yes

Current legislation or rule: Laws 1972, LB 1203, §1, §2, §3, §4 (alternate citation: Public Health & Welfare [Codes] §71-645, §71-646, §71-647, §71-648, §71-649)

Legislation year enacted: 1972

Case Definition

Pregnancy outcome: Livebirths (=> 20 weeks, => 500 grams), Fetal deaths - stillbirths, spontaneous abortions, etc. (=> 20 weeks, => 500 grams)

Age: Up to one year after delivery

Residence: In state birth to state resident, out of state births to state residents when Out State Jurisdiction allows use of data

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation

Vital records: Birth certificates, Death certificates, Fetal death certificate

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

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

Other specialty facilities: Genetic counseling/clinic genetic facilities

Other sources: Midwifery Facilities, Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with an ICD-9-CM code 740-759/ICD-10-CM code Q00-Q99, Any chart with a selected list of ICD-9-CM codes outside 740-759/ICD-10-CM codes outside Q00-Q99, Any birth certificate with a birth defect box checked

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.), Birth defect diagnostic information

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

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: SQL

Data Analysis

Data analysis software: SAS, Reports from Netsmart

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

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Grant proposals

System Integration

System links: Link to other state registries/databases

System integration: Births, Deaths, Fetal deaths

Funding

Funding source: 100% MCH funds

Other

Web site: <http://dhhs.ne.gov/Pages/Vital-Records-Birth-Defects.aspx>

Surveillance reports on file:

<Http://dhhs.ne.gov/Pages/Vital-Statistics.aspx>

Contacts

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