

## North Carolina

### N.C. Birth Defects Monitoring Program (NCBDMP)

**Purpose:** Surveillance, Research

**Partner:** Local Health Departments, Hospitals, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs

**Program status:** Currently collecting data

**Start year:** 1987

**Earliest year of available data:** 1989

**Organizational location:** Department of Health (State Center for Health Statistics)

**Population covered annually:** 120,000

**Statewide:** Yes

**Current legislation or rule:** NCGS 130A-131.16

**Legislation year enacted:** 1995

#### Case Definition

**Outcomes covered:** Major birth defects

**Pregnancy outcome:** Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater), Elective terminations (All gestational ages)

**Age:** 1 year

**Residence:** NC resident births, including out of state deliveries

#### Surveillance Methods

**Case ascertainment:** Active Case Finding

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

**Other state based registries:** Newborn metabolic screening program

**Delivery hospitals:** Disease index or discharge index, Discharge summaries, Obstetrics logs (i.e., labor & delivery), ICU/NICU logs or charts, Postmortem/pathology logs, Surgery logs, Specialty outpatient clinics

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

**Other specialty facilities:** Prenatal diagnostic facilities (ultrasound, etc.), Genetic counseling/clinical genetic facilities

**Other sources:** Positive pulse oximetry screening database

#### 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, All stillborn infants, All prenatally diagnosed or suspected cases, Failed newborn pulse oximetry screen

**Conditions warranting chart review beyond the newborn period:** Any infant with a codable defect

**Coding:** CDC coding system based on BPA

#### 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:** Printed abstract/report submitted by other agencies (hospitals, etc.), 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:** Access

#### Data Analysis

**Data analysis software:** SAS, Access

**Quality assurance:** Validity checks, Re-abstraction of cases, Double-checking of assigned codes, Clinical review, Timeliness

**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, Grant proposals, Education/public awareness, Prevention projects

#### System Integration

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

#### Other

**Web site:** <https://schs.dph.ncdhhs.gov/units/bdmp/>

#### Contacts

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