

Oklahoma

Oklahoma Birth Defects Registry (OBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Data used to educate public in the Oklahoma initiative to reduce Infant Mortality

Partner: Local Health Departments, Hospitals, Advocacy Groups, Universities, Community Nursing Services, Early Childhood Prevention Programs

Program status: Currently collecting data

Start year: 1992

Earliest year of available data: 1992 abbreviated data

Organizational location: Department of Health (Screening and Special Services)

Population covered annually: 52,000

Statewide: Yes

Current legislation or rule: 63 - 1-550.2

Legislation year enacted: 1992

Case Definition

Pregnancy outcome: Livebirths (20 week gestation and greater), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks gestation and greater, * We collect all gestational ages but only those 20 week gestation and greater are included in most analyses and annual reporting.), Elective terminations (20 weeks gestation and greater, * We collect all gestational ages but only those 20 week gestation and greater are included in most analyses and annual reporting.)

Age: 24 months after delivery

Residence: Oklahoma

Surveillance Methods

Case ascertainment: Active Case Finding

Vital records: Birth certificates, Death certificates, Medical Examiner's autopsy reports; Stillbirth certificates

Other state based registries: Newborn hearing screening program, Newborn metabolic screening program

Delivery hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, Specialty outpatient clinics

Other specialty facilities: Prenatal diagnostic facilities (ultrasound, etc.)

Other sources: MFM/Neonatology Case Conference

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 chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All stillborn infants, All elective abortions, All neonatal deaths, All prenatally diagnosed or suspected cases

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, 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

Data Collection Methods and Storage

Data collection: Printed abstract/report filled out by staff, Electronic file/report filled out by staff at facility (laptop, web-based, 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, Comparison/verification between multiple data sources, Timeliness

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Time trends, Observed vs. expected analyses, Referral, Education/public awareness, Prevention projects

System Integration

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

Funding

Funding source: 40% MCH funds, 60% Genetic screening revenues

Other

Web site: obdr.health.ok.gov

Surveillance reports on file: Yes

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