Puerto Rico

Puerto Rico Birth Defects Surveillance and Prevention System (PR-BDSPS)

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

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

Program status: Currently collecting data

Start year: 1995

Earliest year of available data: 1995

Organizational location: Department of Health (Services for Children with Special Medical Needs Division)

Population covered annually: 23,000

Statewide: Yes

Current legislation or rule: Law #351

Legislation year enacted: 2004

Case Definition


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

Age: Up to 6 years after delivery

Residence: In-state births to state residents

Surveillance Methods

Case ascertainment: Active Case Finding

Vital records: Birth certificates, Death certificates

Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program

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, 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

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

Other sources: Physician reports

Case Ascertainment

Conditions warranting chart review in newborn period: Any chart with a birth certificate with a birth defect box checked, 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 infants in NICU or special care nursery, All infants with low APGAR scores, All prenatally diagnosed or suspected cases

Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Cardiovascular condition, Ocular conditions, Auditory/hearing conditions, Any infant with a codable defect

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.), Gravida/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 filled out by staff, Printed abstract/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Access, REDCap

Data Analysis

Data analysis software: SPSS, Excel

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

Data use and analysis: Routine statistical monitoring, Baseline rates, Rates by demographic and other variables, Monitoring outbreaks and cluster investigations, Time trends, Service delivery, Referral, Grant proposals, Education/public awareness, Prevention projects

Funding

Funding source: 67.2% MCH funds, 32.7% CDC grant

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