

Washington

Washington State Birth Defects Surveillance System (BDSS)

Purpose: Surveillance

Partner: Local Health Departments, Hospitals, Environmental Agencies/Organizations, Universities

Program status: Currently collecting data

Start year: 1986 (active), 1991 (passive)

Earliest year of available data: 1987

Organizational location: Department of Health (Office of Family & Community Health Improvement)

Population covered annually: 85,000 est

Statewide: Yes

Current legislation or rule: Notifiable Conditions: WAC 246-101

Legislation year enacted: 2000

Case Definition

Outcomes covered: Case definition for Washington State Birth Defects Surveillance System is based on ICD-9-CM diagnostic and procedure codes as they appear in the hospital medical records. Any child up to age one year, diagnosed or treated, with a reportable birth defect who was a Washington State resident at the time of birth, or treated in a Washington facility is reportable. Information for all stillbirths over 20 weeks gestation diagnosed with a reportable birth defect should also be reported. We receive the following data elements: Child's name, medical record number, date of birth, sex, admission date, zip code, discharge date, ICD-9-CM code for diagnosis, diagnosis, ICD code for procedure, and procedure. Currently required birth defects reporting includes - Anencephaly and similar anomalies, Spina Bifida, Cleft Palate, Cleft Lip, Cleft palate with cleft lip, Abnormalities of Abdominal Wall, Limb reduction defects, Hypospadias and Epispadias, Down Syndrome, Cerebral Palsy,* Fetal Alcohol Syndrome/Alcohol related birth defects* and Autism Spectrum Disorder.* [*Note: Reporting facilities have not been able to report on Cerebral Palsy, Fetal Alcohol Syndrome and Autism Spectrum disorder]

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

Age: We ascertain cases through 1 year of age for structural defects

Residence: Resident births; children born, diagnosed, or treated in-state

Surveillance Methods

Case ascertainment: Passive case-finding without case confirmation

Vital records: Birth certificates, Fetal birth certificate

Delivery hospitals: Disease index or discharge index

Pediatric & tertiary care hospitals: Disease index or discharge index

Case Ascertainment

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.), Tests and procedures, Birth defect diagnostic information

Mother: Identification information (name, address, date-of-birth, etc.)

Data Collection Methods and Storage

Data collection: Printed abstract/report submitted by other agencies (hospitals, etc.), Electronic file/report submitted by other agencies (hospitals, etc.), Case-finding log listing of all required data elements for each case are completed by Medical Records staff sometimes in conjunction with hospital Information Systems staff. Few facilities submit data through hard copies (fax) for cases. Most facilities report electronically through Secure File Transfer (SFT). A revised data system for BDSS is currently in development.

Database collection and storage: Web-based SQL server

Data Analysis

Data analysis software: SAS, Stata

Quality assurance: Validity checks

Data use and analysis: Routine statistical monitoring, Baseline rates

System Integration

System links: Link case finding data to final birth file

Funding

Funding source: 70% General state funds, 30% MCH funds

Contacts

Kevin Beck, MA

Washington Dept. of Health

PO Box 47835

Olympia, WA 98504-7835

Phone: 360-236-3492

Fax: 360-236-2323

Email: kevin.beck@doh.wa.gov

Teresa Vollan, MPH

Washington Dept. of Health; Maternal and Child Health; CSHCN

PO Box 47835

Olympia, WA 98504-7835

Phone: 360-236-3581

Fax: 360-236-2323

Email: teresa.vollan@doh.wa.gov