

Illinois

Adverse Pregnancy Outcomes Reporting System (APORS)

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

Partner: Local Health Departments, Hospitals, Community Nursing Services, Early Childhood Prevention Programs, Drug-testing laboratories; Departments of Human Services, Health and Family Services, Children and Family Services; Newborn Metabolic Screening Program, Specialized Care for Children

Program status: Currently collecting data

Start year: 1986

Earliest year of available data: 1989

Organizational location: Department of Health (Epidemiology/Environment)

Population covered annually: 150,000

Statewide: Yes

Current legislation or rule: Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/77 Illinois Administrative Code 840)

Legislation year enacted: 1984; last amended 2008

Case Definition

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

Age: Up to 2 years after delivery

Residence: In and out of state births to state residents

Surveillance Methods

Case ascertainment: Passive case-finding with case confirmation

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

Other state based registries: Newborn metabolic screening program, Hospital discharge data

Delivery hospitals: Discharge summaries, Reporting from hospital nurseries

Pediatric & tertiary care hospitals: Reporting from hospital nurseries

Case Ascertainment

Conditions warranting chart review in newborn period: Any birth certificate with a birth defect box checked, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease), All prenatally diagnosed or suspected cases, Infants with selected defects noted on a death certificate (up to 2 years of age); any report to the program of a selected defect.

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, Prenatal care

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.), Electronic file/report submitted by other agencies (hospitals, etc.)

Database collection and storage: Access, Purpose-built system linked with Vital Record System

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, Data/hospital audits, 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), Needs assessment, Service delivery, Referral, Grant proposals

System Integration

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

System integration: Cases are collected in a database that is a module of the Vital Record reporting system. Cases may be initiated from the birth certificate, by hospital staff or by APORS staff. Local community health agencies have access to cases in their jurisdiction for provision of case-management services. APORS cases are also included in the Illinois Healthcare and Family Services Enterprise Data Warehouse where they are available to Illinois' Department of Human Services, Department of Children and Family Services, and Department of Healthcare and Family Services staffs.

Funding

Funding source: 100% General state funds

Other

Web site: <http://www.dph.illinois.gov/data-statistics/epidemiology/apors>

Surveillance reports on file: Birth Defects and Other Adverse Pregnancy Outcomes in Illinois 2014-2018; Trends in the Prevalence of Birth Defects in Illinois and Chicago 2002-2018

Additional information on file: QC reports, fact sheets

Contacts

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