Michigan

Michigan Birth Defects Registry (MBDR)

Purpose: Surveillance, Research, Referral to Services, Referral to Prevention/Intervention Services, Prevalence and mortality statistics
Partner: Local Health Departments, Environmental Agencies/Organizations, Advocacy Groups, Universities, Early Childhood Prevention Programs, Outpatient Pediatrics clinics for HL7 reporting pilot
Program status: Currently collecting data
Start year: 1992
Earliest year of available data: 1992
Organizational location: Department of Health (Epidemiology/Environment, Vital Statistics)
Population covered annually: 115,000
Statewide: Yes
Current legislation or rule: Public Act 236 of 1988
Legislation year enacted: 1988

Case Definition
Outcomes covered: Congenital anomalies, certain infectious diseases, conditions caused by maternal exposures and other diseases of major organ systems
Pregnancy outcome: Livebirths (All gestational ages and birth weights), Fetal deaths - stillbirths, spontaneous abortions, etc. (20 weeks or >400 grams)
Age: Up to two years after delivery except that reporting to age 12 for FASD beginning in 2013
Residence: Michigan births regardless of residence, out of state births diagnosed or treated in Michigan regardless of residence

Surveillance Methods
Case ascertainment: Passive case-finding without case confirmation
Vital records: Birth certificates, Death certificates, Matched birth/death file, Fetal birth certificate, Fetal deaths since 2004 only
Other state based registries: Programs for children with special needs, Newborn hearing screening program, Newborn metabolic screening program, Cancer registry
Delivery hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Pediatric & tertiary care hospitals: Disease index or discharge index, Discharge summaries, ICU/NICU logs or charts, Specialty outpatient clinics
Third party payers: Medicaid databases
Other specialty facilities: Cytogenetic laboratories, Genetic counseling/clinical genetic facilities
Other sources: Physician reports, Pediatric Dentistry

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, Any chart with selected defects or medical conditions (i.e. abnormal facies, congenital heart disease)
Conditions warranting chart review beyond the newborn period: Facial dysmorphism or abnormal facies, Failure to thrive, CNS condition (e.g. seizure), GI condition (e.g. intestinal blockage), GU condition (e.g. recurrent infections), Cardiovascular condition, All infant deaths (excluding prematurity), Childhood deaths between 1 and 6, 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.), 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 filled out by staff, 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: FoxPro

Data Analysis
Data analysis software: SPSS, SAS, Access, Fox-pro, Excel
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, Monitoring outbreaks and cluster investigations, Time trends, Observed vs. expected analyses, Epidemiological studies (using only program data), Identification of potential cases for other epidemiologic studies, Needs assessment, Service delivery, Referral, Grant proposals, Education/public awareness

System Integration
System links: Link to other state registries/databases, Link case finding data to final birth file, CSHCS, WIC
System integration: No, data from vital records and other sources are extracted and loaded into registry as opposed to truly integrated database structures.

Funding
Funding source: 10% CDC grant, 90% Other (60% Vital Records Fees, 30% newborn screen revenue)

Other
Web site:
https://www.michigan.gov/mdhhs/0,5885,7-339-73970_2944_4670---,00.html
Additional information on file:
Https://www.michigan.gov/mdhhs/0,5885,7-339-71551_2945_5221-16665--,00.html

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