

Appendix 5A: Data and Information Sources for Case Ascertainment

Appendix 5A identifies specific data sources for case identification and case investigation as outlined in **Chapter 5: Standards Table 5.1.1**. As birth defects surveillance programs engage with data sources to access and review information from the medical records, there are several important considerations:

- **Size and complexity of the organization.** Be aware that different departments, clinics, or providers located within a health care organization may have the same charting system (e.g., all providers use a single shared electronic health record), or separate systems (e.g., a hospital-based surgery center may maintain its records in a different system than the inpatient units, the imaging department, or the laboratory). When requesting records from a data source, ensure that all of the necessary records are included in the request for data.
- **One medical record across multiple encounters.** A healthcare facility or system generally creates one medical record to serve as the repository for data from all admissions and service encounters with a patient over time. In rare situations, multiple medical records are created for the same patient, with different pieces of their health information stored in each record. When requesting records from a data source, ensure that all relevant encounters from the patient's medical record(s) are included in the request for data.
- **Maternal medical record versus infant medical record.** Birth defects surveillance programs should be aware of the following scenarios which affect the location of the infant's medical information. Consult with the data source for clarification about their documentation practices:
 - **Live birth.** The infant and mother will each have individual medical records.
 - **Live birth with neonatal death shortly after birth.** The infant *may* have a newborn medical record. However, the most useful information will be in the mother's delivery medical record (e.g., if autopsy or cytogenetics laboratory work is done, the results might have been placed in the mother's chart).
 - **Non-live birth.** Generally, these cases will not have their own unique medical record for the fetus. Information about these cases is identified through the mother's medical record.

5A.1 Core Data Sources

Hospitals (e.g., Birthing, Pediatric, and Tertiary care)

Hospital Departments

- Laboratory (e.g., serology, microbiology, cytogenetics)
- Obstetrics (e.g., labor & delivery)
- Pathology (e.g., anatomical, forensic, surgical)
- Pediatrics (e.g., neonatal ICU, newborn nursery)
- Surgery (e.g., fetal or postnatal, inpatient, outpatient/ambulatory)

Centers or Facilities

- Birthing Center

5A.2 Enhanced Data Sources

Prenatal Care and Diagnostic Facilities

- Obstetric Specialty Center
- Maternal-Fetal Medicine Specialty Clinic
- Perinatology
- Women's Care Clinics (e.g., Planned Parenthood)
- Diagnostic Referral Sites (e.g., high-level ultrasound clinic)
- Prenatal Genetic Counseling Services

Vital Records Office (Government Agency)

- Birth Certificate
- Fetal Death Certificate
- Death Certificate
- Other Fetal Outcomes Report

5A.3 Extended Data Sources

Specialty Health Care Clinics

- Audiology and Speech
- Cardiology
- Genetics
- Musculoskeletal (e.g., orthopedic surgery, physical medicine and rehabilitation, physical therapy)
- Nephrology

- Neurodevelopmental (e.g., early intervention)
- Neurology (e.g., meningomyelocele clinic)
- Ophthalmology
- Oro-Facial/Craniofacial Surgery
- Pediatric Medicine
- Pediatric Surgery
- Pulmonology/Respiratory
- Urology

Indian Health Services (IHS)

- IHS Hospitals
- IHS Clinics (primary care or specialty)

Laboratory

Includes send-out specimen to state or private lab

- Cytogenetics
- Metabolic
- Prenatal Screening and Diagnosis

Administrative Databases

- Statewide Hospital Discharge Datasets
- Medicaid Datasets
- Health Maintenance Organization (HMO) Datasets
- All Payers Dataset
- Clinic-based Datasets

Other State Programs

Public Health Programs

- Child Fatality/Mortality Review Programs
- Coroners and Medical Examiners (County)
- Newborn Genetic Screening Programs
- Newborn Hearing Screening Programs
- Public Health Maternal Programs
- Public Health Child Programs (e.g., early intervention programs)
- School Records (e.g., IEP, special education)