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Utah Birth Defect Network Public Health Surveillance of Birth Defects

Public Health Surveillance of Birth Defects

What is “public health surveillance of birth defects”?

- “Public health surveillance of birth defects” is the process of obtaining data about cases of birth defects to determine the frequency and geographic location of cases.
- Data can be cross-referenced to identify anomalies, trends, clusters, and possible causes.
- Utah has an Administrative Reporting Rule (R398-5) that requires reporting and/or surveillance of infants and children born with a birth defect.

Why is birth defects surveillance conducted?

- Information about infants and children with birth defects can assist with descriptive epidemiology, etiologic research, education, and advocacy.
- Such data also can be used to target and evaluate public health programs, and identify and refer infants and children to services and programs.

Who collects this information?

- Most birth defects surveillance is conducted by health care professionals at a state agency or at a university, or by other organizations collecting information for public health purposes.

Health Insurance Portability and Accountability Act (HIPAA)

What is HIPAA?

- The Health Insurance Portability and Accountability Act (HIPAA) (Public Law 104-191), which was enacted in 1996 and went into effect in April 2003 includes provisions for making health insurance more accessible and affordable.
- HIPAA is a set of national standards that protects the confidentiality of medical records and other personal health information.

HIPAA and Birth Defects Surveillance

Will HIPAA interfere with reporting and surveillance of birth defects?

No. HIPAA will not interfere with public health reporting. As demonstrated by the Department of Health and Human Services, the HIPAA Privacy Rule provides for reporting to public health agencies without the individual’s written authorization. The HIPAA privacy rule allows a covered entity to disclose personal health information to a public health authority for public health purposes (i.e., disease reporting) or public health surveillance (i.e., tracking of birth defects). In addition, HIPAA allows personal health information to be disclosed when required by law. (45 CFR § 164.512(a-b)) Thus, HIPAA permits disclosures where a public health authority is permitted by law to receive information for a public health purpose.