

Birth Defects Surveillance Program Activities at a Glance

Activity	Key Processes in Establishing a Program
Identify the goals and objectives of the birth defects surveillance program.	The goals inform the objectives, which drive the desired outputs, and will ultimately shape the case ascertainment methods used by the birth defects surveillance program. When developing goals and objectives for a birth defects surveillance program, engagement with key stakeholders is important. See Chapter 1 for details.
Describe the boundaries of legal authority.	When goals, objectives, and desired outputs are developed or changed, consult with authorizing language to confirm the birth defects surveillance program is functioning within its legal authority. Amendments to authorizing language may be needed if a birth defects surveillance program wants to adjust its scope or methods. See Chapter 1 and Appendix 1A for details.
Develop surveillance methods to be used by the birth defects surveillance program.	Develop a list of inclusion criteria and data elements needed to determine which data sources will best meet the birth defects surveillance program's purposes, then define the information requested and coordinate with key staff (which may include IT), and data sources. Document the birth defects surveillance program's procedures and requirements for case identification, investigation, verification, and inclusion review. Include data sources to be used, information to be requested, health information classification system(s) to be used, assignment of a birth defects code, and procedures for follow-up (e.g., medical record reviews) to determine whether potential cases flagged by the case identification and investigation processes meet case inclusion criteria. See Chapters 1-5 for details.
Develop the birth defects surveillance database for health information management to accommodate various methods of receiving, accessing, linking, and reporting data.	Identify the surveillance functions that need to be supported. Design the birth defects surveillance program's database and infrastructure to facilitate engagement with and comparability between multiple data and reporting sources. Considerations include the need to standardize data fields to support electronic reporting (e.g., electronic case reporting, interoperability messaging), record linkage, data pooling at the national level, and programmatic data management functions. Even when data sources use standardized and coded data fields, some reformatting may be needed before integration into the birth defects surveillance database. Programmatic data fields are necessary to measure productivity (e.g., date posts), to link data elements to the source (e.g., related data elements), search capacity, and monitoring. See Chapters 1-5 for details.

Activity	Key Processes in Operating a Program
Train birth defects surveillance program staff to identify potential birth defects cases from the information provided by data sources.	Training includes a thorough understanding of the birth defects case definition criteria, data reporting variables, and systematic methods utilized by the birth defects surveillance program to request and receive information for case identification and verification. Training extends to pertinent IT staff, to ensure they can align the birth defects surveillance program's technological database platform with its case identification efforts. See Chapters 1-5 for details.
Assess the quality of potential birth defects cases that are received or accessed from the data source(s).	Data sources have inherent biases that affect the quality of coded information reported. The birth defects surveillance program's operational procedures determine if the information is accepted as reported (with no or limited follow-up), or if additional data quality procedures are performed. Evaluate each source based on the quality and value of its information for the overall abstract. Some data sources are essential, while others provide supplemental details to a case record abstract. See Chapters 4 and 5 for details.
Abstract and record information from the medical/health records received from data sources.	Birth defects surveillance staff review medical records and health information reports to abstract/record the required information into the birth defects surveillance program's standard forms. Abstracting guidelines and procedures may vary by birth defects surveillance program, but they should be based on established definitions (see Chapter 2 and Appendix 2A). Procedures may include instructions for completing each data element in the abstract, steps to verify a diagnosis, indications for conducting follow-up, and (in some birth defects surveillance programs) instructions for assigning a disease code. See Chapters 3-5 for details.
Conduct quality assurances	Birth defects surveillance programs should monitor the quality (completeness, timeliness, and accuracy) of collected data and adjust surveillance methods as needed to address any deficiencies. See Chapter 7 [June 2004 edition] for details.