

Descriptive Epidemiology and Monitoring Standards

Programs with this focus are able to compute information regarding birth defect prevalence, which may be organized geographically and temporally, for a defined population. To support this, basic demographic data are necessary. These programs also have the ability to investigate suspected clusters of birth defects. The ability to provide descriptive epidemiologic data is considered to be a basic function of a surveillance program, even those with primary goals of research or linking children to services.

These types of descriptive epidemiologic data allow the targeting of prevention efforts to groups identified as being at increased risk for specific types of birth defects. They also support the evaluation of prevention programs.

Data Variables

- See Table 1

Classification and Coding

- ICD-9/10. This coding system allows a level of detail considered to be appropriate for this programmatic objective. While programs are not required to use this coding system they need to use a system that is at least as specific so that diagnostic information may be translated into ICD codes.

Case Definitions

- See list of core diagnoses
- Live-born infants and fetal deaths
- All core conditions diagnosed at delivery/birth or during the first year of life

Data Quality Management

- Programs are required to maintain a manual of operations that describe how these surveillance standards will be implemented.
- For each delivery year, 95% of expected cases should be ascertained within two years of the end of the year.
- Specific requirements for accuracy are under development.

Research Standards

To support research, a program must have complete, accurate, and precise diagnostic information. These data are commonly collected by trained abstractors who review primary medical records. Information that allows parents or the physician of record to be contacted is required so that informed consent to participate in research may be obtained. Extensive demographic data are also collected. Programs must be able identify at least a representative sample of cases across the surveillance population.

Etiologic research, based on analytic epidemiologic methods, is essential to understanding the causes of birth defects in order to develop prevention strategies. The identification of specific risk factors is fundamental to prevention. More clinically focused research is also important for prevention of secondary disabilities/conditions among persons with birth defects, as well as for developing a better understanding of the embryology and natural history of individual types of birth defects.

Data Variables

- See Table 1

Classification and Coding

- BPA System. BPA codes allow a level of detail that is beyond that provided by the ICD-9/10 system. Programs are not required to use the BPA system but they must use a system with a comparable degree of specificity so that diagnostic information may be translated into BPA codes.

Case Definitions

- See list of core diagnoses
- Live-born infants and fetal deaths
- All core conditions diagnosed at delivery/birth or during the first year of life

Data Quality Management

- Programs are required to maintain a manual of operations that describe how these surveillance standards will be implemented.
- For each delivery year, 95% of expected cases should be ascertained within two years of the end of the year.
- Specific requirements for accuracy are under development.

Service/Planning Standards

To effectively link eligible children to services, programs must be able to identify cases in a timely manner. Because speed of ascertainment is more important than diagnostic detail, passive reporting is often used. Fetal deaths may or may not be included. To facilitate planning, these programs also often collect demographic information, which is needed to estimate case burden across the surveillance area. They may routinely collect information on service providers and barriers to service as well.

Linking children with services is essential in preventing the morbidity and mortality associated with many common birth defects. In addition, early intervention programs can prevent some of the functional, educational and social deficits associated with many birth defects. Aligning parents with medical, social and educational services can help prevent some of the adverse impacts that often affect children with birth defects and their families.

Data Variables

- See Table 1

Classification and Coding

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Case Definitions

- See list of core diagnoses
- Live-born infants
- All core conditions diagnosed at delivery/birth or during the first year of life

Data Quality Management

- Programs are required to maintain a manual of operations that describe how these surveillance standards will be implemented.
- Specific requirements for timeliness, completeness, and accuracy are under development.

Common Standards for All Pillars

Case Ascertainment

- Data Sources
 - Vital records
 - Hospital-based data

- Case Finding
 - No specific requirement. It is expected, though, that requirements for case definitions and data quality will partially determine case finding resources and procedures.

Data Management and Security

- Program operations and resources will meet HIPAA requirements for data security.

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Table 1. Core data variables for each program objective.

Data Variable	Descriptive		
	Epi & Monitoring	Research	Service/Planning
Unique ID	X	X	X
Date of Pregnancy Outcome	X	X	X
Sex	X	X	X
Infant's Name			
First	X	X	X
Middle	X	X	X
Last	X	X	X
Suffix	X	X	X
Source of Report	X	X	X
Medical Record Number(s)	X	X	X
Vital Record Certificate Number	X	X	X
Place of Pregnancy Outcome	X	X	X
Pregnancy Outcome	X	X	X
Birth Weight	X	X	X
Plurality	X	X	X
Gestational Age	X	X	X
Diagnosis Code	X	X	X
Name of Responsible Party		X	X
Address of Responsible Party		X	X
Telephone Number of Responsible Party		X	X
Mother's Date of Birth	X	X	X
Mother's Race	X	X	
Mother's Ethnicity	X		
Mother's Name			
First	X	X	X
Middle	X	X	X
Last	X	X	X
Mother's Residence At Time of Pregnancy Outcome			
Street address	X	X	
City	X	X	
County	X	X	
State	X	X	
Zip Code	X	X	