

State Use of Birth Defects Surveillance

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PUBLIC HEALTH IMPORTANCE

Birth defects are the leading cause of infant mortality in the United States, accounting for >21% of all infant deaths in 1991 (Figure 1) (1). In addition, birth defects are the fifth leading cause of years of potential life lost (2), and they contribute substantially to childhood morbidity and long-term disability. Major birth defects are diagnosed for 3%–4% of infants in their first year of life. Of the 100,000–150,000 infants born with a major birth defect each year (3), approximately 6,000 die during their first 28 days of life, and another 2,000 die before reaching their first birthday. The remaining 92,000–142,000 children who survived beyond the age of 1 year are affected by birth defects to various degrees.

Each year about 1.2 million infants, children, and adults are hospitalized for treatment of birth defects; children with birth defects account for approximately 25%–30% of pediatric admissions (4). Total costs for the care of children with birth defects exceed \$1.4 billion annually (5). The continuum of care includes diagnostic and treatment services, education, vocational training, and custodial care. The cost for this care pales in comparison to the loss of creativity and earning power of individuals with handicapping conditions.

Much remains to be learned about the etiology of birth defects. Although several human teratogens have been identified, two thirds of birth defects are of unknown causes (6). One area where substantial progress may be made is the use of folic acid consumption to reduce the number of cases of spina bifida and other neural tube defects (NTDs). The Public Health Service estimates that as many as 50% of cases of spina bifida and other NTDs could be reduced if

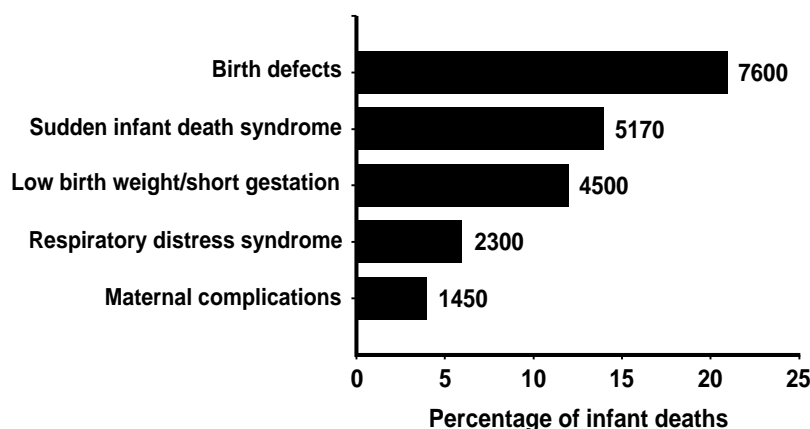
women of childbearing age would consume 0.4 mg of folic acid daily (7). This is an important prevention opportunity in public health. Other types of birth defects that are entirely preventable include fetal alcohol syndrome, congenital rubella, and isotretinoin embryopathy.

Much work is being done to classify infants with birth defects according to biologically meaningful categories that would be useful in identifying etiologic and pathogenetic mechanisms. This improved classification is critical to our continued progress in understanding and preventing birth defects.

The basic definition of a birth defect is a structural abnormality present at birth; most but not all such defects are included within codes 740.0–759.9 of the *International Classification of Diseases, Ninth Revision, Clinical Modification* (8). These conditions include a heterogeneous group of outcomes, each with a different morphogenesis: 1) malformations such as clefts and congenital heart defects, which involve poor tissue formation; 2) deformations such as clubfeet and congenital hip dislocations, which involve unusual forces on normal tissue; and 3) disruptions such as amniotic bands and gastroschisis, which involve the breakdown of normal tissue.

Birth defects are also classified by underlying etiologic or pathogenetic mechanisms including chromosomal aberrations, single-gene (Mendelian) disorders, and sequences (multiple defects that are related to a single problem in morphogenesis).

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FIGURE 1. Leading causes of infant mortality — United States, 1991

Additionally, birth defects can be classified as major or minor. Major birth defects are those that affect survival, require substantial medical care, or result in marked physiologic or psychologic impairment.

Most birth defects occur as isolated defects. In about 20%–30% of affected infants, however, multiple defects are involved. If two or more defects affect an infant, they are considered to be multiple if they occur in different organ systems or body sites, are not part of a known embryological sequence, and do not have a common primary defect.

Surveillance is a critical component in the effort to further reduce the impact of birth defects on public health. Surveillance is necessary to detect the occurrence of birth defects, to investigate potential etiologic agents, to plan and evaluate the effects of interventions, and to ensure appropriate care for persons in need of services (for additional information about related topics and surveillance activities, see the Prevalence of Birth Defects, Infant Mortality, and Neonatal and Postneonatal Mortality chapters).

HISTORY OF DATA COLLECTION

The earliest legislation requiring the reporting of birth defects in the United States was passed in New Jersey in 1926. Widespread interest in birth defects surveillance, however, was not generated until the early 1960s, where an epidemic of limb reduction deformities was associated

with the prenatal use of thalidomide. Few specific causes of birth defects were known, and the epidemiologic patterns of several malformations suggested that unidentified teratogens were important in the etiology of major congenital malformations. Initially, birth defects surveillance systems were designed to monitor secular trends, especially patterns that might suggest environmental causes of birth defects. More recently, innovative, multipurpose systems have integrated traditional monitoring functions with new epidemiologic approaches and service-oriented objectives. Interest in birth defects surveillance has continued to grow, with programs currently monitoring outcomes at the state, national, and international levels.

CDC SURVEILLANCE ACTIVITIES

Twenty-eight states have established a plan to establish birth defects surveillance systems (Table 1). In 1992, seven states had surveillance systems that used active case ascertainment, providing information on approximately 700,000 births—19% of the U.S. births that year. Many of these state surveillance programs are modeled after the prototype surveillance system, CDC's Metropolitan Atlanta Congenital Defects Program (MACDP) (see the Prevalence of Birth Defects chapter for details about MACDP).

An additional 16 states had passive case-ascertainment surveillance systems, which provided information on 1,090,000 births (29% of

TABLE 1. State birth defects surveillance systems

State	Coverage	Legislation	Type of ascertainment
Alabama	None		None
Alaska	None		None
Arizona	Statewide	Yes	Active
Arkansas	Covers about one third of births	Yes	Active
California	Selected areas of state	Yes	Active
Colorado	Statewide	Yes	Passive
Connecticut	Statewide—inactive due to lack of funds	Planned	Passive—inactive due to lack of funds
Delaware	None		None
District of Columbia	None		None
Florida	None		None
Georgia	Five-county metropolitan Atlanta area		Active
Hawaii	Statewide	Yes	Active
Idaho	None		None
Illinois	Statewide	Yes	Passive
Indiana	Statewide	Yes	Passive
Iowa	Statewide	Yes	Active
Kansas	Statewide	Yes	Passive
Kentucky	Statewide—developing	Yes	Passive
Louisiana	None		None
Maine	Statewide—inactive due to lack of funds		Passive—inactive due to lack of funds
Maryland	Statewide	Yes	Passive
Massachusetts	Statewide—developing	Planned	Passive
Michigan	Statewide	Yes	Passive
Minnesota	None		None
Mississippi	None		None
Missouri	Statewide (up to 1988)		Passive
Montana	None		None
Nebraska	Statewide	Yes	Passive
Nevada	None		None
New Hampshire	None		None
New Jersey	Statewide	Yes	Passive
New Mexico	None		None
New York	Statewide	Yes	Passive
North Carolina	Statewide		Passive

TABLE 1. State birth defects surveillance systems – continued

State	Coverage	Legislation	Type of ascertainment
North Dakota	None		None
Ohio	None		None
Oklahoma	Pilot in part of state	Yes	Active
Oregon	None		None
Pennsylvania	None	Planned	None
Rhode Island	None		None
South Carolina	None		None
South Dakota	None		None
Tennessee	None		None
Texas	Developing in part of state	Yes	Active
Utah	Statewide	Planned	Passive
Vermont	None		None
Virginia	Statewide	Yes	Passive
Washington	Statewide	Yes	Passive
West Virginia	Statewide	Yes	Passive
Wisconsin	Statewide	Yes	Passive
Wyoming	None		Noe

the births in the United States), and one state had a system that was based on a supplement to vital records and provided information on 45,000 births. Examples of these passive case-ascertainment systems include systems created by legislative mandates for hospitals or physicians to report the occurrence of birth defects (such systems are now required in New York, New Jersey, and Nebraska); systems created by linkage of multiple data sources (such systems are used in Missouri and North Carolina); and systems that are based on vital statistics data (the Indiana Birth Problems Registry is one such system). Another five states are developing or planning to reactivate birth defects surveillance systems.

GENERAL FINDINGS

Because individual birth defects are rare, researchers have had difficulty obtaining enough cases for etiologic studies. The Birth Defects Monitoring Program (BDMP) provides some limited national data on the occurrence of birth defects. Because the number of hospitals partici-

pating in BDMP continues to decline each year, CDC researchers are investigating new avenues for national birth defects surveillance, including collaboration among state birth defects monitoring programs. Such collaboration substantially increases researchers' power to study relatively rare birth defects, greatly enhancing our understanding of the occurrence and etiology of birth defects. Data from population-based state systems are an important source of information on the prevalence of birth defects, providing a more representative view than the nonrandom sample provided by BDMP (see the Prevalence of Birth Defects chapter).

For example, in a recent study of the incidence and descriptive epidemiology of spina bifida, CDC fostered the collaboration of 16 states (representing 23.5% of the U.S. population) with population-based birth defects surveillance systems (9). Through this cooperative effort, we were able to determine that spina bifida incidence declined from 5.9 per 10,000 births in 1993 to 3.2 cases per 10,000 births in 1990. State-specific rates

varied substantially (range: 3.0 [Washington] to 7.8 [Arkansas]). Spina bifida rates also varied among racial and ethnic groups, being lowest among Asians and Pacific Islanders (2.3) and highest among Hispanics (6.0). The rate among Hispanics, however, declined substantially from 1983 to 1990, and the rate among blacks has remained stable since 1984. Consequently, spina bifida rates among whites, blacks, and Hispanics were nearly identical in 1990.

This collaboration—the first effort among multiple state systems to characterize the incidence of a major preventable birth defect—represents a new direction in birth defects surveillance and epidemiology. More state birth defects surveillance programs are needed in the continued effort to improve knowledge and understanding of birth defects and to further the ability to intervene and prevent this important public health problem.

INTERPRETATION ISSUES

The objective of collecting birth defects surveillance data is to characterize, as well as possible, the birth defects prevalence in a population, using available resources. In the ideal birth defects surveillance system, population-based information is reported in a timely manner. The timely recognition of a birth defect **epidemic**, such as that resulting from the introduction of a new teratogen, depends on rapid reporting of accurate data on the occurrence of birth defects. Timeliness is also important in the identification of children for early intervention programs to prevent secondary disabilities.

Case Ascertainment

To minimize underreporting, case ascertainment should be comprehensive and should usually require a review of data from multiple sources. The inclusion of personal identifiers facilitates follow-up studies and allows investigators to link infant, maternal, and paternal records. To be effective, a birth defects surveillance system should include these characteristics:

- Accurate and precise diagnostic criteria.

- Etiologically and pathogenetically meaningful classification schemes.
- A large database, permitting rate comparison and analysis of trends in the birth prevalence of a relatively rare birth defect.
- The capability to analyze the occurrence of multiple malformations.
- The ability to conduct meaningful and timely analysis.
- A system to disseminate data in a timely manner.
- A mechanism to ensure confidentiality of patient records.

Capacity to Analyze Multiple Malformations

The ability to analyze the occurrence of multiple malformations is also important. Most known teratogens are associated with a spectrum of birth defect combinations. Many birth defects monitoring systems, however, examine trends in rates of single defects, not combinations of anomalies. In some instances, an increase in the rate of birth defects caused by a teratogen may be detected more rapidly by monitoring rates of defect combinations rather than rates of individual defects. The monitoring of multiple birth defects is most effective in instances in which infants exposed to a given teratogen tend to have specific combinations of defects.

Components of a Birth Defects Surveillance System

The components of a birth defects surveillance system include case definition and case ascertainment (including case sources and the method of surveillance used to ascertain cases) as well as data collection, analysis, follow-up, and dissemination.

Cases to be included in the birth defects surveillance system must be clearly defined. Is any birth in which the infant has even a minor birth defect considered a case, or are cases limited to births

in which the infants have at least one major malformation? CDC and a number of state systems maintain a well-developed list of birth defects that are considered normal variants or minor malformations, which are excluded from the case definition.

Age ranges of infants and children who are eligible for inclusion must also be specified (e.g., the newborn period, birth to 1 year, birth to 6 years). In determining which cases may be included, researchers must consider available resources for data collection and management.

Multiple-source case ascertainment provides the best potential for complete case finding. Usual data sources for birth defects surveillance systems include vital records (birth and death certificates), newborn or other hospital discharge summaries, hospital records, and data from cytogenetic laboratories. Each of these sources has strengths and weaknesses.

The advantages of using vital records are that they provide complete coverage of the population as well as some medical and parental data. Vital records also are a relatively inexpensive resource, and they provide data from previous years as well as the potential for follow-up of birth defects cases. The weaknesses of using vital records include the lack of timeliness in reporting data, the underreporting of birth defects (information is often limited to that obtained during the newborn period), and the lack of specific data on most birth defects.

Hospital discharge summary data on newborns are extremely useful in surveillance because they provide a more complete record of birth defects than birth certificates do; they are usually available within 6 months of discharge; they are already computerized and in digital form in many hospitals; and they allow potential follow-up of birth defects cases. Weaknesses of using hospital discharge summary data include the lack of maternal data; the lack of access to personal identifiers, which makes follow-up difficult; frequent difficulty in defining the population base; and frequent difficulty in establishing the representativeness of data. In addition, birth defects information may be incompletely recorded, or the data may reflect an incomplete diagnosis in the newborn period.

The strengths of multiple-source case ascertainment are that the system can be quite rapid, it allows a relatively complete recording, and diagnoses are more precise and accurate. In addition, researchers can more readily conduct follow-up studies of cases, and maternal and infant information is available.

Weaknesses of multiple-source case ascertainment include the expense which often limits use of this method to small populations and the time needed to establish baseline data.

Depending on the methods and sources of case ascertainment used, surveillance systems produce substantially varying birth defects rates (Table 2), ranging as high as 830 per 10,000 births (10).

Determining what data to collect is an important aspect of birth defects surveillance. Optimally, data should include precise descriptions of all birth defects, including syndrome identification by geneticists or dysmorphologists, demographic data, pregnancy history and other birth-related data, cytogenetic and laboratory data, family history, and etiologic information. These data provide the basis for initiating further follow-up studies. CDC currently recommends that workers in state birth defects surveillance programs collect a set of core data items (see the Appendix [11]).

Monitoring and Dissemination

By monitoring birth defects surveillance data, researchers can detect differing birth defects rates in different areas as well as rate changes over time. They can monitor the data by statistically evaluating the difference between observed and expected numbers of specific defects or defect combinations for a specified time in a specified area. Expected numbers are obtained from baseline prevalence data. Such comparisons may lead to the identification of clusters of birth defects; subsequent investigation of such clusters may yield useful etiologic information.

Researchers often conduct monitoring quarterly so they can determine whether flagged defects are increasing or decreasing. Such reviews may lead to investigations about the nature of the changes.

TABLE 2. Birth defects rates* determined by various surveillance approaches

Method and Source	Rate
Birth certificates [†]	88.9
Newborn hospital discharge data [§]	282.5
Mandatory hospital reporting data [¶]	248.0
Linked data sources ^{**}	336.0
Active hospital surveillance data ^{††}	415.0
Physical exam of infant ^{§§}	830.0

* Per 10,000 births.

[†] National Center for Health Statistics, CDC, 1982–1983.

[§] Birth Defects Monitoring Program, 1982–1985.

[¶] Nebraska Birth Defects Registry, 1982–1985.

^{**} Missouri Birth Defects Registry, 1980–1984.

^{††} Metropolitan Atlanta Congenital Defects Program, 1982–1987.

^{§§} Collaborative Perinatal Project, 1959–1966 (10).

Dissemination of data is another important component of a birth defects surveillance system. Routine compilation of rates, changing trends, and other findings are useful to health care providers and to state and local officials. Feedback is also helpful to physicians and hospital officials who support surveillance efforts by providing medical information.

EXAMPLES OF USING DATA

Surveillance systems have numerous functions that extend beyond searching for increases in the incidence of specific malformations to detect the introduction of new teratogens or increased exposure to old ones. They can be used to develop baseline data, provide timely rates, and identify geographic areas of concern for cluster investigations. Surveillance systems also provide the basis for both ecologic investigations and follow-up studies. By monitoring national and local birth defects rates, investigators can correlate changing trends with changes in cultural, social, or environmental factors.

Moreover, state birth defects surveillance systems are useful in identifying infants and children with birth defects. These case registries can be used for etiologic investigations, studies of economic impact, and follow-up studies to assess survival rates and the long-term effects of birth defects, including the development of cancer. Registries

developed from birth defects surveillance systems are also useful in testing hypotheses and in conducting descriptive epidemiologic studies of various malformations. Another possible role of birth defects surveillance is in the identification of children who need special education, social services, and other programs. The use of surveillance systems can also assist in the evaluation of programs and services, including those that use new prevention and intervention strategies, such as prenatal diagnosis and improved genetics counseling. Additionally, data from surveillance systems can be used to educate health professionals and community members about the extent of a particular problem and to respond to the public's health concerns about environmental agents.

The collaborative effort on spina bifida surveillance is one good example of how state-specific surveillance data can be used. Another example is BDMP, which has been useful in evaluating potential environmental teratogens in specific geographic areas. For example, a 1975 investigation of the association between vinyl chloride monomer and an increased incidence of central nervous system defects in West Virginia showed no relationship between exposure and outcome (12). In a 1978 evaluation of the effect of the massive swine-influenza vaccination, no association between vaccination and birth defects was found. In several descriptive studies, researchers have

used BDMP data to characterize cases according to geographic location, seasonal pattern, and race to identify populations and areas with high or low rates of particular defects. In addition, BDMP has been used as a source for both case and control subjects in various case-control studies. Researchers have also used the data to evaluate the effectiveness of surveillance in the National Congenital Rubella Syndrome Registry.

CDC's Birth Defects Risk Factor Surveillance Project is another example of how birth defects data can be used. This project, an additional component to the ongoing MACDP program, involves about 300 selected case subjects and 100 control subjects each year. Parental interviews are conducted to identify possible risk factors, and additional clinical and laboratory studies are performed to identify markers of exposure and susceptibility. In addition to implementing this program within MACDP, CDC has funded two cooperative agreements with state birth defects surveillance systems to begin establishing a population-based network of collaborative institutions that can conduct birth defects risk factor surveillance in addition to their ongoing surveillance activities. Collaboration between increasing numbers of state surveillance systems is critical to the success of birth defects epidemiology as well as intervention and prevention strategies.

FUTURE ISSUES

Organizing a System

The single most important activity in the planning process is to define the purposes of the program. The primary question is, "How will the data be used?" In the past, most monitoring efforts focused on the epidemiologic uses of the data. More recently developed programs have begun to apply surveillance data to service planning and evaluation, professional and community education, and advocacy. Ideally, both epidemiologic and service objectives can be met by a newly established system.

A key step in designing a birth defects surveillance system is to develop a coordinated and unified approach to mobilizing resources within a state. Such a plan, tied to documented local

and state needs, will help garner support for the program. A number of state agencies—in the areas of maternal and child health, genetics, developmental disabilities, epidemiology, vital statistics, and environmental health—have an interest in surveillance. Other organizations that may have an interest include university medical schools, voluntary agencies, advocacy groups, and the state legislature. Identifying potentially interested agencies and participants will facilitate the coordination of their efforts and also help establish a broad base of political and financial support. An advisory group can be helpful in obtaining community support and cooperation and in providing technical consultation.

Funding is a major determinant of the size and scope of a surveillance system. In most cases, creative funding approaches will be needed. States cannot count on obtaining funds from federal programs but must instead develop a base within the state for long-term support. In some cases, funding for systems can be underwritten by other programs in the health department that have peripheral interests in birth defects. A few states have obtained support from foundations, pharmaceutical companies, and universities, whereas others have obtained funding by linking the program to environmental issues. Other potential sources of funds within a state might come from the department of education, department of maternal and child health, department of environmental health, or developmental disabilities councils. In addition to state appropriations, other potential funding sources include Maternal and Child Health block grants and federal grants such as Special Projects of Regional and National Significance grants and grants from the National Institute of Child Health and Human Development and CDC.

Legislation

Before 1981, only Nebraska and New Jersey had legislation that required the reporting of birth defects to the state health department. Since 1981, 19 additional states have passed laws requiring the reporting of birth defects (Table 1). Four states have either pending or proposed legislation. Both the comprehensiveness and specificity of legislation in the various states differ substantially.

State planners should explore potential benefits and limitations of legislation early in the program development phase. Although legislation is not essential to the development and operation of a surveillance system, it can facilitate surveillance by providing 1) the authority and language to enforce rules and regulations regarding surveillance; 2) the authority to collect data for epidemiologic purposes or for case tracking, service provision, or follow-up; 3) a mandate for hospitals, physicians, and other providers to report birth defects; 4) specification of conditions and ages to be covered; 5) a means to access data on an individual patient while ensuring confidentiality; 6) designation of an organization to operate the surveillance activities; and 7) provisions for initial and continued funding. Each of these factors should be considered in drafting and introducing the legislation, because the mere omission or understatement of any single component may impede the full development of the surveillance system. For example, four states found their laws to be barriers because they were not specific enough in defining outcomes to be surveyed, and they did not provide the surveillance programs with enough authority to access data.

Researchers should draft birth defects surveillance legislation with a specific intent in mind and ensure that this intent is incorporated into the legislation. The legislation should define the purposes for which surveillance activities are undertaken such as epidemiologic surveillance, service provision, or both. This will also help states define outcomes and ages to be covered and the most important sources of data to be included.

For case-finding sources other than vital records, the legislation must provide surveillance systems with authority to require reporting, make available hospital discharge data, or allow a review of medical records. Legislation that allows access to hospital records provides surveillance systems with an opportunity to obtain more complete and reliable reporting of birth defects. Mandating reporting from various types of service providers ensures that the health community participates in the surveillance and that available malformation data sets are large enough to be useful.

Legislation that provides explicit authority and designates specific surveillance system functions decreases the need for continual interpretation of some broad authority to justify actions. The responsibility for enacting rules and regulations for reporting, determining reportable conditions, and developing and implementing reporting procedures must belong to the state health department and not be detailed in the legislation.

Surveillance systems often have a mandate to conduct various activities, including etiologic research, planning, evaluation, education, and service provision. Each of these activities requires the use of data on individual patients. Although confidentiality of patient data must be assured within the context of the program purposes and should be addressed in the legislation, confidentiality provisions should not be written in such a way as to inhibit the program from carrying out its lawful functions.

Year 2000 Objectives

Objective 22 of the year 2000 objectives outlines the necessity for conducting and coordinating birth defects surveillance (13). Such programs can play an important role in defining problems and evaluating prevention programs. Adverse reproductive outcomes in general can be reduced through combined efforts—at the international, federal, state, and local levels—involving voluntary organizations, businesses, industries, and health professionals.

Developing a uniform approach that various programs can use to collect and analyze data is a major challenge. By responding to that challenge, we can further improve our knowledge of the causes of birth defects, develop preventive strategies, and assist in the evaluation and delivery of services to children with birth defects.

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APPENDIX. Core data items for collection by state birth defects surveillance programs, as recommended by CDC's National Center for Health Statistics*

Data Item	Recommended Level of Inclusion	Recommended Use of Data	Recommended by NCHS
I. Infant			
A. Date of birth (month/day/year)	Recommended	National	Yes
B. Sex (male, female, ambiguous, unknown)	Recommended	National	Yes
C. Race (generated from parents)	Optional	National	Yes
D. Ethnicity (collected separately from race)	Optional	National	Yes
E. Name (including any alias)	Recommended	State	Yes
F. Unique health identifier	Optional	State	No
G. Date of Report (month/day/year)	Recommended	National	Yes
H. Source of report (name, phone)	Recommended	National	Yes
I. Residence			
1. Mother at infant's birth			
City/county/state	Recommended	National	Yes
ZIP code	Recommended	National	Yes
Census tract (derived from address)	Optional	State	No
2. Mother at conception			
	Optional	National	No

APPENDIX. Core data items for collection by state birth defects surveillance programs, as recommended by CDC's National Center for Health Statistics* – continued

Data Item	Recommended Level of Inclusion	Recommended Use of Data	Recommended by NCHS
J. Place of birth	Recommended	National	Yes
1. Country	Recommended	National	Yes
2. City	Recommended	National	Yes
3. State	Recommended	National	Yes
4. County	Recommended	National	Yes
5. ZIP code	Recommended	National	No
6. Name of hospital/code	Recommended	State	Yes
K. Pregnancy outcome			
1. Live birth	Recommended	National	Yes
2. Still birth at >20 weeks	Recommended	National	Yes
3. Induced abortion	Optional	National	Yes
4. Spontaneous abortion	Optional	National	Yes
5. Unknown abortion	Optional	National	Yes
L. Birth weight in grams	Recommended	National	Yes
M. Apgar score	Optional	National	Yes
N. Plurality	Recommended	National	Yes
O. Gestational age			
1. By last menstrual period	Recommended	National	Yes
2. By newborn examination	Optional	National	Yes
3. By ultrasound	Optional	National	No
P. Diagnosis (description of all defects)	Recommended	National	No
Q. Source and place of diagnosis	Optional	National	No
R. Date of each diagnosis	Recommended	National	No
S. Date of death (month/day/year)	Recommended	National	Yes
T. Place of death			
1. Country	Recommended	National	Yes
2. City/state/county	Recommended	National	Yes
3. ZIP code	Recommended	National	Yes
4. Name of hospital/code	Optional	State	Yes
U. Cytogenetic studies			
1. Performed (yes, no, unknown)	Recommended	National	No
2. Results	Optional	National	No
V. Autopsy			
1. Performed (yes, no, unknown)	Recommended	National	Yes
2. Results	Optional	National	No

APPENDIX. Core data items for collection by state birth defects surveillance programs, as recommended by CDC's National Center for Health Statistics*— continued

Data Item	Recommended Level of Inclusion	Recommended Use of Data	Recommended by NCHS
W. Physicians of record			
1. Pediatrician/obstetrician/family physician (name, phone)	Recommended	State	No
II. Mother			
A. Date of birth (month/day/year)	Recommended	National	Yes
B. Race	Recommended	National	Yes
C. Ethnicity (collected separately from race)	Optional	National	Yes
D. Name (including maiden surname for matching)	Recommended	State	Yes
E. Unique health identifier	Optional	State	No
F. Occupation			
1. Usual	Optional	National	No
2. At time of conception or during first trimester	Optional	National	No
G. Education	Recommended	National	Yes
H. Method of payment	Optional	National	No
I. Summary totals of mother's previous pregnancies			
1. Total of previous pregnancies	Recommended	National	Yes
2. Live births	Recommended	National	Yes
3. Still births at >20 weeks	Recommended	National	No
4. Spontaneous abortions	Recommended	National	No
5. Induced abortions	Recommended	National	No
6. Neonatal deaths	Recommended	National	No
7. Postneonatal deaths	Recommended	National	No
8. Total number of pregnancies	Optional	National	No
J. Risk factors for the current pregnancy			
1. Complications during pregnancy	Recommended	National	Yes
2. Illnesses or conditions during pregnancy	Recommended	National	Yes
3. Complications of labor and delivery	Optional	National	Yes
4. Method of delivery	Optional	National	Yes
5. Month prenatal care began	Optional	National	Yes
6. Number of prenatal visits	Optional	National	Yes
7. Parentally identified teratogenic exposures	Optional	National	No
8. Use of tobacco	Optional	National	Yes
9. Use of alcohol	Optional	National	Yes

APPENDIX. Core data items for collection by state birth defects surveillance programs, as recommended by CDC's National Center for Health Statistics*— continued

Data Item	Recommended Level of Inclusion	Recommended Use of Data	Recommended by NCHS
10. Use of nonprescription drugs	Optional	National	No
11. Prenatal diagnostic procedures	Optional	National	Yes
12. Family history of malformations	Optional	National	No
III. Father			
A. Date of birth (month/day/year)	Recommended	National	Yes
B. Race	Recommended	National	Yes
C. Ethnicity (collected separately from race)	Optional	National	Yes
D. Name	Optional	State	Yes
E. Unique health identifier	Optional	State	No
F. Occupation			
1. Usual	Optional	National	No
2. At time of conception or during first trimester	Optional	National	No
G. Education	Optional	National	Yes

* Adapted from Lynberg and Edmonds (11).

