

*Appendix 6.1*

*Data Source Described in Detail – Vital Records*

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#### Source or Site

- Birth certificates
- Fetal death certificates
- Elective termination reports
- Death certificates

Birth, death, and fetal death certificates provide a standardized way of reporting vital events that occur in a politically defined unit, a state. Vital records include facts about an individual and the specific circumstances regarding the reported event. Vital records are particularly important in that they fulfill two significant functions: they provide a mechanism for registering the occurrence of vital events, and they provide a mechanism for collecting demographic, social, and health information regarding the person in a standardized way. Integral to these functions is the fact that they are population based.

#### Legal or Professional Mandates

Federal law mandates birth and death registration. The lead federal agency is the National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention (CDC). NCHS maintains the national birth and death registration system and is the recipient of vital records data from the states and territories. Recording births and deaths is the responsibility of the individual states and territories. The procedures and regulations regarding the reporting of these vital events are established by the individual states and territories. NCHS provides guidelines and recommendations for standardization of the information collected by birth and death certificates by promulgating standard certificates. Although federal law does not mandate the reporting of fetal deaths, there is an NCHS-recommended standard fetal death certificate. See <http://www.cdc.gov/nchs> for further information.

#### Mission or Objective

Provides a population-based statistical database of all births and deaths that occur in the United States.

#### Scope or Breadth

The birth, death, and fetal death certificates provide for registration of a defined vital event at a point in time. There are established criteria for what constitutes a live birth, but there is evidence to suggest that those criteria are not always followed. Registration of fetal deaths is usually defined on the basis of gestational age, with  $\geq 20$  weeks as the cut-off used by most states. Some states require the reporting of all fetal deaths, regardless of gestational age, and there is recognized underreporting of early fetal deaths.

## Operational Structure

- *Data.* NCHS recommends standard data elements on birth and death (and fetal death) certificates. States are required to complete a minimum data set for national reporting and may add other data elements to their certificates. The birth certificate is usually revised and updated every decade. In 2003, the final drafts of a new version of the certificate are being reviewed. Please refer to <http://www.cdc.gov/nchs> for further information.
- *Certification.* State statutes, regulations, and procedures stipulate who is responsible for certifying a live birth, death, or fetal death. The designated person is required to certify date, time, and place of birth/death as well as other priority areas on the certificate. The completion of death certificates has additional protocols, procedures, and instructions because of the many circumstances that may surround a death.
- *Filing the certificate.* State statutes, regulations, and procedures stipulate time requirements for filing. Although the timing varies among states, the certificate is usually filed with the state registrar's office within 5 to 10 days of the event. Many states now have methods for entering and filing birth certificates electronically. The timing for filing a fetal death certificate depends on state guidelines. Although filing a death certificate is required within a specified time period, it may not be complete at filing, as some data elements may be missing due to autopsy, coroner investigation, or other legal proceeding. These data may or may not be added subsequently and the certificate revised.
- *Unique identification of an individual event.* Each state has a numbering system that uniquely identifies the respective event.
- *Storing the information.* Most states have a centralized database specifically designed to collect, amend, transmit, retrieve, sort, print, and analyze vital records information.
- *Reciprocity.* Agreements with bordering states ensure reporting of life events occurring in neighboring states to the state of residence.

## Types of Information Collected

- NCHS and other interested parties have developed a set of standardized data elements or **minimum data variables** that are required to be reported, as well as a set of **recommended data variables** and recommended standard certificates. Of importance is the unique identifying information per person, per event.
- The birth certificate and fetal death certificate are each divided into two sections: legal and statistical. The **legal section** contains the unique identifying information about the person, date, time, place, and type of life event. It is this portion of the certificate that registers the vital event. The information in the legal section is certified, and this is the part of the certificate that is issued to individuals when proof of the life event is required. The **statistical section** – labeled “Information for medical and health purposes only” – contains demographic, prenatal care, pregnancy risk factors, and medical conditions of the mother and of the newborn, including congenital anomalies. The statistical part is not released to the public, and many states do not keep the statistical part attached to the legal certificate. The statistical information is usually data entered and maintained in a database.
- The death certificate is a certified legal document, and it is available to authorized individuals in its entirety.

## Accessibility and Retrievability

States transmit vital records information to NCHS electronically. State laws and regulations stipulate how the information is made available for other users at the state level. Due to the confidentiality of the information, states protect the medical and health information on vital records from unwarranted or indiscriminate disclosure. Most states have legal safeguards in place to further protect the information.

- The information contained in the birth, death, and fetal death master index computer file is usually available to authorized public health programs. Sometimes confidentiality or security agreements are required.
- Many states copy the legal sections of the hard copy certificate into a permanent electronic storage format (e.g., microfiche, film, CD-ROM). The storage format is cataloged for easy information retrieval.

## Strengths as a Data Source

- *Timeliness.* Electronic filing allows information to be available to users as soon as the reports are filed in the state database. This may be as early as 30 days after the event.
- *Population base.* Provides statistical and denominator data.
- *Unique identification.* States assign a unique ID to each person, per vital event.
- *Legality of case report.* State laws require that some information must be certified for all births and deaths. Additional attention to legal procedures is required for death registration.
- *Comprehensiveness as a data source.* Over 97 percent of all births occur in a hospital or birthing facility. Out-of-hospital births are also registered because of the necessity for a child to have a birth certificate. There may be some underreporting of early infant deaths, and there is marked underreporting of fetal deaths at early gestational ages.
- *Existing data set and one that is accessible over time.* There is historical depth to vital records, but there have been major changes in format, content, and coding over time.
- *Record linkage.* Useful in combination with other data for building the case record. The use of unique identifying information permits matching and linking with other data sources. Many states routinely link vital records to each other, for example a death certificate with the birth certificate, providing a linked birth-infant death file.
- *Risk factor screening tool.* Some data elements can be used to identify potential birth defects cases. Examples include: low birth weight, prematurity, low Apgar scores, neonatal death, multiple births.
- *Intervention.* The availability of information in a timely manner is conducive to rapid intervention or investigation.

## Weaknesses as a Data Source

- *Data quality.* Much of the medical information on the certificate has been shown not to be reliable.
- *Case ascertainment.* The birth certificate has been shown to underreport birth defects. As shown in Section 6.4, rates from this source are 1.5 percent, compared to 3 to 4 percent for hospital reporting and from using linked data sources.

## Liaisons and Partnerships

- *Vital records/registrar's office.* These are staff that are involved in managing the activities involved in filing the certificate. These staff often go to hospitals to train personnel in the procedures and methods of filling out the certificate. Other activities include amending a certificate, maintaining the centralized database, and cross-referencing other vital record certificates.
- *Hospital.* These are staff that are involved in providing information for completing the certificate. Includes medical records services, neonatal nursing, labor and delivery unit staff.

## Hints and Tips

- *Neonatal and infant death.* A death certificate is issued upon death for any infant who was live born, regardless of duration of the pregnancy. These individuals will have a birth and a death certificate. There is no distinction in death certificates for 'neonatal' or 'infant' deaths. Many vital records divisions cross reference the birth and death certificate numbers to make sure that a birth certificate is issued if a neonatal or infant death is reported. Sometimes, the facility will overlook filing a birth certificate for an early neonatal death. Sometimes a fetal death certificate is filed as well as a birth certificate and/or a death certificate. In these situations further investigation should occur to determine the actual vital status at birth.
- *The timing for filing birth and death certificates is similar.* However, often the birth certificate is processed by vital records more quickly since many hospitals use the electronic birth certificate. It is important for birth defects programs to be aware of these timing issues if they refer children to services, especially if they refer children based on low birth weight, prematurity, and other severe conditions. Regardless of how quickly a case report is sent to the surveillance program, it is a wise practice to allow a period of time to elapse before referring a child with severe conditions. A time period to consider before referring a child to services is 60 to 90 days past the date of birth.
- *Fetal death certificate.* This certificate is usually issued for any pregnancy that results in a non-live outcome at the end of a pregnancy that is  $\geq 20$  weeks gestational age. What constitutes 'live' is subject to legal definition, and most states have clear guidelines in state statutes for what is considered a 'live birth'. Some states accept any sign of life (e.g., a pulse), regardless of the intent for the delivery (e.g., elective termination). Surveillance systems need to understand the definition of 'live birth' in their state. There may be instances when an Apgar score is a very low number (e.g., 1) at the first minute, and 0 for the fifth minute. Some states might count this as a live birth or a termination, depending on the age of the fetus and intent of the delivery. Some states have guidelines that exclude filing a fetal death certificate if the intent of the pregnancy delivery is for a termination, regardless of the gestational age.
- *Termination reports.* Some states collect statistical information on terminations. Often there is no identifying information; however, a birth defect may be listed as a reason for the termination. In most instances these reports do not have sufficient identifying information to link to an individual. Additionally, although some states require the filing of these reports, compliance is notably poor, such that there is an underreporting of these events and conditions.

## References

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