



STATE OF TENNESSEE
Department of Health
Office of Policy, Planning and Assessment
Division of Health Statistics
Cordell Hull Building, 4th Floor
425 Fifth Avenue North
Nashville, TN 37247-5262

HEALTH DATA RELEASE POLICY

SYSTEM NAME: Fetal Death Statistical System

DESCRIPTION: This health data release policy applies to the release of individual-level records from the fetal death statistical system. Computerized information for each fetal death occurring in Tennessee* is captured from fetal death reports submitted to the Department. As defined in Tennessee Code Annotated 68-3-102, fetal death means death prior to the complete expulsion or extraction from its mother of a product of human conception; the death is indicated by the fact that after such expulsion or extraction the fetus does not breathe or show any other evidence of life such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles. By law, a fetal death must be reported to the Department if the weight of the fetus is 500 grams or more, or in absence of weight, if the completed weeks of gestation is 22 weeks or more. Included in this data file is identifying information (such as mother's name and address), demographic information (such as mother's age, and sex of the fetus) and general information about the fetal death (such as date and place of fetal death). Other information from the fetal death report, such as time of fetal death, and occupation/industry of the mother and father, is not maintained on the fetal death data system.

*It is important to note that not all fetal deaths to Tennesseans occur in Tennessee, and not all fetal deaths that occur in Tennessee are to residents. This file includes all fetal deaths occurring in Tennessee (recorded in Tennessee) regardless of residence. This file does not include data on induced terminations of pregnancy; such data are reported using different report forms and procedures.

GENERAL ACCESSIBILITY: Release of individual fetal death records includes access to identifying information (such as mother's name and address). All identifying data captured from the fetal death report is considered confidential and access will be limited to approved research projects only.

Access to fetal death data differs based on the type of request being made. Generally, there are two types of requests for fetal death data: 1) research related requests, and 2) requests to support program activities of governmental agencies.

Access to identifying and confidential information from individual fetal death records for those events that occurred in Tennessee can be provided once a **Request for Data** form is completed by the requester and the access to data has been approved by the Department of Health. All research related projects requesting access to confidential data with identifying factors where the individual will not be contacted must be approved by either an Institutional Review Board (IRB) or the Health Data Policy Committee. Reviews made by the Health Data Policy Committee will use the information provided on the **Request for Data** form. For research related requests where individuals or the families of individuals will be contacted during the project, the Department of Health's IRB must provide approval. If approved, research related requests may have access to fetal death record information before it is considered final (see ACCESS TO PROVISIONAL DATA below).

HEALTH DATA RELEASE POLICY

Fetal Death Statistical System (continued)

ACCESS TO PROVISIONAL DATA: The term “provisional data” is used to describe a data file which is not considered to be finalized. For example, providing 2003 fetal death records to a researcher during 2003 would mean providing access to provisional data. Not all 2003 fetal death records would be available, and some data elements within individual records could be changed prior to the file being designated as “final”. (Most often, changes to data within the record occur when the original record is submitted with incomplete information or when the original record is submitted with inconsistent information.) Fetal death data for each calendar year is normally considered final by September of the following year (e.g., 2003 fetal death data was final by September 2004).

Since provisional data indicates only a “snapshot” of the data at that point in time, data users need to be aware that a “snapshot” of the same data at a later point in time may reflect significant differences in any data summary or analysis.

INACCESSIBLE RECORDS: Identifying information from the individual-level fetal death record for events that occurred outside Tennessee to residents of Tennessee is not accessible. The state where the event occurred must provide access to the individual fetal death record information since the event was recorded there. Tennessee receives notice from other states regarding resident events occurring outside Tennessee through the Vital Statistics Cooperative Program Interstate Exchange Agreement. According to this agreement, statistical information from these out-of-state records can be provided in summary form (e.g., numbers by race/sex/age can be included in Tennessee resident event totals); however, identifying information on a record by record basis is restricted.

CHARGE POLICY: Fetal death data will be provided at no charge.

PROVISION OF DATA: All data will be supplied in a fixed format text file. Depending on the number of records, data will be supplied on floppy disk or 3480 cartridge.

The data file will contain all records accessible for a given year. Requesters will be provided with documentation (code sheets and file layouts) to correctly interpret the data. Requesters will be required to customize the data set as needed to meet their needs.

Data cannot be released to any other organization.

BREACHES OF CONFIDENTIALITY: The Department of Health may choose to take legal action if confidentiality is breached. Breaches of confidentiality will require the requester to immediately cease use of the data; return all data to the department; and forfeit all rights to access data in the future.