

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: Death Statistical System

DESCRIPTION: This health data release policy applies to the release of individual-level records from the death statistical system. Computerized information for each death <u>occurring in Tennessee*</u> is captured from death certificates. Included in this data file is identifying information (such as name, address, and social security number), demographic information (such as age, race, and sex of the decedent) and general information about the death (such as date and place of death). Other information from the death certificate, such as time of death and burial information, is not maintained on the death data system.

*It is important to note that not all Tennesseans die in Tennessee, and not all those who die in Tennessee are residents. This file includes all deaths occurring in Tennessee (recorded in Tennessee) regardless of residence.

GENERAL ACCESSIBILITY: Release of individual death records includes access to identifying information (such as name and address). Data captured (or generated) from the death certificate related to cause of death is considered confidential and access will be limited to approved research projects only.

Access to death data differs based on the type of request being made. Generally, there are three types of requests for death data: 1) research related requests, 2) requests to support program activities of local and state governmental agencies, and 3) requests from public agencies and businesses.

For research related requests, access to identifying and confidential information from individual 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 death record information before it is considered final (see ACCESS TO PROVISIONAL DATA below).

For requests to support program activities of local and state governmental agencies, access to identifying information from individual 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. If approved, governmental agency requests may have access to death record information before it is considered final (see ACCESS TO PROVISIONAL DATA below).

<u>Note:</u> If a governmental agency is doing research and needs access to confidential data, they must meet the requirements under research related requests.

<u>For public access to identifying information from death records</u>, there will be a charge for file preparation (see CHARGE POLICY section below).

HEALTH DATA RELEASE POLICY Death Statistical System (continued)

If the request is from the media (e.g., newspaper, radio, television, etc.), the Public Information Officer for the department should be notified before releasing the information.

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 death records to a researcher during 2003 would mean providing access to provisional data. Not all 2003 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.) Death data for each calendar year is normally considered final by September of the following year (e.g., 2003 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.

INFORMATION NOT ACCESSIBLE:

1. **FIELDS DESIGNATED AS CONFIDENTIAL BY STATUTE:** In Tennessee, cause of death information is considered confidential by statute. This protection extends to any fields that may be generated based on cause (or multiple cause) codes, such as cause of death group code. Computerized information from the record that would identify an individual's underlying cause of death (or multiple causes, if year of death = 1998 or later) is accessible only to approved health-related research projects. (Note that Social Security Number of decedent is not protected and may be provided to approved applicants.)

Confidential information with personal identifiers is accessible only to approved research projects.

2. RECORDS: Identifying information from the individual-level death record for events that occurred <u>outside Tennessee</u> to residents of Tennessee is not accessible. The state where the event occurred must provide access to the individual 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: Requests for public access to death data will be charged ten cents (\$0.10) per record plus processing costs of \$70 per annual data file for a computer file. The \$70 per annual data file charge covers the costs associated with processing the request for death information (including computer run time, output media, employee time, and mailing costs).

Access to individual-level death data may be provided at no charge to university-affiliated research organizations, Tennessee state and local government agencies, and other non-profit entities. Charges may be waived by the Commissioner for agencies who submit data to the Department in compliance with Tennessee statutes.

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 <u>and</u> all variables EXCEPT those protected by statute (unless access to confidential data has been approved). 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.

HEALTH DATA RELEASE POLICY

Death Statistical System (continued)

Data cannot be resold or released to any other organization.

BREACHES OF CONFIDENTIALITY: The Tennessee 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.

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