

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: Birth Statistical System

**DESCRIPTION:** This health data release policy applies to the release of individual-level records from the birth statistical system. Computerized information for each birth occurring in Tennessee\* is captured from birth certificates. Included in this data file is identifying information (such as infant's name, mother's name and address), demographic information (such as mother's age, and sex of the infant) and general information about the birth (such as date and place of birth). Other information from the birth certificate, such as time of birth, father's birthplace, and occupation/industry of the mother and father, is not maintained on the birth data system.

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

**GENERAL ACCESSIBILITY:** Release of individual birth records includes access to identifying information (such as name of infant, mother's name and address). Some data captured from the birth certificate is considered confidential (such as medical risk factors of the mother, congenital anomalies of the infant) and access will be limited to approved research projects only.

Access to birth data differs based on the type of request being made. Generally, there are three types of requests for birth 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.

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

<u>For requests to support program activities of local and state governmental agencies</u>, access to identifying information from individual birth 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 birth record information before it is considered final (see ACCESS TO PROVISIONAL DATA below).

## HEALTH DATA RELEASE POLICY Birth Statistical System (continued)

<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 birth records</u>, there will be a delay in availability. The public release of birth data will be restricted for 18 months after the end of the calendar year. For example, birth data for 2003 would be available for public release after June 30, 2005.

This delay in public access is necessary to protect the identity of the family of infants who may be adopted or who may die within the first year of life. Since the legal process surrounding adoptions is time consuming, the Department may not be notified for 12 to 18 months after a birth that a particular infant was adopted. Although some adoptions do occur after this time period, it is estimated that the 18 month delay will provide protection in the vast majority of cases. This delay will also allow the birth record to be flagged if the child dies within the first year of life. The families of these infants do not want to be contacted about the birth of their child who died.

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 birth records to a researcher during 2003 would mean providing access to provisional data. Not all 2003 birth 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.) Birth data for each calendar year is normally considered final by September of the following year (e.g., 2003 birth 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, the following fields are considered confidential by statute:
  - Mother's Social Security Number
  - Father's Social Security Number
  - Mother's Race
  - Father's Race
  - Mother's Hispanic Origin
  - Father's Hispanic Origin
  - Mother's Education
  - Father's Education
  - Mother's Pregnancy History (Live births Now Living, Live Births Now Dead, Date of Last Live Birth, Other Terminations, Date of Last Other Termination)
  - Mother's Marital Status
  - Date Last Normal Menses Began
  - Month Prenatal Care Began
  - Number of Prenatal Visits
  - Birthweight
  - Clinical Estimate of Gestation
  - Plurality
  - Birth Order, if not single birth
  - Apgar Score (at 1 minute and at 5 minutes)
  - Mother transferred from another facility prior to delivery?

## HEALTH DATA RELEASE POLICY

Birth Statistical System (continued)

- Infant transferred to another facility after delivery?
- Mother's Medical Risk Factors
- Other Risk Factors (tobacco use, alcohol use, weight gain, chemical substance abuse)
- Obstetric Procedures
- Complications of Labor and/or Delivery
- Method of Delivery
- Abnormal Conditions of the Newborn
- Congenital Anomalies of Child

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

2. RECORDS: Identifying information from the individual-level birth 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 birth 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 birth data will be charged ten cents (\$0.10) per record plus processing costs of \$150 per annual data file for a computer file. The \$150 per annual data file charge covers the costs associated with processing the request for birth information (including computer run time, extra processing required to compare birth records to the Vital Records database which contains indicators for infants who were adopted or infants to died prior to 1 year of age, output media, employee time, and mailing costs).

Access to individual-level birth 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.

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.