



Texas Department of State Health Services
November 2012



Texas Cancer Registry

Texas Cancer Registry Limited-Use Data Agreement

Protecting patient confidentiality and other protected health information (PHI) is paramount to the Texas Cancer Registry (TCR), Cancer Epidemiology and Surveillance Branch, Texas Department of State Health Services (DSHS) and required by state law and rule (Health and Safety Code, §82.009; Texas Administrative Code, Title 25, Part 1, Chapter 91, Subchapter A). All personal identifiers (name, date of birth (excluding year), social security number, address (excluding county), census tract, block, latitude/longitude, reporting health care facility, pathology laboratory, or health care practitioner) must be removed from data before release, unless prior approval is obtained from the DSHS-IRB. Limited Use data, or any de-identified data provided in electronic format, does include certain demographic information such as sex, race, etc. for research purposes. We require that all research results be presented/published in a manner that ensures that no individual can be identified. In addition, there must be no attempt to identify individuals either from any computer file, or by linking with a computer file containing patient identifiers.

Instructions: Before we can provide a limited-use dataset, please complete and return this form to the Texas Cancer Registry at cancerdata@dshs.state.tx.us or fax to 512-458-7681; Attn: Cancer Data.

1. Name and address of person, title, agency/institution requesting access to data.

2. Name, degree(s), title, mailing address, email address, and phone number of person who will direct the project or study.

3. Summary/synopsis of the project or study.

4. Is the project or study funded? Yes No

If yes, please list the funding entity.

In order for the Texas Cancer Registry to provide a limited-use or another version of data to you, it is necessary that you agree to the following provisions.

1. You will not use nor permit others to use data in any way other than for statistical reporting and analysis for research purposes. If you discover a breach of confidential information, you must notify the Texas Cancer Registry without delay (John Hopkins, Core Business Operations Manager, or Melanie Williams (512)458-7523), describing the known facts of the incident, and the immediate mitigation steps taken, so that we can begin the process of mitigating the effect of the breach and prevent any additional loss of data as soon as possible.
2. You will not present/publish data in which any individual can be identified. You will not publish any statistics on a single individual including any information generated on an individual case by the case listing session of SEER*Stat, or any other analysis software. In addition, publication of small cell sizes should be avoided.
3. You will not attempt to link nor permit others to link the data with individually identified records in another data base.
4. You will not attempt to learn the identity of any person whose cancer data is contained in the supplied file(s).
5. If the identity of any person is discovered inadvertently, then the following must be done:
 - 1) No use will be made of this knowledge,
 - 2) The TCR will be notified of the incident without delay (John Hopkins, Core Business Operations Manager, or Melanie Williams, Branch Manager, (512)458-7523),
 - 3) No one else will be informed of the discovered identity.

6. You will not release nor permit others to release the data in full or in part to any person except with the written approval of the Texas Cancer Registry. In particular, all members of the research team who have access to the data must have signed data-use agreements.

7. You will use appropriate safeguards to prevent use or disclosure of the information other than as provided for by this data-use agreement. If accessing the data from a centralized location on a time sharing computer or LAN with SEER*Stat or another statistical package, you will not share your logon name and password with any other individuals. You will also not allow any other individuals to use your computer account after you have logged on with your logon name and password.

8. The source of information should be cited in all publications. The appropriate data citation is associated with the specific data file used. In addition, the TCR requests that you include the following statement of acknowledgement in the text or frontispiece of the presentation, report or publication: "Cancer incidence data have been provided by the Texas Cancer Registry, Cancer Epidemiology and Surveillance Branch, Texas Department of State Health Services, PO Box 149347, Austin, Texas, 78756".

My signature indicates that I agree to comply with the above stated provisions.

Signature

Date

Printed Name

Printed Title

Phone Number

Please indicate format of requested dataset:

SEER*Stat Cancer Incidence dataset

Please check if this agreement form is for the use of an existing dataset you already have:

SAS Cancer Incidence dataset

Name of Person Responsible: _____.

Data Request Number _____ (Internal Use Only)