



Texas Cancer Registry Limited-Use Data Request Form

Background: 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, telephone number, and date of diagnosis] 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 and race, for research purposes. The TCR requires 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 another source of data containing patient identifiers.

Instructions: Before the TCR can provide a limited-use dataset, please complete and return this form to the TCR at CancerData@dshs.texas.gov or fax to 512-776-7681, Attn: TCR Epidemiology Group.

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

Ms. Dileka Gunawardana
95 Deerfield Drive, Easton, CT
UT Health Houston

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

Ms. Dileka Gunawardana, BS in Statistics from Rice University (expected graduation 2022)
Same information as above

3. Summary/synopsis of the project or study:

Understanding, modeling & visualizing the spatiotemporal relationships of various types of lung cancers across the state of Texas.

4. Is the project or study funded? ☒ Yes ☐ No

If yes, please list the funding entity:

CPRIT

In order for the TCR 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 TCR without delay (Saroj Rai, Epidemiology Manager, 512-776-3515, or Melanie Williams, Branch Director, 512-776-3633), 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 database.
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:
 - a. No use will be made of this knowledge;
 - b. TCR Branch Director, Melanie Williams, PhD, be notified of the incident immediately by calling 512-776-3633 and/or emailing Melanie.Williams@dshs.texas.gov; and
 - c. 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 TCR. 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, 1100 West 49th Street, Austin, TX 78756."

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



Signature

6/15/20
Date

Dileka Gunawardana
Printed Name

203-644-2968
Phone Number

Ms.
Title

Please indicate format of requested data set:

☒ SEER*Stat Cancer Incidence data set

☐ SAS Cancer Incidence data set

Name of Person Responsible: Dileka Gunawardana

Data Request Number: _____ (Internal Use Only)