

Data Release Policy

October 2021

Purpose

The Texas Cancer Registry (TCR) analyzes and disseminates cancer incidence and mortality data to assist with health care assessment, evaluation, and planning, identifying populations at increased risk of cancer, facilitating research related to cancer etiology, prevention, and control, monitoring trends in cancer incidence and mortality so that appropriate and timely interventions are undertaken, and investigating public cancer concerns.

TCR Data Release Goals

1. Maximize Texas cancer incidence and mortality data availability and use;
2. Release meaningful and epidemiologically sound cancer incidence and mortality data, while still maintaining the privacy of individuals and small populations;
3. Provide data at a level sufficient to answer a customer's question, while still protecting the confidentiality of the cancer patient and/or cancer reporting entity; and
4. Comply with all federal and state laws, rules, and Texas Department of State Health Services (DSHS) policy.

Confidentiality

Protecting patient confidentiality and protected health information is paramount to the TCR and required by [state law and rules \(Health and Safety Code, Section 82.009 and Texas Administrative Code, Title 25, Chapter 91, Subchapter A, respectively\)](#). Subsequently, the following procedures have been developed for releasing individual record level cancer incidence data and aggregate statistics.

Please note that the statement "may be released" is permissive, and should not be interpreted to mean, "is required to be released." If at any time upon review of a data request there is concern regarding the protection of patient confidentiality or other restricted health information, the TCR has the discretion to request prior review and approval by the DSHS [Institutional Review Board \(IRB\)](#) and/or the DSHS Office of General Counsel before releasing any data.

Standard Methods used by the TCR for Minimizing Risk of Patient or Reporting Entity Disclosure

1. Release aggregate rather than individual record level de-identified data.
2. Release de-identified rather than identified individual record level data.
3. Apply numerator/denominator rules for data aggregation/cell suppression.
4. Employ complimentary suppression.
5. Reduce geographic specificity.
6. Aggregate years of data.
7. Remove extremely rare events (e.g., transsexual cancers, prostate cancer in a male less than 20 years old).
8. Provide only those variables necessary to answer the customer question.
9. Categorize and recode variables to aggregate data values (e.g., provide age groups rather than individual age, provide year of birth rather than birthdate, provide age at diagnosis or diagnosis year rather than date of diagnosis).

Requested Citation / Acknowledgement of TCR Data Use

The TCR requests that any person or organization reporting results or analyses using cancer incidence and/or mortality data provided by the TCR include the following acknowledgement statement in the analysis, presentation, report, or publication:

"Cancer 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, <https://www.dshs.texas.gov/tcr/>."

Data Charges

The TCR reserves the right to charge for data requests at any time. The TCR will notify you in advance of fulfilling the request if charges will be assessed.

Release of Texas Cancer Incidence Data

1. No person will attempt to use these data to learn the identity of any person or cancer reporting entity without prior DSHS IRB approval.

2. If the identity of any person or cancer reporting entity should be discovered inadvertently:
 - No use will be made of this knowledge;
 - The TCR Branch Manager, Melanie Williams, Ph.D., will be advised immediately of the incident by calling 512-776-3633 and/or emailing Melanie.Williams@dshs.texas.gov;
 - The information that would identify an individual or cancer reporting entity will be safeguarded or destroyed, as requested by the TCR; and
 - No one else will be informed of the discovery.
3. Data requests will be completed using the most current and complete Texas resident cancer incidence data available. Statewide data are at least 90% complete before being used, in accordance with national cancer surveillance standards.
4. Data files containing individual cancer records with personal identifiers will not contain cancer records reported to the TCR by other state cancer registries or the Veterans Health Administration (VHA) due to their confidentiality requirements. De-identified files and aggregate statistical analyses will contain these records. Out of state and VHA reported Texas resident cases account for less than 4% percent of the total cancer incidence file.
5. Texas cancer rates and associated counts are suppressed when there are fewer than 16 cases on public query tools, such as the Web Query Tool (cancer-rates.info/tx/) and others provided by the National Program of Central Cancer Registries (NPCR) at the Centers for Disease Control and Prevention (CDC), the North American Association of Central Cancer Registries (NAACCR), and the Surveillance and Epidemiology End Results (SEER) Program at the National Cancer Institute (NCI). Customers may contact the TCR at cancerdata@dshs.texas.gov to request data that are not provided on these public tools.
6. Counts alone at the county or state level will not be suppressed when a request is made directly to cancerdata@dshs.texas.gov and evaluated by the TCR. This is due to the large number of Texas counties that have small populations and the responsibility to provide cancer data for all 254 counties in Texas.

7. Rates at the county or state level will be provided without suppression so long as confidence intervals and/or standard errors are provided to allow for evaluation of statistical reliability. An incidence or mortality rate based on fewer than 16–20 cases or deaths will likely result in an unreliable/unstable rate. A rate is not considered statistically reliable if the standard error of the rate is at least 25 percent as large as the rate itself and/or the 95% confidence interval around the rate is at least as large as the rate itself.
8. Social security number will not be released by DSHS and can only be used for linking purposes.
9. All statewide, public health region, council of regional government, or county level data may be released for single years without concern for cell size.
10. DSHS IRB approval must be obtained for release of less than three years combined zip code level data.
11. Zip code level counts may only be released without prior DSHS IRB approval for:
 - A minimum of three years combined data that is grouped by no more than two additional variables (e.g., cancer site and sex, but not cancer site, sex, and age);
 - 10-year or greater age groups (if age is requested); and
 - No more than 10 zip codes.
12. Zip code level incidence rates will not be provided by the TCR due to the lack of zip code level population data for all data years and the small numbers of cases.
13. Geocodes for Texas census tract, census block, latitude, and longitude are currently available. Address data required to geocode to the census tract or smaller level will not be released without DSHS IRB approval.
14. Aggregate or individual record-level data containing no other personal identifiers other than the name(s) of a specific health care facility, clinical laboratory, or health care practitioner data may only be released if:
 - Data release is to the health care facility, clinical laboratory, or health care practitioner that reported the data;

- Prior written authorization is obtained from the health care facility, clinical laboratory, or health care practitioner that reported the data; or
 - DSHS IRB approval is obtained.
15. For DSHS IRB applications that include international data release or access, a signed Addendum to the TCR Confidentiality Agreement for International Data Release is required.
 16. The TCR may provide patient-specific information back to the reporting entity (i.e., health care facility, clinical laboratory, or health care practitioner) that supplied the specific data without DSHS IRB approval, so long as a written/signed request is first received from the reporting entity.
 17. Patient-specific information may be shared with another state cancer registry by the TCR after receiving a written request and confirming there is a current out-of-state data exchange agreement between the requesting state cancer registry and the TCR.
 18. An individual's cancer record or information contained on that cancer record may only be released to a member of the general public as specified in a signed Authorization for Release of Medical Records Form. Patient-specific TCR data are not considered "Open Records."
 - The Authorization for Release of Medical Records Form must be signed by the cancer patient, parent or legal guardian of the patient if he/she is a minor, legal guardian if the patient is incapacitated, an attorney ad litem for the patient, or if the patient is deceased—an executor, independent executor, administrator, independent administrator, or temporary administrator of the decedent's estate.
 - Once the signed Authorization for Release of Medical Records Form is received, the TCR will contact the DSHS Open Records Coordinator in the Office of General Counsel to verify that the form contains all required information and is signed by an authorized individual before sending out any confidential information.

Release of Texas Cancer Mortality Data

1. The TCR provides aggregate cancer mortality statistics for Texas resident deaths occurring from 1990 to their most recently available mortality year. For DSHS IRB and/or [Committee on Requests for](#)

[Personal Data \(CORPD\)](#) approved studies involving TCR cancer cases, TCR will provide linked mortality information such as dates and causes of death.

2. The TCR refers all requests for aggregate cancer mortality data prior to 1990, individual record-level cancer mortality data files (no cancer incidence data included), and cancer mortality data below the county level to the DSHS CHS. You can call DSHS CHS at 512-776-7261 or visit <https://www.dshs.texas.gov/chs/contact.shtm> for detailed contact information.
3. The TCR populates cancer incidence cases with the patient's state, date of death, underlying cause of death, and death certificate number via an annual linkage with Texas mortality data provided by the DSHS [Center for Health Statistics \(CHS\)](#) and the National Center for Health Statistics (NCHS) National Death Index (NDI).
4. The TCR does not release cancer mortality statistical data below the county level. Otherwise, the TCR utilizes the same data release procedures for both cancer incidence and mortality statistical data.
5. Data with personal identifiers and information provided by the NCHS NDI may be released, providing DSHS IRB approval. A list of these studies and approvals is provided to the NDI on an annual basis.