Texas Cancer Registry
Data Release Policy

October 2026

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, at a level sufficient to answer a customer's question, while still protecting the confidentiality and privacy of cancer patients, cancer reporting entities, and small populations; and
3. Comply with all federal and state laws, rules, and Texas Department of State Health Services (DSHS) policies.

Confidentiality

Protecting patient confidentiality and protected health information is paramount to 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). Therefore, no person will attempt to use TCR data to learn the identity of any person or cancer reporting entity. If the identity of any person or cancer reporting entity should be discovered inadvertently:

- No use will be made of this knowledge;
- TCR will be advised immediately of the incident by calling 512-776-3080 or emailing CancerData@dshs.texas.gov;
- The information that would identify an individual or cancer reporting entity will be safeguarded or destroyed, as requested by TCR; and
- No one else will be informed of the discovery.

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, 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.

TCR Data Citation and Acknowledgment

TCR requests that any person or organization reporting results or analyses that use cancer data provided by TCR include the following acknowledgement statement in the analysis, report, presentation, or publication:

> Texas cancer data have been provided by the Texas Cancer Registry (TCR), Cancer Epidemiology and Surveillance Branch, Texas Department of State Health Services, 1100 West 49th Street, Austin, TX 78756 (www.dshs.texas.gov/tcr). Data from the TCR is supported by the following: Cooperative Agreement #1NU58DP007140 from the Centers for Disease Control and Prevention, Contract #75N91021D00011 from the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program, and the Cancer Prevention and Research Institute of Texas.

Standard Methods Used by 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 complementary suppression (suppression of small cell counts).
5. Reduce geographic specificity.
6. Offset precise locations, mask geographic areas with low case numbers, and display ranges instead of exact values to retain confidentiality when creating maps.
7. Mask extremely rare events (e.g., 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., group years of data, provide age groups rather than individual ages, provide year of birth rather than birthdate, provide age at diagnosis or diagnosis year rather than date of diagnosis).

Release of Texas Cancer Incidence Data

1. Data requests will be completed using the most current and complete Texas resident cancer incidence data available. Statewide data are at least 95% complete before being used.
2. Data files containing individual cancer records with personal identifiers will not contain cancer records reported to TCR by other state cancer registries, the Veterans Health Administration (VHA), or the Department of Defense (DoD) due to their confidentiality requirements. De-identified files and aggregate statistical analyses will contain these records. Out of state, VHA, and DoD reported Texas resident cases account for less than 4% of the total cancer incidence file.
3. Texas cancer rates and associated counts are suppressed when there are fewer than 16 cases on public query tools, such as the TCR Data Visualization Tool (cancer-rates.info/tx/) and others provided by the National Program of Central Cancer Registries (NPCR) at the CDC, the North American Association of Central Cancer Registries (NAACCR), and the SEER Program at the National Cancer Institute (NCI). Rates based on fewer than 16 cases tend to be unreliable and unstable.
4. When a request is made directly to CancerData@dshs.texas.gov, cancer incidence rates and counts at the state, public health region, council of regional government, or county level are not suppressed as long as no further demographic stratifications (e.g., by age group or race/ethnicity) are requested. 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. Confidence intervals or standard errors will be provided with rates to allow for evaluation of statistical reliability. To protect patient confidentiality, rates and counts at the state, public health region, council of regional government, or county level broken down by demographic subpopulations (e.g., by age group or race/ethnicity) are suppressed when the count is between 1-9.
5. Zip code level data and geocoded data, such as census tract, latitude, and longitude, are available but require sufficient justification and approval by the DSHS IRB or the department's designated IRB.
6. Social security numbers will not be released for studies and can only be used for linking purposes.
7. Aggregate data containing no identifiers other than the name(s) of a specific health care facility, clinical laboratory, or health care practitioner may only be released if (a) data release is to the health care facility, clinical laboratory, or health care practitioner that reported the data or (b) written

authorization is obtained from the health care facility, clinical laboratory, or health care practitioner that reported the data.

8. TCR may provide record-level, patient-specific information back to the reporting entity (i.e., health care facility, clinical laboratory, or health care practitioner) that supplied the specific data, so long as a written request is received from the reporting entity.
9. Patient-specific information may be shared with another central cancer registry by TCR after receiving a written request and confirming there is a current data exchange agreement covering this data sharing.
10. TCR data, including any datasets linked to TCR data, may not be transferred to, stored in, or accessed in data repositories, collaborative research platforms, data portals, data enclaves, data commons, or similar environments for secondary research uses if the dataset does not have a national or nationally-representative scope.
11. 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, a 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, 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. TCR populates cancer incidence cases with the patient's state of death, date of death, underlying cause of death, and death certificate number via linkages with Texas mortality data maintained by the DSHS Center for Health Statistics (CHS) and with National Death Index (NDI) data maintained by the National Center for Health Statistics (NCHS). For studies that request TCR cancer cases and are approved by the DSHS IRB, the department's designated IRB, and/or the Committee on Requests for Personal Data (CORPD), TCR will provide linked mortality information that is included in the cancer incidence records.

2. TCR provides aggregate cancer mortality statistics for Texas resident deaths occurring from 1990 to the currently available mortality year. TCR follows DSHS CHS suppression guidelines for the release of cancer mortality statistical data: non-zero counts less than 10, or rates based on fewer than 21 deaths, are suppressed.
3. 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 CHS. See CHS contact information to request these data.