Cancer Data Request and Release Guide:

Policies and Guidelines for Requesting and Releasing Cancer Data

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I. Background

The Texas Cancer Registry (TCR) is a statewide, population-based registry that serves as the foundation for measuring the cancer burden in Texas. TCR data support comprehensive cancer control efforts, identification of health disparities, monitoring trends in prevention, diagnosis, treatment, and survivorship, and other cancer-related research. These priorities cannot be adequately addressed in public health, academic institutions, or the private sector without timely, complete, and accurate cancer data.

TCR is one of the largest cancer registries in the United States. It is one of twelve central registries funded by both the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) Program and Centers for Disease Control and Prevention's National Program of Cancer Registries (NPCR). TCR currently meets the NPCR high quality data standards, and is Gold Certified by the North American Association of Central Cancer Registries (NAACCR).

TCR's mission is to collect, maintain, and disseminate the highest quality cancer data that contribute towards cancer prevention and control, research, improving diagnoses, treatment, survival, and quality of life for all cancer patients.

In support of this mission, TCR provides cancer statistics and may release Texas cancer data for research related to cancer etiology, prevention, and control. Responsible stewardship of the state's cancer data also requires protection of patient confidentiality. Protecting patient confidentiality is paramount to TCR and is required by state law and rules (Health and Safety Code, Section 82.009; Texas Administrative Code, Title 25, Part 1, Chapter 91, Subchapter A). Please note that the statement "may release" is permissive and should not be interpreted to mean "is required to release." 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.

II. General guidelines and information

A. TCR Data Release Policy

The Data Release Policy outlines TCR policy for the release of Texas cancer incidence and mortality data. Additional information pertaining to items in the Data Release Policy can be found in the subsections below. If you have any questions or need additional information regarding the TCR Data Release Policy, please email CancerData@dshs.texas.gov.

B. 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) policy.

C. Confidentiality

Any data that may lead to re-identification of any patient, physician, or reporting facility should be treated as confidential. 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 informed immediately of the incident by emailing CancerData@dshs.texas.gov or calling 512-776-3080;
- 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.

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. Visit the TCR's Laws and Rules website for more information on confidentiality.

D. Standard Methods Used for Minimizing Risk of Patient Disclosure

The following procedures have been developed for releasing individual record level cancer incidence data and aggregate statistics.

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 the minimum data necessary to answer a question.
9. Categorize and recode variables to aggregate data values (e.g., group years of data, provide age groups rather than individual ages, provide years or groups of years rather than complete dates).

E. Suppression Guidelines

TCR has data and statistical reporting guidelines to ensure confidentiality and stability of the data. TCR uses the following suppression methods when producing statistics. Users of TCR data are expected to adhere to standards for suppression at least as strict as those shown below. Departure from these guidelines requires a detailed justification and description of the data product(s) which must be approved by the DSHS IRB or the department's designated IRB.

	Incidence	**Mortality**
Counts	• Non-zero counts of 1-15 are suppressed on available public facing tools. For data requests made directly to CancerData@dshs.texas.gov for geographies at the county level or larger: • Non-zero counts of 1-9 are suppressed in tables with demographic breakdowns (e.g., by age or race/ethnicity) or additional stratifications that would risk re-identification • Counts are not suppressed if there are no additional demographic breakdowns or additional stratifications that would risk re-identification.	• Non-zero death counts of 1-9 are suppressed. • No values or cells can be reported in a manner that allows non-zero death counts of 1 to 9 to be back calculated.
Rates	• Rates based on non-zero counts of 1-15 are suppressed on available public facing tools.	• Rates based on fewer than 21 deaths are suppressed.

	For requests made directly to CancerData@dshs.texas.gov for geographics at the county level or larger: • Rates based on non-zero counts of 1-9 are suppressed in tables with demographic breakdowns or additional stratifications that would risk re-identification, • Rates are not suppressed if there are no demographic breakdowns or additional stratifications that would risk re-identification, and confidence intervals or standard errors are provided. • Confidence intervals or standard errors will be provided along with rates to allow for evaluation of statistical reliability. Rates based on fewer than 16 cases tend to be unreliable and unstable.	
Population threshold	• For sub-county geographies, caution is warranted when reporting rates for small populations. TCR staff do not provide counts or calculate sub-county rates, either internally or for external requests.	• No additional guidelines. Reach out to the DSHS Center for Health Statistics for more information on mortality data.

Please note, TCR considers both the volume of the request and the planned use of the data in determining the final suppression standard, which may be stricter than what is listed in the table above. Requests for extensive data tables (e.g., data by individual cancer sites, years, and counties) are unlikely to be approved.

F. Data Security Guidelines

Prior to accessing TCR data, all users must have mechanisms in place to protect patient confidentiality and prevent unauthorized use. Before receiving TCR data, institutions may be required to enter into data agreements that stipulate additional data security and destruction requirements.

Users of confidential and/or record-level TCR data must follow security practices to safeguard the data, including, but not limited to:

- Use individual login names and passwords for authorized users.
- Use authentication technology for access control.
- Employ controlled access to servers.

- Use encrypted data access such as Secure Shell (SSH) or Virtual Private Network (VPN) when accessing systems remotely.
- Use encrypted, password protected laptop or desktop.
- Avoid placing data on removable media, or if necessary, portable media must be encrypted and stored in locked facility with restricted access.
- Securely destroy electronic files.
- Destroy media according to National Institute of Standards and Technology (NIST) Guidelines for Information Media Sanitization.
- Use encrypted cloud computing with a security plan that utilizes best practices for security and confirms the secure and permanent destruction of backup or archived copies of data.

Additional resources:

- U.S. Department of Health and Human Services (HHS) Security Rule Guidance Material
- North American Association of Central Cancer Registries (NAACCR) Data Security and Confidentiality

G. Data Availability

Data requests will be completed using the most current, complete, and high-quality Texas cancer data available. Statewide data are at least 95% complete before being used.

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.

H. Costs Associated with TCR Data Requests

At present, TCR does not charge a fee for data requests that are permitted by statute. However, exceptions can be made for requests that are extensive in complexity, scope, or amount of agency resources needed to fulfill the request.

I. Acknowledgement of TCR Data Use

TCR requests that any person or organization reporting results or analyses that are based solely on cancer data provided by TCR include the following acknowledgement statement in the analysis, report, presentation, map, statistical compilation, or publication:

> Texas 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 (www.dshs.texas.gov/tcr). Data from the Texas Cancer Registry 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 Texas Department of State Health Services. The ideas and opinions expressed herein are those of the author(s) and do not necessarily reflect the opinions of the State of Texas, Department of State Health Services, the National Cancer Institute, and the Centers for Disease Control and Prevention or their contractors and subcontractors.

An abbreviated acknowledgment is acceptable for results or analyses based on data from multiple cancer registries or data sources. This abbreviated acknowledgment should include, at a minimum, recognition of the "Texas Cancer Registry."

J. Publications

Prior to dissemination or publication, recipients of TCR data will provide TCR with a citation and copy of any forthcoming publications, abstracts, presentations, manuscripts, maps, or other materials generated with TCR data by emailing CancerData@dshs.texas.gov. TCR does not routinely review publications for approval or endorsements. However, TCR reserves the right to review and inform users of potential data issues concerning confidentiality or misleading results and interpretations.

Manuscripts, posters, abstracts, or other items for public dissemination that include TCR staff as a collaborator should be provided to TCR for review ahead of submission. Please contact your TCR collaborator for more information on necessary timelines.

K. TCR Staff Collaboration

TCR staff provide substantial contributions to research studies involving TCR confidential data. TCR asks that data requesters provide TCR staff with the option to serve as a collaborator on any research project requesting a data linkage, patient contact study, or other complex dataset. These datasets often require significant input and planning from the TCR program contact during the DSHS IRB application stage. Upon IRB approval, conducting probabilistic data linkages, generating patient listings for patient contact studies based on detailed sampling and selection criteria, or producing other datasets according to specific criteria require significant expertise, experience, and time. TCR staff are knowledgeable about TCR data and well-trained in the methods and software needed for these tasks. In addition, TCR staff in collaborator roles can provide support needed throughout the process, whether that is preparing the study data set for linkage, interpreting results, understanding strengths and limitations of TCR data or linked results, and describing TCR data, or the methods used. This collaborator should be listed on the DSHS IRB Personnel Log (role: Research Team Member) submitted through the OneAegis system.

III. Access to Publicly Available Data

Below is a non-exhaustive list of Texas cancer incidence, prevalence, survival, and mortality data resources that are currently available to the public. Some national databases are restricted to users who meet institutional requirements or have signed data agreements. TCR aims to make Texas cancer data widely available and accessible and therefore encourages the use of publicly available data whenever possible.

Statistical Compilations and Reports

Name and Link	Description
Texas Cancer Registry: Cancer Statistics	Data and statistics related to cancer incidence, survival, prevalence, and mortality in Texas updated annually or biennially. Includes reports, statistical tables, maps, and links to interactive tools.
National Cancer Institute: Cancer Stat Facts	Statistical summaries of frequently requested statistics for common cancer types using SEER data. Available statistics include incidence, mortality, survival, stage, prevalence, and lifetime risk.
American Cancer Society: Cancer Facts & Figures	Annual report with national and statewide cancer statistics including estimated new cases and deaths; incidence, mortality, and survival rates; and estimated cancer deaths averted.

Databases (Public Use and Restricted Access)

Name and Link	Description
United States Cancer Statistics: Public Use Databases	CDC's public use database that includes cancer incidence and population data for all 50 states, and by demographic characteristics (e.g., age, sex, and race) and tumor characteristics (e.g., year of diagnosis, primary tumor site, histology, behavior, and stage at diagnosis).
SEER Incidence Data	SEER collects cancer incidence data from population-based cancer registries covering approximately 46 percent of the U.S. population, including data on patient demographics, primary tumor site, tumor morphology, stage at diagnosis, first course of treatment, and vital status. Data access requirements differ by database.

Customizable Data Visualizations (Tools, Tables, Graphs, and Maps)

Name and Link	Description
TCR Data Visualization Tool (formerly called Web Query Tool)	Incidence and mortality tables and maps. Data available by cancer site, sex, year, race/ ethnicity, county, public health region, council of government, metro statistical area, and micro statistical area.
CDC United State Cancer Statistics Data Visualizations	Incidence, mortality, survival, and prevalence tables and maps. Data available by cancer site, sex, age, race and ethnicity, and geography (national, state, county, and congressional district).
SEER*Explorer	Incidence, mortality, survival, and prevalence, and other statistical tables and graphs. Data available by cancers site, sex, race/ethnicity, and age.
NCCR*Explorer	Incidence, survival, and prevalence, and other statistical tables, and graphs for cancers among children, adolescents, and young adults in the National Childhood Cancer Registry (NCCR). Data available by cancer site, sex, race/ethnicity, and age.
State Cancer Profiles	Incidence, mortality, risk factor, and screening cancer data maps and tables. Data available by cancer site, national, state, and county.
NAACCR Cancer Maps	Mapping tool for US and Canadian cancer incidence statistics for the most current 5 years of data available. Data available by cancer site, sex, and race.
NAACCR CiNA Explorer	Incidence, survival, and prevalence tables, and graphs for cancers in North America (US and Canada). Data available by cancer site, sex, race/ethnicity, and registry/region.
National Environmental Public Health Tracking Network Data Explorer	Customizable maps, charts, and tables for a variety of health topics, including cancer. Statistics include incidence, prevalence, and standardized incidence ratios. Data available by cancer site, year, state, and county.
American Cancer Society Cancer Statistics Center	Detailed statistics shown in graphs, charts, and maps for estimated new cancer cases and death, rates of incidence, mortality, and survival, as well as trends and risk factor screening rates. Data available by cancer site, sex, state.
SEER Cancer Query Systems (CanQues)	Display reports from SEER statistical databases.
GIS Portal for Cancer Research	Create maps, tabular data, or downloadable spatial datasets.

IV. Requests for Aggregate, Tabular, or Statistical Data

Aggregated data combines information into a summary table that displays a set of data fields or statistical measures such as counts or rates. TCR staff will refer individuals to existing resources if the requested data are publicly available. Refer to Section III for other sources of data. Complex or large requests may require approval from the DSHS IRB or the department's designated IRB.

A. Data Request Process for Aggregate, Tabular, or Statistical Data

Follow the instructions below to submit a request for aggregated, tabular, or statistical cancer data:

Step 1: Review existing publications and data tools on the Texas Cancer Registry (TCR) Cancer Statistics page. TCR has made significant efforts to ensure that Texas cancer data are available and accessible through interactive online tools, maps, and graphs as well as statistical tables and reports that are typically updated every year with new data. If you do not find what you need, proceed to Step 2 below to submit a data request.

Step 2: Fill in the details below and email to CancerData@dshs.texas.gov:

- **Requester Information:**
  - Name:
  - Institution/organization:
  - Role with Institution/organization:
- **Planned Use of Data:** *[Briefly describe how the data will be used.]*
- **Requested Completion Date:** *[Fill in the date by which the data are needed. With some exceptions, requests for aggregate data can be completed within 2 weeks.]*
- **Data Request Description:**
  - Statistical measures requested: [Incidence counts/rates, mortality counts/rates, prevalence, survival, etc.]
  - Demographic groups: [All Texans, or a specific sex, race/ethnicity, or age group, etc.]
  - Timeframe: [Years of diagnosis or death]
  - Geographic area of interest: [Texas statewide, specific Public Health Region, specific county. Note, the smallest unit available for aggregate data requests is the county level.]

Step 3: TCR staff will review the request to verify availability of data, staff, and resources and to determine if the data request is permissible per policy. Requesters may be asked to provide additional information for staff review. For complex requests involving multiple stratifications or subgroups, table shells may be required. TCR leadership approval may be required for lengthy requests that involve multiple stratifications and subgroups.

Step 4: Once the request is reviewed, provided it meets requirements, staff will process the request. TCR will send the requested data via email or other DSHS-approved data transfer mechanism.

B. Completion Timeline for Aggregate, Tabular, or Statistical Data

Please allow up to 21 business days for aggregate, tabular, or statistical cancer data requests to be completed. This includes the time needed to complete the data request as well as important data quality assurance checks. In addition, the length of time needed to complete a request depends on factors such as the current data request volume, staff availability, complexity of the request, and other pressing priorities for the program. Large or complex requests will require more time, and frequent requests may require an additional assessment to determine the long-term feasibility and availability of staff resources.

V. Requests for Data for a Research Project

All proposals for research projects involving record-level TCR data must be approved by the Department of State Health Services (DSHS) Institutional Review Board (IRB) or the department's designated IRB. If you are requesting TCR data through NAACCR's Virtual Pooled Registry, please refer to their website: https://apps.naaccr.org/vpr-cls/ and do not follow the steps below.

Release of zip code level data and geocoded data, such as census tract, latitude, and longitude, requires sufficient justification and approval by the DSHS IRB or the department's designated IRB. Social security numbers will not be released for studies and can only be used for linking purposes.

Note: The Texas Cancer Registry and the Texas DSHS IRB are separate entities. For questions regarding the DSHS IRB process, please contact InstitutionalReviewBoard@dshs.texas.gov.

A. Steps to Request Confidential TCR Data for a Research Project

1. Send a concise (one paragraph) summary of your project to the TCR Epidemiology Team at CancerData@dshs.texas.gov. This summary should be specific to TCR data, focusing on why TCR data are requested and how TCR data will be used in your project.

2. TCR will assess the summary within one business week and may provide feedback or seek clarification for the research team before determining feasibility. This discussion is crucial prior to completion of any steps listed below to avoid unnecessary paperwork and delays.
3. If your study is determined to be feasible by the Epidemiology Team, you will be directed to complete the TCR Confidential Data Request Form. TCR will provide feedback and questions as necessary to ensure the request is clear.
4. Once the TCR Confidential Data Request Form is considered complete, you will be directed to complete a full IRB application on our agency's web platform: DSHS IRB OneAegis System.
5. You will submit your application in OneAegis. Please note, this is not your final DSHS IRB submission. Before it is assigned for DSHS IRB review, your TCR program contact will review relevant portions of the application. Once programmatic approvals are in place, the TCR program contact will submit a program review form with the application to the IRB for official review. See Section B below for more information on the review and approval process.
6. Your program contact will review your application and provide feedback within the OneAegis platform. If your request involves data from more than one program, there will be multiple program contacts reviewing the application.
7. When your application is considered complete, TCR leadership will review further. It is common for TCR leadership to request edits beyond those requested by your program contact.
8. After TCR leadership approval, there are several levels of review and approval required before the IRB application can be submitted to the DSHS IRB. This includes review and approval by the TCR program attorney, the Environmental Epidemiology and Disease Registries Section, and the Community Health Improvement Division, at a minimum; these reviews could result in additional requested edits. Once these approvals are obtained, your TCR program contact will submit the application to the IRB.

B. Review by the DSHS IRB and RESC

The DSHS IRB meets once per month, and each meeting has a submission deadline for applications (see the meeting schedule and submission deadlines here). After the IRB review, the application is reviewed by the DSHS Research Executive Steering Committee (RESC).

C. Memorandum of Understanding (MOU)

If TCR, the DSHS IRB, and the DSHS R-ESC approve an IRB application, a signed MOU will be requested from the researchers' institution(s). This process occurs outside of TCR in the DSHS Contracts Management Section.

D. Timeline for Requests Requiring DSHS IRB Approval

In general, the amount of time from the initial IRB application submission to the Program until the final DSHS IRB and R-ESC determination is approximately 4-6

months, but it can take longer if there are multiple revisions required (and delays in receiving revised documents back) or questions or concerns are raised during the review process. The requirement for MOUs to be in place for all DSHS-IRB approved protocols went into effect in November 2022; please note, MOUs are managed outside of TCR. Therefore, TCR cannot responsibly provide an estimate of how long the MOU process will take for a given study.

E. Common Types of Research Data Requests

1. Analytic Datasets

When publicly available datasets do not meet the needs of a research team (e.g., an investigator requires small geographic areas), TCR can provide customized, record-level incidence datasets for use in research projects related to cancer etiology, prevention, and control.

2. Patient Contact Studies

TCR can provide contact information for eligible patients in the registry for approved research studies requiring patient contact for recruitment.

3. Student Projects

Student projects require a letter of support from a mentor at an academic institution. TCR encourages students to carefully consider timelines given the potentially lengthy IRB and MOU process. The use of publicly available datasets such as those from SEER and CiNA is strongly encouraged whenever possible.

4. Data Linkage

Data record linkage is the process whereby it is determined if a record in one file matches to one or several records in another file. Data linkages may be requested by researchers to link a study's data set to the TCR database to obtain cancer-related information on the study's patients. Both data sets must contain common data items (e.g. name, social security number, date of birth, sex, residence, etc.) to conduct a linkage.

i. Linkage – Virtual Pooled Registry-Cancer Linkage System (VPR-CLS)

Coordinated by the North American Association of Cancer Registries (NAACCR) with funding from the National Cancer Institute, the VPR-CLS provides a single location to facilitate timely access to and use of high-quality cancer surveillance data for minimal risk linkages with multiple U.S. population-based cancer registries. Find more information here: https://www.naaccr.org/apply-for-linkage/

ii. Linkage – Centers for Medicare and Medicaid Services (CMS)

TCR data are included in the SEER-Medicare linked dataset. More information on requesting this dataset can be found here: https://healthcaredelivery.cancer.gov/seermedicare/obtain/

All other requests to link TCR data to CMS data are facilitated by the Research Data Assistance Center (ResDAC). Their website is here: https://resdac.org/

iii. Linkage – to an external cohort

TCR can perform linkages to external cohorts for researchers seeking information on cancer outcomes among their cohort members. These linkages are performed in-house at TCR and require DSHS IRB approval, per the processes described above. More information can be found here: https://www.dshs.texas.gov/texas-cancer-registry/data-requests-tcr/research-data/data-linkages

iv. Linkage – to other DSHS Program

With the approval of all programs involved, TCR can provide data in support of linkages to other DSHS program data, including Birth Defects, Center for Health Statistics, and HIV.

v. Linkage – to publicly available aggregate data

Linking or attempting to link TCR data to other individual, patient-level data is prohibited. However, researchers often seek to merge or link TCR data to other sources of aggregate or area-based data. For example, researchers may want to use census tract from a patient's record to estimate a census tract level measurement available in the U.S. census data. These efforts must be described in the DSHS IRB application.

F. Continuing Review of Approved DSHS IRB Applications

DSHS IRB-approved studies require renewal progress reports. IRB determinations typically expire 1-2 years after review depending on the risk level for the study. Patient contact studies have 1-year renewals and most other TCR supported studies have two-year renewals.

If the DSHS IRB has not received a continuing review application by the IRB approval expiration date, the protocol will be administratively closed by the IRB. An administrative closure notice requesting a final report form and proof of data destruction will be sent to principal investigators and program contacts on the first business day of the month following the protocol's expiration.

G. Amendments to DSHS IRB applications

Principal investigators are required to submit an amendment application when there is a change to their protocol. Amendment applications may fall under the expedited review category or need to be reviewed by the full board depending on whether the change is deemed as more than minimal risk by the DSHS IRB chair. Depending on

the requested change, different application materials will need to be submitted. Please refer to Guidance on Using the DSHS OneAegis System on how to submit Legacy or Non-Legacy amendment applications.

If requesting data from TCR that has yet to be approved (e.g., new data items, more recent diagnosis years, expanded recruitment criteria) an amendment must be filed. The first step is to reach out to the TCR Epidemiology Team (CancerData@dshs.texas.gov, please include your DSHS IRB protocol number for reference) to summarize the changes and explain what is being requested of TCR. Once feasibility is confirmed, you will be directed to complete a new TCR Confidential Data Request Form and then further prompted to submit an amendment in OneAegis when it is appropriate.

VI. Requests for Public Health Practice Data

A proposed request for confidential data may be classified as a public health practice request if there is no research being conducted and all data are solely being used for public health practice. Public health practice requests may undergo a different review process. If you believe your request qualifies as public health practice, clearly communicate this in your initial email to CancerData@dshs.texas.gov.

VII. Requests for 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. Refer to Suppression Guidelines for more information.
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 request procedures for vital statistics data.

VIII. Requests for Vital Status Reports

Some cancer centers are evaluated on the completeness of their analytic patient follow-up/vital status (patients who were diagnosed and/or treated at the facility, based on the "class of case" field). These facilities do not need DSHS IRB approval to receive vital status information from TCR for their own patients. Authorized individuals should send the following information to CancerData@dshs.texas.gov to request a vital status report for their facility.

- TCR Facility ID: 000000XXXX

[Replace the x's with the facility ID]

- Admission Years: YYYY–YYYY

[Provide range of years; 1995 is the earliest year available]

- Vital Status: Both (deceased and presumed alive) *or* Deceased patients only

[Select one]

- Case Type: All (analytic and non-analytic) *or* Analytic cases only

[Select one]

- File Format(s): .csv, .xlsx (Excel), .xml (NAACCR formatted)

[Select one. If .xml format is requested, TCR will provide current version unless earlier version specified on the request form.]

IX. Data Sharing with Central Cancer Registries and Cancer Reporters

Facility Type	Patient-level data	Aggregate data
Central Cancer Registry	Patient-specific information may be shared with another central cancer registry by TCR after receiving a written request and confirming there is a current out-of-state data exchange agreement covering the exchange.	Contact CancerData@dshs.texas.gov
Cancer Reporters	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	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

	request is received from the authorized cancer reporter from the reporting entity.	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.

X. Requests for Letter of Support

Researchers can request a letter of support from TCR to include with grant applications by contacting CancerData@dshs.texas.gov. Do not include drafts of the letter of support in the request. Rather, TCR staff will draft the letter based on information provided by the requester. The letter, written by and on behalf of TCR and signed by the registry director, states TCR's willingness to support the proposed research study or project proposed by the requestor with data from TCR if the study is approved by TCR, the DSHS IRB, and the DSHS R-ESC. When requesting a letter of support, researchers should include:

- Name of the study/project.
- Brief explanation of how TCR data will be used.
- Grant or funding opportunity.
- Requester name, title, and department/institution.

XI. Inquiries into Unusual Patterns of Cancer

DSHS investigates unusual patterns of cancer. The results of these investigations are available online at https://www.dshs.texas.gov/environmental-surveillance-toxicology/environmental-epidemiology.

Individuals may reach out to the Environmental Surveillance and Toxicology Branch at epitox@dshs.texas.gov with any further inquiries.

XII. Patient Requests for Access to Data

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 (EF88-13920) must be signed by the cancer patient, a parent or legal guardian of the patient if the patient 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.
- The signed Authorization for Release of Medical Records Form should be submitted to CancerReporting@dshs.texas.gov. Once 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 sharing any confidential information with the requester.

XIII. Frequently Asked Questions

For any questions or additional information regarding requests for Texas Cancer Registry data, please contact CancerData@dshs.texas.gov.

1. Where can I find statistics on cancer incidence in Texas?

Visit the Texas Cancer Registry Cancer Statistics website, and refer to Access to Publicly Available Data.

2. How can I request TCR data?

Most Texas cancer incidence data can be requested by emailing CancerData@dshs.texas.gov. Refer to the sections below for instructions:

- Requests for Aggregate, Tabular, or Statistical Data
- Requests for Data for a Research Project
- Requests for Public Health Practice Data
- Requests for Texas Cancer Mortality Data
- Requests for Vital Status Reports
- Patient Requests for Access to Data

3. How much will my data request cost?

Refer to Costs Associated with TCR Data Requests.

4. Where can I find information on secondary data sharing?

Investigators must abide by the requirements of the DSHS-IRB approved protocol and MOU. Please connect with your contact at the DSHS Contracts Management Section (CMS) for more information.

5. Does my request need to be approved by the Texas DSHS IRB or department's designated IRB?

Texas DSHS IRB reviews requests submitted to DSHS programs that involve the use of identifiable information or specimens. Certain studies involving VPR-CLS linkages may instead require approval and oversight from the department’s designated IRB. Email CancerData@dshs.texas.gov if you need assistance determining if your request requires IRB review and approval.

6. What are state rules and laws for Texas cancer data?

Refer to Texas Health and Safety Code, Chapter 82.

XIV. Abbreviations and Acronyms

CDC	Centers for Disease Control and Prevention
CiNA	Cancer in North America
DoD	Department of Defense
DSHS	Department of State Health Services
IRB	Institutional Review Board
GIS	Geographic Information System
HHS	Health and Human Services
MOU	Memorandum of Understanding
NAACCR	North American Association of Central Cancer Registries
NCCR	National Childhood Cancer Registry
NIST	National Institute of Standards and Technology
NPCR	National Program of Cancer Registries
R-ESC	Research-Executive Steering Committee
SEER	Surveillance, Epidemiology, and End Results Program
SSH	Secure Shell
TCR	Texas Cancer Registry
VHA	Veterans Health Administration
VPN	Virtual Private Network
VPR-CLS	Virtual Pooled Registry-Cancer Linkage System