

STANDARDS FOR CONFIDENTIALITY, DISCLOSURE OF DATA, AND QUALITY ASSURANCE

Confidentiality

Data obtained under the *Texas Cancer Incidence Reporting Act* are for the confidential use of the Texas Department of State Health Services, including persons, and public or private entities that are necessary to carry out the public health interests of the Act. The data are privileged and may not be divulged or made public in a manner that discloses the individual identity of any patient. All reporting entities that are performing in compliance with the Act are immune from civil and criminal liability for furnishing the required information.

Disclosure of Data

All data reported to the TCR are available for use in aggregate form for analysis by facility registry staff, physicians, health care workers, cancer researchers, and the public. Reports of cancer incidence are available on the TCR website under Cancer Statistics. A Web Query Tool which generates customized maps and tables of Texas cancer incidence and mortality rates is also available on the website at <http://www.dshs.state.tx.us/tcr/data.shtm>. Public access to aggregate data is available through published reports, or through the TCR, if in accordance with its data release policies and procedures.

The TCR **may** exchange patient-specific data with the reporting facility, any other cancer-control agency, clinical facility, pathology laboratories, or physician's offices for the purpose of obtaining information necessary to complete the abstract or follow-up information, provided that these agencies and facilities comply with the TCR's confidentiality policies. However, no facility-specific patient information can be released unless authorized under law. The TCR can contact the facility where the patient was seen and obtain consent to release information other than that authorized by law.

To achieve complete case ascertainment, the TCR **may** exchange patient-specific data with other state cancer registries if reciprocal data sharing agreements and confidentiality provisions are implemented.

The TCR **may** grant researchers access to confidential information concerning individual cancer patients, provided that those researchers comply with the provisions and confidentiality policies mandated by the Texas Department of State Health Services Institutional Review Board.

Quality Assurance

The TCR implements an extensive series of quality assurance procedures that are based on the SEER Program, CDC recommendations, and NAACCR standards. These procedures, which consist of both internal and external processes, ensure the reliability, completeness, consistency and comparability of TCR data.

Internal Process

Submission Review:

The TCR's data upload system currently checks all submitted abstracts for errors. All abstracts are reviewed for possible duplicate records and multiple primaries. As abstracts are uploaded into the system, they are intensely scrutinized for identification of:

- Possible duplicate submission of existing abstracts.
- Unacceptable codes for any field or inter-field inconsistencies.
- Invalid or unusual site/sex, age/site, age/morphology or site/morphology combinations.

Abstracts returned to the facility for correction do not count toward compliance. All abstracts with errors will be rejected for correction of the specified errors and subsequent re-submission. The error-free abstracts retained will be counted towards reporting compliance.

*Note: Facilities **must** run their data through the appropriate NAACCR and TCR edits and make necessary corrections before submitting a file to the TCR.*

External Process

Facility Training:

TCR staff provides technical assistance, training, and continuing education for cancer registrars and medical records personnel on standards and procedures for reporting. Requests for training and technical assistance should be directed to the appropriate TCR Regional Office. See page 21 for a list of regional contacts.

Casefinding Data Quality Audits:

TCR staff or a TCR representative review casefinding sources such as disease indices, pathology reports (including cytology and autopsy reports), outpatient records, radiation therapy logs, and appropriate oncology logs for missing cases. Periodically, facilities are randomly selected for a casefinding audit. A casefinding audit is a systematic method of reviewing the facility's casefinding procedures and identifying all reportable cases in order to assess completeness and timeliness. The audit is a tool to improve a facility's casefinding process and is not a punitive measure. Sometimes chart review may be performed on records identified from the audit to determine case reportability. Casefinding procedures are located in the *Casefinding Section* beginning on page 27. Results from a specific facility's data quality audit are not shared with other entities without the facility's approval.

Reabstracting Data Quality Audits:

TCR staff, or a TCR representative, performs complete re-abstracting of a sample of reported cases without reference to the original abstract. If discrepancies are identified, they are used to assess the quality of the facility's cancer case reporting and training needs.

Death Clearance

TCR staff performs additional checks of reporting completeness through the death clearance process. Each year the TCR electronically matches existing incidence cases in the cancer master file against the Vital Statistics Unit (VSU) death certificate records for the year. If a match is found, the date of death is updated for the record in the TCR's database and the underlying cause of death added. For non-matches, queries to facilities are made for patients who have a diagnosis of cancer on the death certificate and expired at a reporting facility but were not reported to the TCR. Facilities are required to submit abstracts for all missed cases. In some instances, there may not be evidence of active cancer. If there is no documented evidence of a reportable diagnosis on a queried case, please notify the Vital Statistics Specialist at the TCR central office using the Facility Death Clearance Report.

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