
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 Health and the persons, public or private entities that the Board of Health determines are necessary to carry out the interest of the Act. The data are privileged and may not be divulged or made public in a manner that discloses the identity of the patient. All reporting entities that comply with the Act are immune from 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 registry staff, cancer researchers and the public. Reports of the incidence of cancer for the state can be generated. 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, or clinical facility for the purpose of obtaining information necessary to complete the abstract or follow-up information, provided 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 those researchers comply with the provisions and confidentiality policies mandated by the Texas Department of Health's Institutional Review Board.

QUALITY ASSURANCE

The TCR has an elaborate 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: All abstracts are reviewed for possible duplicate records and multiple primaries. As data are uploaded into the system, it is intensely scrutinized for identification of:

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

The TCR's data upload system currently checks all submitted records for errors. Records returned to your facility for correction do not count towards your compliance. In the near future, we will have an acceptable percentage of records with errors that will be accepted and processed. We will have criteria in place on different levels of errors, and when data will be rejected and returned for correction and re-submission.

EXTERNAL PROCESS:

FACILITY TRAINING: Continuing education and training of cancer registrars, as well as medical records personnel, on standards and procedures for reporting is provided by TCR staff. Requests for training and technical assistance should be directed to your appropriate regional office.

CASEFINDING: TCR staff reviews 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. Facilities are periodically selected for a casefinding audit. A casefinding audit is a systematic method of identifying all reportable cases in order to assess completeness and timeliness. This process helps to identify missed cases for a selected calendar year and review casefinding procedures in place for your facility. Sometimes a 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 14.

RE-ABSTRACTING STUDIES: TCR staff performs complete re-abstracting of a sample of reported cases without reference to the original abstract. Discrepancies are identified and used to assess the quality of the facility's cancer case reporting and training needs.

DEATH CLEARANCE: An additional check of reporting completeness is performed by TCR staff through the death clearance process. Each year the TCR electronically matches existing incidence cases in our cancer master file against the Bureau of Vital Statistics (BVS) death certificate records for that year. If a match is found, the date of death will be updated for that record in the TCR's database. 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 an abstract 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, please contact your regional office.