MISSION STATEMENT

The California Cancer Registry (CCR) is California's statewide population-based cancer surveillance system. The CCR collects information about all cancers diagnosed in California (except basal and squamous cell carcinoma of the skin and carcinoma in situ of the cervix). This information furthers our understanding of cancer and is used to develop strategies and policies for its prevention, treatment and control. Many cancers can be cured if detected early and treated promptly. Some can be prevented with behavioral or lifestyle changes. The availability of data on cancer in the state allows health researchers to analyze geographic, ethnic, occupational and other differences that provide clues that point to risk factors, and help determine where early detection, educational or other programs should be directed.

In 1985, statewide, population-based cancer reporting was required with the enactment of sections 103875, 103885, and 100330 of the California Health and Safety Code. The CCR is now recognized as one of the leading cancer registries in the world. Due to the size and diversity of the California population, more is now known about the occurrence of cancer in diverse populations than ever before. The CCR has proven to be the cornerstone of a substantial amount of cancer research in the California population.

The California Cancer Registry is a collaborative effort involving the California Department of Health Services, ten regional registries, hospitals, cancer researchers throughout the nation and the Public Health Institute. To date, the CCR has collected detailed information on over 2.5 million cases of cancer, with over 140,000 new cases of cancer, with over new cases added annually. The CCR database includes information on demographics, cancer type, extent of disease at diagnosis, treatment and survival. With this high quality data, cancer researchers are able to advance scientific knowledge about the causes, treatment, cures and prevention of cancer.

INTRODUCTION

Accuracy is of utmost importance in producing valid analysis of data collected by the California Cancer Registry. Computer edits are in place at all levels of data collection. The cancer registry software available to hospital and regional cancer registry abstractors contains a substantial number of edits. The software used to collect data reported by cancer reporting facilities also contains a large number of computer edits.

In addition to computer edits, regional registries are required to perform visual editing and provide feedback on 40% of cases submitted by reporting facilities.

In order to provide consistency in the visual editing process and to quantify the accuracy of cancer data from cancer reporting facilities, visual editing standards have been developed. This document will provide information on the methodology used for these standards.
VISUALLY EDITED DATA ITEMS

The data items that are visually edited by regional staff to determine the accuracy rate of hospital reporting are:

- County of Residence at Diagnosis
- Sex
- Race
- Spanish/Hispanic Origin
- Date of Diagnosis
- Diagnostic Confirmation
- Site/Subsite*
- Laterality (Only paired sites listed in Volume I)
- Histology
- Tumor Size
- CS/EOD - Extension (For prostate--count as one discrepancy)*
- CS/EOD - Lymph Node Involvement
- CS/EOD - Number of Regional Nodes Positive/Examined*
- CS Metastasis at Diagnosis
- CS Site Specific Factors 1-6*
- Class of Case
- Grade

- Count as one discrepancy

Note: For cases diagnosed 1/1/04 and for cases with an unknown date of diagnosis first seen at a facility prior to 1/1/04, Extent of Disease (EOD) fields are visually edited.

These data items were selected because they affect the overall quality for data usage. In other words, County of Residence at Diagnosis, Sex, Race, and Spanish/Hispanic Origin are important demographic items in analyzing cancer trends in California. Date of Diagnosis is key to calculating survival rates. Diagnostic Confirmation provides information with regard to the distribution of histologically confirmed cancers in the CCRs database. Site/Subsite, Laterality, and Histology are used to produce statistics showing the distribution of specific cancers in the population. And finally, Collaborative Staging/Extent of Disease fields is included in this list because accurate staging is very important for measuring survival.

At this time, only these seventeen (fifteen for cases prior to 1/1/2004) data items are visually edited because of the funding level presently allocated for the CCR and its regional registries. At such time as funds become available, treatment and/or other data items may be added to the list of data items that will be visually edited by the regions and included in the CCRs accuracy rate.

Data items not included in this list will not be counted in the accuracy rate. However, regions may visually edit additional items and provide feedback to abstractors on those data items.

VISUAL EDITING DISCREPANCIES

Revised July 1, 2008
A discrepancy is defined as the quality or state of being discrepant, i.e., disagreeing, being at variance. A discrepancy arises when a more appropriate code should have been selected for a data item based on submitted documentation. Discrepancies are counted prior to cases being linked in the regional registry's database, thus eliminating the possibility of a data item being counted discrepant due to information received from another facility. Discrepancies are counted if data items do not meet standards outlined in Cancer Reporting in California: Abstracting and Coding Procedures for Hospitals, Volume I, the SEER Extent of Disease Manual, the Collaborative Staging Manual, the California Cancer Registry Inquiry System, or Guidelines distributed by the California Cancer Registry. Although there may be a discrepancy in codes between the region and the registrar, it may not always be counted. A set of guidelines has been developed to assist the regional registries in deciding when to count a discrepancy.

ACCURACY RATE STANDARD

The visual editing accuracy rate for the seventeen data items is 97%. Accuracy rates are generated semi-annually by the regions.

This rate applies to cancer reporting facilities and not to individual cancer registry abstractors. The reporting facility is responsible for cancer reporting requirements, not specific individuals; therefore, an accuracy rate reflects the facility’s compliance with regulations. It is up to the facility to decide whether they wish to calculate individual rates.

Non-analytic cases are included in the accuracy rate. They are visually edited by the regions, although not as extensively as analytic cases. Review is limited to verifying that there is supporting documentation to validate the coded data field. Information on the medical record may be incomplete or inaccurate on these cases; however, the non-analytic case may be the only case that is in the CCR database on a particular patient.

Class 6 cases -- patients diagnosed and all of the first course of treatment only in a staff physicians office -- are not included in the determination of the facilities accuracy rate.

CALCULATION OF ACCURACY RATES

The method for calculating the accuracy rate is as follows: The number of discrepancies is divided by the number of data items -- 17 (15 for cases diagnosed prior to 1/1/2004)) multiplied by the number of abstracts edited. This is multiplied by 100 in order to produce a percent discrepant, which is subtracted from 100% to arrive at the accuracy rate. See the example.
# of discrepancies

\[ \frac{33}{300 \times 17} \times 100 = 0.65\% \]

then,

100% minus percent discrepant = accuracy rate or 100% - 0.65% = 99.35%

Automated software calculates accuracy rates using the above formula. This software has the capability of tracking discrepancies for a six-month period. A data item can be flagged to be counted as a discrepancy, or not, at the time of visual editing. Monthly generated feedback in the form of discrepancy reports to the cancer reporting facilities includes the submitted code and the changed visually edited code for each data item. The report may provide a reference source and comment as to why the data item is discrepant.

**FEEDBACK FROM CANCER REPORTING FACILITIES**

Timely feedback from registrars on visual editing done by the region is very important. Disputed corrections should be returned to the region within three (3) weeks of receipt of visual editing discrepancy reports. If the visual editor is incorrect, the alleged discrepancy is subtracted prior to the calculation of the accuracy rate.

Unresolved cases are not included in the accuracy rate for the current evaluation period. When the case is resolved, if appropriate, the resolution will be reflected in the upcoming evaluation period.

Disagreements between the regional registry and the cancer reporting facility with regard to discrepancies are to be discussed with the regional registry quality control coordinator. Any unresolvable issues are referred to the California Cancer Registry Data Standards and Quality Control Unit. The outcome is sent to the cancer reporting facility and the regional registry.

**DISSEMINATION OF ACCURACY RATES**

Accuracy rates are sent to the cancer reporting facility semi-annually and are sent within 45 days of the end of the period evaluated to allow adequate time for the region and CCR to evaluate any disagreements. In addition to the accuracy rate for the facility, the report provides the number and percent discrepant for each data item for this cancer reporting facility comparing it to the regions overall results. Summary reports for each region are routinely monitored by the regional registries and the CCR. If the reporting facility contracts to meet their reporting requirements, the accuracy rate is also sent to the vendor that has the contract with the facility or the field abstractor.

Regional registries are available to assist cancer registrars with methods for improving their accuracy rate, particularly for facilities which are below the 97% accuracy rate. This assistance may be in the form of special training workshops or individual training, as time and funding will allow.
CONSISTENCY IN ACCURACY RATES

In order to be consistent in the determination of what constitutes a discrepancy, the California Cancer Registry’s regularly scheduled Statewide Quality Control Teleconference calls discuss visual editing issues. These teleconferences include visual editors at the regional registries and the quality control specialists at the California Cancer Registry. Cases with inconsistencies in the 17 data items are discussed during these calls.

In addition to these teleconferences, the Data Standards and Quality Control Unit conducts a breakout session at the CCR technical workshop once a year for the regional cancer registries. The goal of these technical workshops is to discuss issues related to the collection of accurate and consistent data.

In order to evaluate the quality of regional registry visual editors, the automated software program, allows regions to monitor the quality of their visual editors. In addition, the CCR conducts recoding audits of regional registry visual editors, annually.

Educational workshops for cancer registry personnel are conducted by both the regional and central registry. In addition, both state and local cancer registries associations hold educational workshops. It is important for cancer registry personnel to make every effort to attend these workshops.