CALIFORNIA CANCER REGISTRY

CALIFORNIA CANCER REPORTING SYSTEM STANDARDS

VISUALLY EDITED DATA ITEMS

STANDARDS FOR DATA ACCURACY

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Informational Packet for Cancer Reporting Facilities

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 CCR is a collaborative effort involving the California Department of Public Health (CDPH), CalCARES UC Davis Health System (manages the central registry), the three SEER regional registries in California, hospitals, and cancer researchers throughout the nation. To date, the CCR has collected detailed information on over 5 million cases of cancer, with over 150,000 new cases of cancer 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 CCR. 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 manual review and visual editing to provide feedback on 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, standards for data accuracy have been developed. This document will provide information on the methodology used for these standards.

Visually Edited Data Items

Visually edited data items were selected because they affect the overall quality for data usage. In other words, data items such as County of Residence at Diagnosis, 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. Several Staging fields are included in this list because accurate staging is very important for measuring survival. Over the years, based on needs, available staff and funding level allocated for the CCR and its regional registries, the number of data items has changed significantly. Treatment and/or other data items have been added to the list of data items that will be visually edited by the regions and included in the CCRs accuracy rate.

The list of visually edited data item groups and individual data items included in those groups, by each year of diagnosis starting from 2002, that are visually edited by regional staff to determine the accuracy rate of hospital reporting can be found in the visually edited data item lists for selected years or all years combined. 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

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 and all other guidelines that are in effect for that year of diagnosis, or Guidelines distributed by the CCR. Multiple discrepancies in the same visually edited item group for the same case, is counted as one. 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 is 97%. The number of data fields visually edited may vary from year to year. 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.

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.

Excluded from a facilities accuracy rate calculation are Class 30-38; Class 40-42; Class 43; and Class 49.

Calculation of Accuracy Rates

The method for calculating the accuracy rate is as follows: The total number of discrepancies is divided by the maximum possible number of discrepancies, multiplied by 100 in order to produce a percent discrepant, which is subtracted from 100% to arrive at the accuracy rate. To get the maximum possible number of discrepancies, the number of reviewed cases for each year of diagnosis is multiplied by number of data item groups for respective year of diagnosis. All the products are summed up for all the year of diagnosis reviewed.

See the example:

Visual Editing Accuracy Rates Calculations

Year DX (VE Item Groups)	2005 (12)	2012 (16)	2016 (20)	2018 (21)	Total
Cases Reviewed	1	2	5	8	
Date of Diagnosis			1		1
Site	1				1
Race		1			1
Grade	1		1	1	3
Spanish Origin		1			1
Treatment				1	1
SSDI				1	1
Total Discrepancies	2	2	2	3	9
Max Possible Discrepancies	12	32	100	168	312
Accuracy Rates: 100% - (2+2+2+3)/(12x1+16x2+20x5+21x8)*100					97.12%

Note: Although a data item might be included in the VE items list, the visual editor may uncheck the box on the VE screen or a data item may not be included in the visually edited data item list for a particular year of diagnosis. In these cases the discrepancy would not be counted.

Automated software calculates accuracy rates using the above formula. 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.

Dissemination of Accuracy Rates

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.

Statewide abstractors have various resources available 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 evaluate the quality of regional registry visual editors, the automated software program allows CCR ability to monitor the quality of submitted data. The CCR conducts recoding audits of these data annually.

Educational workshops for cancer registry personnel are available through different resources including, but not limited to FLccSC and SEER*Educate. In addition, both state and local cancer registrars' associations hold educational workshops. It is important for cancer registry personnel to make every effort to attend these workshops.

Feedback from Cancer Reporting Facilities

Timely feedback from registrars on visual editing done by the region is very important. All visual editing discrepancies that are not disputed must be corrected in the cancer reporting facilities data base thereby ensuring that a modified record will be transmitted with the correct data in a timely manner.

Disagreements between the regional registry and the cancer reporting facility with regard to discrepancies are discussed with the assigned regional registry quality control coordinator.