

Data Collection-Beyond The Routine

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If asked to list the data collection activities of the California Cancer Registry's (CCR) regional registries, hospital cancer registrars would most likely list casefinding, abstracting, follow-up, and death clearance follow-back. These "routine" data collection activities are authorized under California's cancer reporting legislation which grants to the regional registries of the CCR authority to access all information that profiles the individual cancer patient.

Routine data collection activities identifies all reportable patients, captures demographic data, and records pertinent medical information including that may impact diagnosis and treatment options. Additionally, characteristics of the cancer, cancer treatment, and follow-up/outcome data are also collected. Regional registries are also required under the legislative mandate to conduct activities to verify and enhance the information that is initially abstracted and reported. This effort includes re-abstracting activities performed to assure completeness and accuracy of the data.

Each year, the regional registries of the CCR participate in the National Cancer Institute's SEER program's Patterns of Care Study (POC), part of the process of quality control that is an essential component of state-mandated cancer surveillance. The primary goal of the POC is to document and verify the types of treatment that adults and children are receiving for specific types of cancer. Sites selected for review have included solid and hematopoietic malignancies and brain tumors. The regional registries have recently completed data collection for the 2009-2010 POC which included patients diagnosed in 2008 with Chronic Lymphocytic Leukemia (CLL), Non-Hodgkins Lymphoma (NHL), Prostate Cancer, and Gastrointestinal Stromal Tumors (GIST).

While termed a "study", the POC is actually an audit or evaluation of data that has been submitted by hospital registrars as opposed to a study which would typically be a separate research project directed by a researcher. A small sample of patient records for inclusion in the annual POC is obtained from all hospitals in each of the SEER regions nationwide.

In California, the names of patients selected for inclusion in the POC are obtained from each regional registry. The regional registry POC data collection staff receive special training in the identification of current diagnostic and treatment modalities for the site-specific conditions under review in order to verify and augment the information that is routinely abstracted and reported from hospital records but is often incomplete at the time the abstract is submitted. For a selected sample of patients, the physicians of record are also contacted to verify the treatment (s) that were recommended and received.

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As your facility's cancer reporting expert, the regional registries need your help in communicating to your Health Information Management (HIM) colleagues the importance of requests by the regional registry data collectors to obtain and review medical records for the POC. This effort assures the quality and completeness of the data you have already submitted to the CCR as a function of mandated cancer reporting.

As cancer registry professionals, our mission is to collect the most complete, high quality data in order to advance scientific knowledge and clinical practice as to the causes, treatment, cures and prevention of cancer. The CCR and the regional registries sincerely thank you for your assistance and support in facilitating the medical record requests for this important data collection activity.

Should you or your facility have questions about the SEER POC, please feel free to contact your regional registry's study coordinator.

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