Steps to Ensure a Successful CoC Survey-
Data Quality/Integrity (Article 3 of 4)

Cancer Registry Data Collection

Data collection in the cancer registry is governed by standard setting agencies, SEER, NPCR, CoC, NAACCR, CDC and state cancer registries. Each agency provides manuals, resources and tools to aid in correct data collection. Data collected by a hospital cancer registry are useful on several levels. The hospital cancer registry records personal and medical information necessary for planning and evaluating the patient's case management. The registry data provide administrative information for facility planners, cancer committees, and practitioners. When the data are consolidated by population-based central/state registries, they are used by government and private agencies for developing and evaluating cancer control programs. Registries also provide a rich source of data for investigative cancer research.

Most hospital-based registries are required to meet the reporting standards of more than one organization and may also add specific variables to meet their own facility needs. Many registries in hospitals are required to meet the data reporting standards of both the CoC and their state central cancer registry.

Standard codes are necessary for reporting or exchanging data amongst all of the standard setting agencies. The standards specify not only what codes to apply to "known and unknown" categories but also distinguish categories for unknown data such as "not available in the record," "not appropriate to this case," or "not collected by this registry." Rules on how to apply the codes are also provided. Rules for data collection go beyond codes for many data items. For example, how exactly does a registrar select among multiple references to morphology (cell type of tumor) in a patient record? When does the first course of therapy begin and end? Where does a transient live?

All of these factors impact data quality and integrity.

How can cancer registrars ensure the data entered into their cancer registry is accurate and complete?

First and foremost, cancer registrars must know who they are reporting their data to. This will dictate which reporting requirements they must follow. Each state cancer registry will have their own Data Standards Manual. It is important of keep a copy of this manual nearby for use when questions of reporting requirements come up.

For registries in CoC programs, the manual for data collection rules, codes and coding rules is FORDS (Facility Oncology Registry Data Standards) manual. This is available free of charge as a download at: http://www.facs.org/cancer/coc/standards.html. The current version is *FORDS – 2013*. This is also a "must have" in the cancer registry resource manuals. Do not rely on your registry software for data collection rules. Many only provide codes and abbreviated definitions. The *FORDS* manual should be used for all coding rules. It is very important for every registrar that is abstracting in a CoC program to have read at least SECTION ONE: *Case Eligibility and Coding Principles*. SECTION TWO: *Coding Instructions* provides the complete definition and

coding rules of each data item. Be sure to utilize *FORDS-2013* as your primary reference. Many examples are provided for unusual circumstances. Following the rules for data collection is essential for quality data.

Additional essential reference manuals and resources for every cancer registry include, but are not limited to: *International Classification of Diseases for Oncology*-ICD-O, 3rd edition (site and histology codes); AJCC Staging Manual, *7th edition*; SEER RX (drug classification database) http://seer.cancer.gov/seertools/seerrx/; and Multiple Primary and Histology Coding Manual, http://seer.cancer.gov/tools/mphrules/download.html.

Data Edits and their use to ensure high quality data

Data edits for state reporting and NCDB are not enough for high quality data. The NCDB data edits may be different than State edits or very similar in some regions. Passing those edits is not enough for quality data.

Many steps can be taken to improve the quality of data in the registry.

- It should be routine to document enough text to support the coding. Text does not have to be repeated in more than one text field. Keep it to the point and do not write a book. Use of standard abbreviations is helpful. All abstractors should focus on how to best tell the cancer patient's story. Text is important for many uses. At the state level, text is extremely helpful to assist in the determination of merged records. At the hospital level, text can be used to support rationale for coding and to explain or document items that are not currently captured in code. ER/PR values, PSA and CEA values are important in some instances and should be routinely recorded in Lab text fields. This will aid in the quality reviews of abstracts.
- Review of all "Unknown Primaries" should be done annually to determine if a primary site was eventually determined.
- Review all "Class of Case 00" to determine if treatment was actually given elsewhere, otherwise this may need to be changed to 14 if observation was the planned treatment.
- Review all "Class of Case 10, 20, 30" cases to identify more specific coding of Class of Case. In most cases more specific Class of Case is possible.
- Review all Unknown Stage cases to determine if staging evaluation was appropriately done. This may be an opportunity for improvement, if insufficient staging procedures are identified. Utilize your Liaison Physician to assist in this assessment.
- Review all site codes with ".9" as fourth digit. Radiology reports may often provide more definitive site information that can be used to be more specific with site coding.
- Each of these reviews should be done prior to data submissions to the state and/or NCDB.

What should be evaluated during an Abstract Audit?

While the above data reviews will help identify overuse of inconclusive codes, it does not replace routine audits of abstracts. Abstracts should be evaluated for accuracy of coding site, histology, grade, stage of disease, class of case and the capture and coding of complete treatment information. An audit form with data fields to be included in this audit will help keep the auditor focused.

The auditor must have knowledge of staging and expected treatments to assess whether the data was accurately and completely captured. A review of the patient medical records is necessary to ensure that the abstract contains complete and accurate information regarding your cancer patient encounters and an accurate accounting of the diagnosis and treatment at your facility. Text documentation included in the registry abstract will help greatly with abstract reviews. It is especially important to document in text any work-up or treatment given at other institutions.

NCCN treatment guidelines may also be utilized as a reference for the auditor to determine if all usual work-up and treatment were captured in the registry abstract. While registries do not utilize NCCN guidelines for data collection, the NCCN guidelines are very helpful when the auditor may not know the expected treatments.

For CoC programs, 10% of annual analytic cases are required to be audited by a physician. This can be a random sampling or select site as long as 10% of annual analytic cases are done. This audit must be performed each year. Residents, and other physicians not necessarily on the cancer committee, can be utilized for this audit. Findings of the audits should be shared with all abstractors and reported to the cancer committee as part of your Registry Quality Control Plan.

Feedback to the abstractors is especially important. This should be done as a learning opportunity and not judgmental. Once abstractors are more educated on treatment expectations they can be proactive in looking for this when they are abstracting.

In summary, registry data requires continuous evaluation and audits to ensure quality of data. It is better to be proactive and audit your data before a study or data request which results in a challenge or exposure of inaccurate data. The registry should be a repository of good data that can be analyzed to show your facilities experience in quality care of your patients internally and externally.

Look for our next article on *Data Reporting – Uses of registry data beyond your registry*.