

# REGISTRAR PIP

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## Making a Good First Impression with Data – Part One



According to a Forbes article published back in June of 2018, it only takes 7 seconds for us to make a good first impression on someone else. It got me thinking about how long it might take a cancer registry to make a similar impression when it comes to the quality of the data it produces. No matter how you look at it, seven seconds isn't going to be in the ballpark when it comes to making an assessment because that assessment will likely involve a multi-step approach to determine the quality of our data and this takes time. When you think about it, registry data has the potential of making an impression on both the direct user of the data as well as those impacted by those who used the data to make decisions.

Oftentimes those responsible for collecting high quality registry data are not frequently recognized for the work performed and the effort it takes to produce it. Registrars fly under the radar at many facilities even though the data we produce is critical to supporting the work of physicians, researchers, epidemiologists, public health planners, legislators, facility administrators, and others. For some reason it seems easier to pinpoint when our data makes a bad first impression. It's that moment when someone used our data to support a decision that negatively impacted patient care or research results, or cost a facility resources that could have been better spent in other ways.

With the importance and use made of our data, tracking and sharing information on its quality helps resolve any issues identified in the data and provides a mechanism to assess whether our data is fit to serve its intended purposes. The following are just some of the most active users of cancer registry data who rely on its accuracy, completeness, and timeliness for multiple reasons.

- **Healthcare providers** - to propose diagnostic and treatment options to patients that will minimize risks while enhancing outcomes and to also assist in efficiently designing medical policies and procedures
- **Researchers** - to obtain reliable and accurate results in data-driven research projects
- **Facility Administrators** - to design marketing strategies, improve patient relations, and increase profitability for the organization
- **Public health officials** - to define and monitor cancer incidence at the local, state, and national levels, investigate patterns of cancer treatment, and evaluate the effectiveness of public health prevention efforts

In the next few newsletters, we will share the documentation and coding issues identified in abstracts submitted to us by registrars and CSS staff. In the first couple of newsletters we will identify local issues identified that need to be addressed. In early 2023, we will share the data quality issues targeted at the national level by the Surveillance, Epidemiology, and End Results (SEER) Program.

Ideally, it would be best to provide specific feedback to individual abstractors and editors known to be repeatedly omitting documentation requirements or submitting coding errors. Unfortunately, that isn't possible given our current central registry software capabilities and the time and staff resources necessary to perform such an effort manually. However, it is possible to identify and share with everyone the commonly occurring issues. Even if we

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are certain we are not making any of the errors that follow, it will serve to reinforce that we are correctly handling such cases when we are staring at them and trying to decide how to proceed.

## General Issues

### Avoid abstracting in all caps

- Writing in all caps is usually a bad idea. Reasons?
  - ▶ It is more difficult to read text written in ALL CAPS; it is not easier.

Honestly, which is easier for you to read?

Capital letters look more similar than lower case letters. They all have the same relative height and most have the same relative width. They also tend to have the same blocky shape.

versus

CAPITAL LETTERS LOOK MORE SIMILAR THAN LOWER CASE LETTERS. THEY ALL HAVE THE SAME RELATIVE HEIGHT AND MOST HAVE THE SAME RELATIVE WIDTH. THEY ALSO TEND TO HAVE THE SAME BLOCKY SHAPE.

Keep in mind that with much more text commonly seen on an abstract, it only makes the ALL CAPS problem worse.

- ▶ ALL CAPS actually de-emphasizes what is important.
- ▶ While ALL CAPS has a place when trying to convey excitement, sarcasm, passion or raising the volume associated with what is written, it isn't the best choice when abstracting. Numerous studies conducted over the past decades (since as early as 1914!) also suggest that text written in all capitals takes more time and effort to read than text in standard sentence case. You have to admit, one thing none of us have is extra time!
- ▶ Some registry software products, such as the one CSS uses, automatically shifts patient names and address information to all uppercase. Name and address information in upper case is acceptable and stands as the only exception to the "avoid ALL CAPS when abstracting" rule.

### Abbreviations

- Adopting the North American Association of Central Cancer Registries' (NAACCR) standard for allowable abbreviations to use while abstracting will improve everyone's ability to understand the writer's intent. Institution-specific abbreviations or using personally devised shortcuts instead of using standard abbreviations results in confusion, especially for new staff and non-registry users of the data trying to interpret the text. Those working with investigators are often asked, "What does this mean?" when they run across non-standard abbreviations.

Here is the link to the NAACCR Recommended Abbreviations for Abstractors list:

<http://datadictionary.naacccr.org/default.aspx?c=17&Version=23>

### Dates

- When documenting any note or procedure, we need to make sure we've started the documentation with the full date used in the report from which we are taking our information.

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- ▶ This is especially critical to central registry staff when consolidating records from multiple facilities. When dates differ between facilities, it can be difficult to determine which documentation is “correct” or who might be estimating dates.
- ▶ When Physical Exam notes are undated, determining whether information can be considered as part of the clinical staging timeframe is problematic. This is especially true for prostate primaries when we need to know when the digital rectal exam (DRE) was actually done.
- ▶ When coded dates have been estimated, document in the appropriate text field the basis for the estimate, especially when your software does not allow you to code 9’s in the date fields to reflect either unknown or the fact that dates are being estimated.

### Ambiguous terminology

- There are separate rules for casefinding versus trying to determine tumor involvement or coding a field such as histology when ambiguous terminology is used by clinicians and/or pathologists. We need to be aware that differences exist and to pop open the manuals or check online documentation to refresh our memories regarding the rules that apply given the task at hand. Histology coding is particularly problematic.
  - ▶ **Coding histology for hematopoietic/lymphoid cases:** While these rules have been in place for a while, applying them is still problematic today.
    - If a single histology is described by ambiguous terminology, the single histology can be coded. (Example: Ileum biopsy -> **favor extranodal marginal zone (MALT) lymphoma**; assign histology to 9699/3.]
    - If the NOS histology and a more specific histology described by ambiguous terminology are given in a pathology report, further clinical confirmation of the more specific histology must be found in the medical record and documented in the abstract in order to code the more specific histology. In other words, the ambiguous terminology alone cannot be used to code the more specific histology in this situation. (Example: Ileum biopsy -> **low grade B-cell lymphoma, extranodal marginal zone (MALT) lymphoma is favored.** Without clinical confirmation of marginal zone lymphoma, the histology should be coded to 9591 for this diagnosis.)
  - ▶ **Coding histology for solid tumors:** Code a histology when described by ambiguous terminology ONLY when:
    - Histology is clinically confirmed by a physician (attending, pathologist, oncologist, etc.)
    - Patient is treated for the histology described by an ambiguous term
    - Case is accessioned based on a single histology described by ambiguous terminology and no other histology information is available/documented

### Site-specific rules

- Don’t fall into the trap of applying a site-specific rule to other sites. One of the most common coding errors is coding “lymphadenopathy” as tumor involvement for sites other than lymphomas. That’s a big no-no.

### Difficult coding situations

- If you’ve done extensive research to code a data item given an unusual or tricky patient presentation, put the details in the Remarks section of the abstract so others can understand the reason(s) behind your final coding

decision. It will spare others duplicating research you've already done, avoid a request for clarification from the central registry, or worse, causing a data item to be subsequently recoded by the central registry staff to unknown because supporting text is missing.

**Conclusion**



Given that making a good first impression with our data is a shared goal among registries, a logical starting point is standardizing how we document patient demographics, tumor characteristics, treatment, and staging information on our abstracts. Text documentation should be completed before coding begins. When recording what is pertinent be sure to include both positive and negative findings. Keep in mind that when coded values differ from information provided in text documentation, the central registry staff will give the text documentation precedence.