REGISTRAR PIP

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Follow the Leader

Background

Why do the standard setters bother producing various coding and procedure manuals? In spite of the effort involved to create and annually update such manuals, think of the alternative -- our jobs without them. It's more than a little scary to think of the quality of the national data if we all make up our own coding rules and decided not only what we'd capture, but how we'd code all the data items.

Widespread adoption of data standardization is necessary to improve the exchange and usefulness of medical data. The use of coding standards reduces ambiguity and improves understanding which leads to improved knowledge about cancer diagnosis and treatment. If we all don't adhere to the national data collection standards, the result is incomplete and inaccurate data. Researchers will not be able to rely on it to help improve healthcare practices and patient outcomes.

Some might question the risk and sanity of widely sharing what you are about to read next. However, I decided it was more important to share our registry's past practice in case anyone else is currently making the same mistake. Before sharing, let me start by saying that allowing a procedure to continue because "that's how things have always been done" has to be the weakest reason to continue any practice, especially one that reduces the consistency and usefulness of our data at a national level.

Confession Time . . .

For years, at CSS we kept two enormous 3-inch binders referred to as the ***CSS Coding Notes.*** In them we tracked the date, source, and summary of decisions related to how we managed casefinding and coding issues we'd discussed with a local pathologist, who was the source of the majority of these notes. We believed our pathologist consultant knew more than SEER staff (may have been true, but not actually relevant in the big scheme of things) and he certainly responded in a timelier fashion to our questions than SEER.

Eventually, we stopped sending many of our casefinding and coding questions not addressed in a manual to SEER. At the time, I'm not sure why none of us ever thought of the bigger picture . . . the impact of each such decision on the national data. While we may have been able to achieve consistency within our own registry by handling all these questions internally, did our data look anything like the other registries' data?

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In addition to recording monthly updates in the ***CSS Coding Notes***, we actually changed coding scheme verbiage by either adding or crossing out text in the standard setter manuals! Yeah, when going "maverick" we figured we might as well go all in. We felt our actions were justified because we had a local pathologist guiding us through the process.

The Light-Bulb Moment

It wasn't until the Seattle registry was assigned the task of performing quality control on the content in the SEER Inquiry System (SINQ) we were smacked in the face with the impact of our earlier decision to go our own way. During our meetings with NCI staff, we repeatedly questioned many of SEER's decisions and corresponding rationales in SINQ because they didn't correspond with documentation we had in our ***CSS Coding Notes.*** The NCI SEER QC team repeatedly responded with, "Why are you doing that?" If one ever gets asked such a question multiple times by the standard setter, who happens to be the registry's primary funding source, one might consider the possibility that perhaps there's a registry practice in place that needs to stop.

As most are probably aware, the SINQ system is an application designed to capture coding-related questions that pop up while we code cancer cases. The responses are to be used as a reference when current coding manuals are not clear about how to manage issues not covered in the manuals. While initially SEER didn't do so, SEER now uses SINQ as one source of information to update new releases of its manuals.

Learning Opportunity

Our decision to internally handle many coding and casefinding issues not addressed in the current documentation in manuals had two unintentional results:

- CSS ran the risk of producing data that could yield unpredictable or less reliable results unless other registries independently made decisions like those we made when faced with similar situations
- Lost the potential to improve documentation in the manuals which could have improved coding accuracy and consistency at a national level

Learning is nothing if not a humbling experience especially when it points out the shortsightedness of a past decision. But, learn from it we did.

Conclusion

To improve national data quality, we need to be willing to do two things. First, we all need to commit to challenging the standard setters on casefinding and coding issues that come up during our workday that are not addressed in the manuals or in one of the tools intended to clarify new or confusing topics (i.e., ***SINQ***, ***Ask a SEER Registrar*** and ***CAnswer Forum***). We need to understand that any ***local*** decision on handling the reportability of case types or data item coding should be seen as a ***temporary*** solution. (Yes, we need to do something temporarily to promote consistency in our registry while awaiting a response.) We have to kick our questions up the food chain to the standard setter and make any necessary changes locally after receiving their responses.

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Second, even if we or our local pathologists and physicians disagree with the national standard setter's decision on how handle a particular situation, we must follow the national guidelines established. This was, and occasionally continues to be, a tough one for us to follow. However, we have come to embrace the fact that we are part of one or more national data collection efforts. We need to do our best to promote sharing data collected according to national data standards. We cannot inadvertently be a party to collecting data that is really more appropriate for hospital or central registry level data silos than cancer research at the national level.

We each have a responsibility to work in collaboration with one another to improve the accuracy and consistency of the data for the benefit of cancer research community and ultimately, the cancer patient. That's right . . . this is a time and a place for ***Follow the Leader.*** Mavericks need to sit this one out and reserve their visionary innovation to the areas of improving our data collection processes and thinking of ways to expand the usefulness of the data we collect.

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