

# REGISTRAR PIP

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## November 2023 Registrar PIP Sometimes It's Not What You Hear . . .

### Introduction

What we see at a meeting may make an impression that spurs us into action. Typically, advance publicity surrounding a meeting highlights the invited speakers. However, we've decided for this edition, it's time to give the poster presenters their due. To that end, we are taking everyone on a quick tour of some of the most memorable graphics from the North American Association of Central Cancer Registries' (NAACCR) meeting in New Orleans held earlier this year.

It shouldn't surprise any of us that others have developed guidelines to consider when drafting a poster presentation. According to Muriel Moyo, MS, BSN, RN, CCRN-K, NE-BC, a poster presentation is a visual representation of research, quality, or process improvement work in which someone (or a group) is involved. Effective presenters should adhere to the "5 C's of poster creation, that is, Compliant, Catchy, Concise, Clear & Clutter-free." Learn something new every day, right?



### Posters

There were many more posters displayed in the Exhibit Hall during the meeting than reported in this article. We've opted to highlight those most applicable to us as central and hospital-based registrars.



"A Comprehensive Usability Engineering Framework for Cancer Registry Information Systems"  
by Ian McClendon

**Author's take-home message:** Software usability is strongly correlated with user productivity, user satisfaction, and lower error rates.

**Local Commentary:** Any of us who have argued with a vendor to have more data items on our screens or indicated we don't want to endlessly mouse-click to find where we can add something in our software would appreciate this poster creator's message. Data and software changes matter and they impact productivity. A wise vendor watches as we use our abstracting software in order to understand **our** workflow process. This is the best way to learn how we do what we do and to tailor **their** software to best meet **our** needs. We usually know best how we want and need to do our jobs most efficiently and accurately. When working with a vendor, insist they make additional changes when **their** "new and improved" is less than optimal for **us**. Their software needs to align with our workflow, not the other way around. Too often we merely accept what is delivered to us and we don't challenge their design. Don't be afraid to speak up.

Process Improvement Pointers • Feedback/Questions to [Registrar-PIP@FredHutch.org](mailto:Registrar-PIP@FredHutch.org)

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*"Analysis of Cancer Incidence During COVID-19 Onset Compared to Pre-COVID-19 Years"*  
by Abby Hold

**Author's take-home message:** COVID-19 caused a delay in cancer screening, diagnosis, and incidence reporting. In a community level study involving 5 states a decrease of weekly cancer diagnoses was observed for 10 weeks following the onset of the pandemic.

**Local Commentary:** Those who perform concurrent abstracting **and** routinely monitor abstract completion rates are able to identify shifts in hospital and incidence reporting first. In our registry, we were able to provide SEER a heads-up about COVID-19's impact on incidence reporting very early in 2020. We suggested to them it was likely going to be necessary to adjust their previously indicated "expected" incidence volumes to reflect the current "observed" reality in our region. While we were the first region to observe and report this phenomenon to our funding agency, we were not the last or only one to do so.

An advantage to having the Seattle-Puget Sound region in the SEER Program is its potential to be a national program's "canary in the coal mine." Any of us who rapidly ascertain cases have many of the necessary details available to assist national standard setters and hospital medical and administrative staff in making needed decisions. This is one reason we at the central registry perform rapid case ascertainment using pathology reports while we wait for abstract submissions from the hospitals. Granted, the central registry reporting from pathology reports is incomplete when compared to the abstracts received from hospital registrars; however, our concurrent reporting of preliminary pathology report details is complete enough to be critically important for many real time clinical and financial decision making situations.

Think about this, when funding is tight, who do you believe is in the stronger position of being retained? Will it be those who position themselves to be among the first to report an issue or those who hear about the issues from others? Operating concurrently heightens not only the profile of the registry, but our profile as registrars too. While this poster dealt with the impact of COVID-19 resulting in delayed cancer incidence reporting, it made many of us think about the advantage we provided the SEER Program because we could actually demonstrate COVID-19's impact on reporting in real time.



*"Implementation of a Standardized Template to Improve the Timeliness and Consistency of Early Case Reporting of Pediatric, Adolescent and Young Adult Cancer Cases to the Rhode Island Central Registry"*  
by Paulette Zinkann

**Author's take-home message:** In Rhode Island, a state mandate required all cancer incidence be reported to the state central cancer registry within 30 to 45 days of the first contact with a physician. Critical to achieving this goal was to create a template of minimally required data fields to streamline the reporting process and improve the timeliness of the monthly reports submitted. When the **template** was first introduced in May 2022, 56% of all facilities reporting cancer cases for the 0 to 29 age group used the template. By December 2022, 89% of facilities used the template.

**Local Commentary:** Again, the advantage of "real time reporting" is demonstrated in a poster presentation. It's not only our standard setters who want us to shorten the time between diagnosis and preliminary reporting. Our clinicians and patients want and need this data too. Real-time data can assist physicians in making the best treatment decisions by analyzing concurrent staging, biomarkers, and prognostic factor data. Selective demographic, diagnostic, and staging data can help identify potential patients earlier for clinical trials, resulting in an increase in eligibility. This would support a facility's goal to offer the best treatment options to their patients. In addition, real time reporting will assist the oncology program staff in measuring and analyzing quality metrics and help them create improvement strategies for the organization. It seems pretty clear to us, those who continue to resist moving toward implementing a more rapid procedure for reporting will be fighting a losing battle that could potentially jeopardize funding and support for their registry.



*"Results of Data Quality Evaluation: Completeness Follow-back of the Centers for Disease Control's (CDC) National Program of Cancer Registries (NPCR)"*  
by Maricarmen Traverso-Ortiz

**Author's take-home message:** CDC monitors the NPCR data quality by routinely auditing each central registry's data. During the last three years, CDC contracted with Westat, a management services company, to assess the completeness of some data items for selected cancer sites. Forty-eight NPCR-funded central cancer registries (CCRs) participated in this audit and here is a brief summary of the results:

Across all evaluation years, 40% of the data items with unknown values were updated after follow-back. Oops! Really big oops! By site, data items with highest and lowest percentages requiring updating were:

- Colorectal (RX summary radiation and radiation regional RX modality, both 59% vs. grade, 17%)
- Female breast (RX hormone, 61% vs. estrogen and progesterone receptors, both 28%)
- Ovary (RX summary primary site, RX summary chemotherapy, and grade post therapy, all 53% vs. grade pathological, 19%)
- Pancreas (grade post therapy, 48% vs. tumor size summary, 28%)
- Urinary bladder (RX summary BRM, 59% vs. grade pathological, 20%)
- Brain (summary stage 2018, 83% vs. grade post therapy, 21%)
- Esophagus (phase I radiation treatment modality, 47% vs. grade clinical, 12%)
- Liver and intrahepatic bile duct (RX summary chemotherapy, 52% vs. grade clinical, 12%)

**Local Commentary:** After checking these national results, we should probably ask ourselves if the data items involving these same primary sites in our databases have similarly high rates of unknown values. If so, we have some "fixing and training" to do too. Their sample size was likely representative of the magnitude of the problem given that forty-eight central registries participated in this audit. We think we will take a look at our database to see whether our unknown rates are better, similar, or worse than that observed by Westat. The most common reasons for unknown values were:

- Unknown value was correct
- Abstractor coding error
- Central registry consolidation was either incomplete or completed with errors

We will report our local findings in a future edition of the Registrar PIP.



*"Using LexisNexis to Improve Social Security Number Information in the New York State Cancer Registry (NYSCR)"*  
by Dr. Baoshen Quao

**Author's take-home message:** Social security numbers (SSNs) collected by cancer surveillance registries are used for patient matching, deduplication, follow-up, and linkage studies. There is a growing number of patient records with missing or inaccurate SSNs which comprises these registry activities. To try to improve the completeness of SSNs, the NYSCR performed a linkage with LexisNexis, a software company having the largest electronic database with legal and public-records-related information.

Prior to the LexisNexis linkage, 47,271 (3.4%) of the registry's patients had missing SSN, with higher percentages among the younger age groups, Black, Asian Pacific Islander (API), Hispanic, and foreign born. The percentages with no LexisNexis match or matched without LexisNexis SSNs tended to be higher for the same sub-groups of patients. After the linkage between the registry and LexisNexis, a larger absolute reduction of unknown SSNs was observed for younger age groups, API, and alive patients. Bottomline, LexisNexis proved to be a valuable resource to improve the quality of SSN information for the New York registry. Their preliminary results show the percentage of patients missing SSNs was reduced from 3.4% to 2.0%.

**Local Commentary:** Sometimes the quickest, least expensive, and most accurate way to improve and/or expand our registry dataset is to look to other groups or organization for a little help . . . especially if “link and upload” is presented as an option to do so. There would have been no way to **manually** achieve the same level of success than what the New York registry staff observed through their linkage with LexisNexis to improve SSN completeness and accuracy.

A linkages to improve SSNs is only the tip of the iceberg. At a national level, there is a growing interest to increase the use of linkages to improve the usefulness of our registries because linkages have the potential to not only significantly improve our data accuracy, quality, and completeness but expand its research potential. According to the NAACCR website, “Data linkages identify missing cancer cases, cross-validate data, and help with studies about comorbidities and survival. They also provide opportunities for registries to enhance relationships with other cancer control programs while potentially decreasing the cost of data collection.”

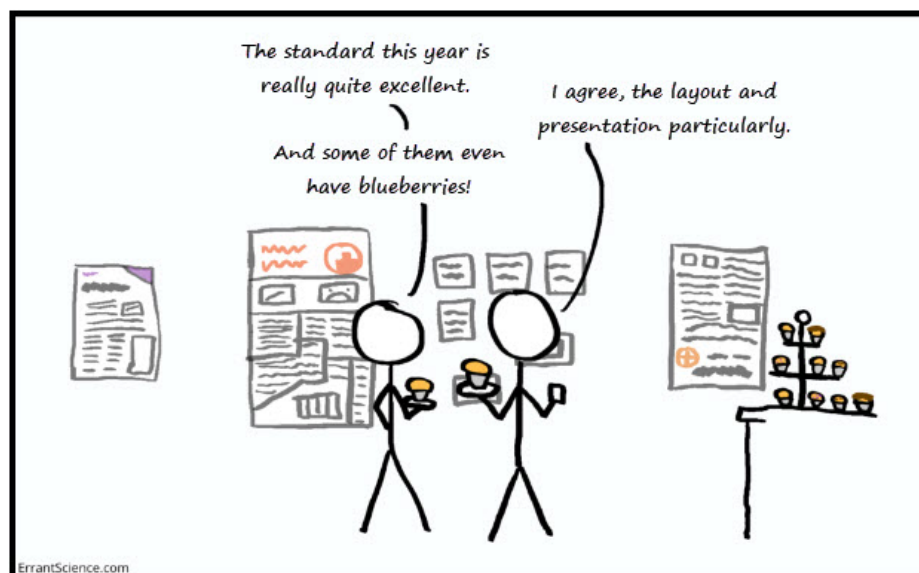
“Data linkages populate or enhance data such as patient identification number, date of birth, sex, race, address including ZIP Code, Social Security number, type of health plan and coverage, primary site and number of sites, date and method of diagnosis, cancer stage, date and cause of death, Medicare and Medicaid eligibility, and cause of death and comorbidities/complications. Linkages expand the richness of cancer registry data by facilitating examination of a variety of health-related issues. Data linkages with private and publicly available databases may decrease the cost of data collection and improve the timeliness of reporting.”

Expect more linkages in our future.

## Conclusion

How much can we learn from a static “snap shot” that provides an overview of a single topic in a poster? According to some research done by Nicholas Rowe, an educationalist, “39% of study respondents indicated posters are a good medium for transferring knowledge. It is not surprising that “visual appeal” was cited as more influential than subject content, with 94% agreeing that poster imagery is most likely to draw a viewer’s attention.” Does that mean we need something eye-catching on a poster or nobody is going to bother to stop and check out a poster’s message?

Admittedly, it is tough to look at a poster of dense tiny text without any graphics. If time is limited, those types of posters probably get more of a “walk by” rather than “read.” Catchy poster titles that seem most relevant for our registry typically draw us in.



*Muffins are an integral part of any academic conference*

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We should all take time to check out the posters in Exhibit Room at our next national meeting. Who can't make a little time to "stroll and read" while biting into a meeting muffin? We are bound to discover at least one idea worth "stealing." Undoubtedly, we will learn about something we can use to either enhance our registry efficiency, improve the quality and timeliness of our data collection procedures, or learn specific ways researchers use our data to improve their understanding of cancer, which ultimately will improve the lives of cancer patients. Isn't that what gaining knowledge is all about?

It's like we always say, "Some of the best ideas to consider implementing locally are those we can steal from others!" There are a lot of talented people in this profession. We should take every opportunity to learn from them so we might improve our own registry operations.