REGISTRAR PIP

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Will Improved Timeliness Enhance Productivity and Data Usage?

Introduction

Let's be honest. There are some data users who believe anything short of concurrent processing results in data too old to be of value to them. (Why aren't you and your laptop parked in the surgical suite or the pathologist office to collected data immediately?) If we are also being honest, users of national data want it sooner than the current 22 month delay of both the Surveillance, Epidemiology, and End Results (SEER) Program and the National Program of Central Registries (NPCR). While there has been extensive use of historical registry data made by physicians, researchers, health planners and administrators, there is an argument to be made that probably most users of the data would applaud improving our timeline in making data available sooner.

For some reason, quotes from Alice in Wonderland pop into my head when I listen to reactions to the idea of adopting a concurrent abstracting process at registries. They range from "we're all mad here" to "I'm late! I'm late! I'm late!" In other words, registrars fall into one of two camps . . . ***it's never gonna happen at my registry*** *versus* ***it should have happened yesterday.***

Concurrent Abstracting (aka the Initial Less is More)

Concurrent abstracting, as the Queen might have said to a doubting Alice, doesn't have to be just one of those "impossible things thought of before breakfast." After all, the Queen believed an impossible idea was merely the starting point for change that could materialize. Perhaps this is an area where population-based central registries should take the lead because they may be in the best position to work out the kinks in the process. They have access to the needed electronic data and can work with standard setters to create the infrastructure needed to at least identify and report potential incidence cases more rapidly.

Currently, most central registries postpone the creation of a cancer case until a hospital abstract is received. Why? "Because that is the way we have always done it and we want to touch the case only once with the information from all the pathology reports and all the hospital abstracts being considered at the same time." We may believe that is the most cost-effective way for us to process our workload. What's the problem with that approach? Doing so delays when cases are eligible to be linked to outside sources of information (e.g., molecular data, outpatient scans, specialized testing, longitudinal pharmacy data, etc.) that can further enhance the value of the central registry data.

While a hospital abstract is the critical source of crucial information found in a patient's medical record, it doesn't necessarily need to be the starting point of data collection at the central registry. However, central registry information systems need to be developed to efficiently consolidate the expanding number of data sources available prior to our receipt of hospital abstracts because these data sources provide only some of the required and desired information.

Cancer Surveillance System (CSS) Approach: In-house Essentials

While all central registries must perform core registry operations processes, the manner in which these activities are performed vary from registry to registry for several reasons, such as differences in state cancer reporting rules, differences in computing capabilities, and historical practices. The primary initiator of change for registries is the

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needs of those who use the data. In order to be able to effectively respond to the user data demands, we recognized decades ago that establishing an internal process improvement program was required to critically evaluate current procedures.

Implementing process improvement methodology required us to not only document all procedures, but track the time spent on all activities and quantify the work performed in order to identify potential opportunities to improve the relevance, completeness, accuracy, and timeliness of registry data. Doing so not only helped put us in a position to meet new goals and objectives intended to improve staff performance; it ultimately contained registry costs while either maintaining or even improving data quality and timeliness in various areas of registry operations.

There were unique features that existed two decades ago in our region and central registry that didn't exist anywhere else in the country. In 1992, our staff visited (in person) one of the large path labs to review the past month's binders of new path reports to perform casefinding and learned the lab had gone paperless. We had to find a new way to identify histologically confirmed cases immediately which was long before the idea of "national standards" for electronic path reporting was a twinkle in any standard setter's eye. Perhaps being in Microsoft's backyard caused the quick shift to electronic path reporting in our region. We worked with the labs to develop reporting mechanisms to meet the casefinding reporting challenge before other central registries encountered this issue.

Once we had regional electronic path, we had the potential to activate a near real-time regional incident reporting system given our unique program functionality:

- E-path submission files that identified greater than 90% of our caseload
- An internally developed pathology reportability filter and a combination electronic and manual screening procedure to assign primary site, histology, behavior, grade, and laterality to each pathology report within 48 hours of the pathology laboratory file submission
- An internally designed and primarily automated casefinding system that could utilize the now coded pathology reports and the submitted disease index and radiation treatment files to identify potential new and subsequent primaries
- Access to all facilities' electronic health records to quickly confirm reportability of a subset of all the potentially reportable cases found using pathology, disease index and radiation therapy files that could not be confirmed using solely casefinding sources
- Coding and consolidating incident cases within a week of processing casefinding files allowed researchers to access those cases immediately

We made incremental improvements over time and now have incident cases reflected in the central registry database more quickly. Hats off to our staff for making big changes from 2017 forward so that we could get path-based cases reflected within days of receipt of the pathology reports at our office.

When hospital abstracts are submitted months later, the staging and treatment information is updated. Keep in mind that between the time we identify cases and we receive the hospital abstracts, all the patients reflected in the database are eligible to participate in outside linkages that can further expand the central registry dataset and data utility. The work we did in our region proved itself to be a successful pilot test in evaluating the feasibility and cost of expanding a form of this methodology to other parts of the country.

Expansion after the Seattle Pilot – Phase 2

Given that a majority of the SEER registries now use the same database management system (SEER*DMS) and the CSS staff utilized a combination of SEER*DMS plus stand-alone internally-developed registry applications to accomplish the improved timeliness of reporting in our region, SEER needs to make a financial investment in the following areas in order to assist other registries in improving their timeliness of reporting:

- Increase the coverage of electronic pathology reporting

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- Expand the use of clinical documents (e.g., pathology and radiology reports) as merely casefinding tools to being the source to also initiate a reportable case in the database
- Make necessary changes to the SEER*DMS operations workflow to allow the shift from an abstract-centric starting point to one capable of utilizing clinical documents to initiate a case in the central registry
- Improve SEER*DMS functionality for handling corrected abstracts from hospital registries

Conclusion

Although there are challenges in moving toward concurrent processing by central registries across the country, those interested in expanding the use of central registries for research purposes to include identifying patients for rapid case ascertainment studies and clinical trials, and to produce preliminary incidence statistics are in favor of following ole Alice down that rabbit hole to investigate how best to accomplish this goal. Doing so would open up other opportunities for the use of registry data as well. We need to start believing in the impossible or improbable, otherwise it will be difficult to improve the timeliness of reporting and ultimately increase the value of the registries to those interested in using the data.

Bottomline . . . if central registries adopted a combination of effectively using available electronic data sources and modernizing their data processing infrastructure, a near-concurrent multi-tiered approach to cancer data collection is feasible. The big steps in the process are conceivable. Initially, the central registry needs to use a minimum data set sufficient to describe population incidence and prevalence to create cases. While waiting for additional staging and treatment information from hospital registry abstracts, central registries could expand the scope and value of the central registry by obtaining and linking targeted outside information in response to identified research needs.

The financial and technical support of standard setters is key to making this more than simply one of those "impossible things thought of before breakfast." Clearly, it is possible because CSS has already moved in that direction.

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