2022 NPCR IDAHO SUCCESS STORY

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Making Every Cancer Count by Counting Every Cancer: Ensuring Data Completeness at the Cancer Data Registry of Idaho

National Program of Cancer Registries
SUCCESS STORY

SUMMARY

Complete case capture is the foundation of cancer surveillance and accurate cancer statistics. When staff at the Cancer Data Registry of Idaho (CDRI) investigated unusual patterns in their data, we found that some tumors that facilities had marked as reported to the central registry had in fact never been sent. CDRI worked with Idaho hospitals to develop a process that improves complete reporting of tumors diagnosed or treated in Idaho.

CHALLENGE

CDRI has been supported by National Program of Cancer Registries (NPCR) since 1995. In 2020, over 9,000 invasive tumors were reported to CDRI, for an age-adjusted incidence rate of 419 cases per 100,000 population. CDRI has achieved the North American Association of Central Cancer Registries (NAACCR) Gold Certification for data quality, accuracy, and completeness since 1999.

CDRI receives data from many sources to record incident tumors, including monthly data submissions that we receive from 12 Idaho hospitals that abstract and send their own cases ("export hospitals"). Although reportable tumor data have been submitted to CDRI per the NAACCR standard for many years, the data files sent to CDRI come from a range of vendors and their software (e.g., METRIQ, Rocky Mountain Cancer Data Systems, OncoLog Cancer Registry, and ERS).

These monthly downloads are sent to CDRI by the hospitals during the first week of each month and processed in CDRI's registry software in near real time. These files contain data on each tumor that is marked as "completed" by the hospital registrars. Upon transmission, these tumors are flagged in the vendor's software as having been sent to the central registry.

In 2014, CDRI noted an unusual pattern in the data whereby hospitals stated that they had reported a case to the central registry and these cases were indeed marked as sent in the hospital's software, but no data on the tumor were ever included in the file sent to CDRI – creating a reporting gap with potentially serious implications for case completeness in the state. CDRI began a process to work with Idaho's export hospitals to identify the reason for the gap and create a solution.

SOLUTION

Collaboration with Idaho hospitals identified that cases "in suspense" or incomplete cases were sometimes inappropriately flagged as having been sent to CDRI, depending on the timing of when files were sent and when case were completed.

"In suspense" or incomplete cases are those tumors for which the hospital is awaiting additional information but have enough information to be used to identify incident cases.

CDRI and export facilities agreed that the most reliable way to ensure that all appropriate cases were reported prior to the annual data submission would be to review data on all cases initiated or updated by the hospital during the past two years. Thus, prior to the annual call for data – for which CDRI finalizes the submission file in October – and after export hospitals send CDRI their regular monthly submission file for September, CDRI requests "Special Follow-Up" ("SFUP") files; the SFUP files include all cases that the hospital "touched" or updated in the two years from the date of request, i.e., files requested in September 2021 will include cases from September 2019 to September 2021.

Hospitals create two SFUP files, one that includes cases that are not "in suspense" and are complete and one that includes cases that are "in suspense" and incomplete. Facilities use the "Date Case Last Changed" field (NAACCR item #2100) to identify eligible cases. CDRI requests that prior to creating either of the two files, facilities first review the cases that are "in suspense" or incomplete and mark any cases that are complete as such, which provides opportunities for data clean-up at the hospital registry.

I'm not sure how we got to this point, but it's time to request the "Special Follow-up" file(s) so CDRI can start working on our call for data submissions for SEER, NPCR, and NAACCR. Submission files are due in November, so **we would like you to create the special follow-up file(s) immediately after you create your September monthly download file.** CDRI uses these files to identify missing cases and for data cleanup.

Follow-up files: (two files from each hospital)
RMCDS – Cases NOT in suspense (1) and cases IN suspense (2)
Metriq – Complete (1) and Incomplete (2) cases
Oncolog – Complete (1) and Incomplete (2) cases (assumed terminology)
ERS – Complete (1) and Incomplete (2) cases (assumed terminology)

Note: Before your create your suspense/incomplete file, please review these cases for any that could be completed and included in your September download.

Please use the criteria below to identify cases and use NAACCR v21 XML format to create your special follow-up files.

NAACCR Field Name	NAACCR Item Number	Minimum	Maximum
Date Case Last Changed	2100	09-bb-2019 (September 2019)	09-99-2021 (September 2021)

EXAMPLE OF INSTRUCTIONS SENT TO IDAHO'S EXPORT FACILITIES REQUESTING THE SPECIAL FOLLOW-UP FILE.

Upon receipt of the SFUP files, CDRI uses SAS-based process (version 9.4; SAS Institute, Inc., Cary, NC) to identify records submitted by facilities that are for new persons (NAACCR abstract records for tumors diagnosed among people missing in the CDRI database for that facility) and new tumors (NAACCR abstract records for potential new tumors diagnosed among people already present in the CDRI database for that facility). Splitting the records in this way simplifies the review and consolidation required of CDRI data quality staff. All complete files submitted as part of the SFUP submission are run through this SAS process to identify potential missing persons and potential missing primaries. Suspense files are reviewed manually to look for possible records that could be completed and submitted to be included in that year's upcoming data submission.

More precisely, existing data from the specific facility are compared to cases submitted in the special annual files using personally identifiable information including hospital accession number, hospital tumor record number, SEER site recode, primary site, laterality, behavior, and date of diagnosis. CDRI harnesses matching software to identify matches at the person level between registry and SFUP data. The resultant NAACCR XML files created by this process are of potentially missing persons and potentially missing primaries, which are then reviewed by data quality staff prior to loading to CDRI's live database.

RESULTS

In 2021, CDRI processed over 60,000 records from facilities as part of the special follow-up process. Because most of the process is automated in SAS, CDRI was able to greatly reduce the amount of review required by CTR data quality staff while increasing the number of incident tumors that otherwise would have been missed or delayed. In 2015, the first year of conducting this process, CDRI identified dozens of missing incident tumors. Although the yield has decreased over time, in 2019 CDRI identified 14 previously unreported tumors via this process – the equivalent of ~1 case per 10,000 incident cases. The special follow-up method has proved crucial in "making every cancer count."

SUSTAINING SUCCESS

In August 2022, CDRI presented this process to an audience of quality improvement experts and other cancer registry professionals. Other registries expressed that they had also needed to establish processes to handle similar challenges, and still others indicated that they would adopt CDRI's process into their own registry operations. By starting a conversation amongst registries and raising awareness around this issue, CDRI hopes that the registry community will be able to continually refine operational processes to improve reporting completeness and work with vendors and funding agencies to identify and implement systems-level solutions – ensuring that every cancer is counted, and every cancer counts.

REGISTRY CONTACT INFORMATION

208-338-5100
Cancer Data Registry of Idaho Website

U.S. Department of Health and Human Services
Centers for Disease Control and Prevention

REFERENCES

U.S. Cancer Statistics Working Group, United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. U.S. Cancer Statistics Data Visualizations Tool, based on 2021 submission data (1999-2019). June 2022.