WEST VIRGINIA CANCER REGISTRY

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NPCR 2024 SUCCESS STORY

Additional Processing for Cases with Age 100+

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SUMMARY

Cancer registries that do not perform routine active follow-up run the risk of accumulating patients who are coded as alive but who may have been missed during death linkage activities. These "immortals" can falsely elevate survival rates. Many data sources are available to aid in manual cleanup of such cases.

CHALLENGE

Various methods can be used to identify immortals, such as performing a survival curve analysis or performing active follow-up on a subset of long-term survivors. These methods can be time-consuming and costly to perform, and small registries often do not have the resources for such activities. During the 2023 data submission, West Virginia Cancer Registry staff observed a high number of living cases over age 100. After the submission, staff considered available resources and how to evaluate these cases.

SOLUTION

Immortals commonly result from incorrect or missing patient demographics. Differences in name, Social Security number, or birth date can result in non-matches that are not likely to come up again in a future linkage, resulting in immortal records. Fortunately, some registry staff have direct access to West Virginia death certificates and West Virginia Health Information Exchange (HIE) records. CDC's National Program of Cancer Registries (NPCR) provides a Social Security Death Index search and access to National Death Index (NDI) linkages at no cost to the registry. Using these data sources, the registry decided to create a list of all living cases over age 100 and search the data sources manually.

RESULTS

The initial list contained 274 records, including multiple primaries. Given time constraints, staff were only able to search about half (139) of the records before the 2024 state and NDI death linkages. An exhaustive manual search using demographic data was performed in state death certificates, HIE records, SSDI records, and online obituaries. Many incorrect Social Security numbers, birth dates, and names were found and corrected, and vital status was updated to deceased. Of the 139 records, 30% (42) were found deceased outside of West Virginia. Nearly half of these records linked with NDI deaths in the September 2024 linkage. Nearly 22% (30) previously died in West Virginia, and all vital information was obtained from the death certificates. About 23% (32) died recently and were updated in the March 2024 state death linkage. Only 10% (14) were not found through any search. Saving the best statistic for last, 15% (21) were still alive per state HIE records. Staff plan to search the remaining half of the list to make data corrections before the state and NDI death linkages are performed in 2025.

CONCLUDING REMARKS

Even small data corrections make cancer registry data more accurate and usable. Registries can use many data sources to conduct simple data-cleaning activities. Since this subset of cases has never been reviewed and only 72 immortals were found, we conclude that our state and NDI death linkages are successful. Registry staff plan to review a list of cancer patients who are 100 or older annually, before state and NDI death linkages, to complement those linkages and pick up the very few immortals who may fall through the data linkage cracks.

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