

Improving Cause of Death Accuracy Through Vital Statistics Linkages

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SUMMARY

A manual review of cause of death (COD) codes received from Montana vital statistics showed that some COD codes previously linked to Montana Central Tumor Registry (MCTR) had been updated. This challenged the assumption that COD codes remained consistent, and new data would not become available for cases that had already had a code uploaded to the tumor registry. A new linkage was performed for death years 2003 through 2022, which updated 796 (1.2%) deaths in MCTR.

Analysis was performed to explore which cases were most likely to have had a changed COD, and how these updates may affect previous analysis. No difference in the likelihood of a cause of death update was found by sex. However, the likelihood of a COD being updated was significantly associated with age and race. The most frequent COD change was *Unknown COD (C80.9 and R99)* to a specific COD. MCTR has updated its vital statistics death record linkage protocols to include previously linked but updated data to improve accuracy.

CHALLENGE

When performing annual linkages with vital statistics, it had been assumed that the record data received was final and would not receive any future updates. In 2024, a manual review of the 2022 new death record linkage file (during routine death clearance procedures searching for multiple primary tumors) indicated that some data which had been linked to the tumor registry in previous years had been changed in this new dataset. Further investigation revealed that some COD codes had been changed each year following linkage going back to 2003, with 796 total changes within the entirety of the tumor registry, or 1.2% of all causes of death recorded in the registry. Which data were changed, and how they may have affected previous analysis, required further investigation.

SOLUTION

To address the uncertainty of the effect of the update, we investigated whether the odds of any given cause of death being updated were independent of race, sex, and age at time of death. Further, we explored which COD codes were most likely to have been changed in the registry (updated to and from), and whether these changes might have affected previous analysis and assumptions. We also updated our protocols for linking COD data with vital statistics so that future updates to previously linked data would be integrated into the tumor registry each year.

RESULTS

MCTR staff and Montana Vital Statistics collaborated in investigating updated COD codes. This investigation revealed which deaths were most likely to be updated, and the demographics most relevant to these updates.

A chi squared test indicated the likelihood of a COD code being updated did not appear to be different by sex ($p = 0.547$) but was significantly higher among American Indian people than White people ($p = 0.033$), and a higher likelihood among younger age groups at the time of death ($p = 5.411$).

Of the COD codes that were updated, 21% were changed to a cancer-related COD, either from a non-cancerous COD before, or from a different cancer code. There were only 15 instances of a cancer-related COD being updated to a different cancer COD. Most of the updated causes of death changed from an unknown cause to a more specific cause (78%).

Overall, updated death codes displayed a trend of moving from more ambiguous codes to specific codes, indicating an important data improvement. Increased likelihood of COD recodes among Montanan American Indian people and those who are younger at the time of death indicates that this protocol may help address a previously unknown bias in the tumor registry. However, given the relatively small number of cancer-related causes of death updated each year, we do not believe these biases would have significantly affected previous analysis involving these data.

CONCLUDING REMARKS

Continuously challenging assumptions about registry operations is one of the most sustainable strategies for improving data quality and completeness. In this case, further collaboration with other state registries may help provide greater insight into this investigation.