

## 2020 NPCR NEVADA CENTRAL CANCER REGISTRY SUCCESS STORY

STORY TOPIC: National Death Index (NDI) Linkage

STORY: Registry Operations

STORY TITLE: How Linkages Can Improve Registry Data

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### SUMMARY

The Nevada Central Cancer Registry (NCCR) provides statistical data to assist epidemiologists, health researchers, and individuals in the medical and allied health professions. This data helps identify cancer risk, evaluate cancer patient care, and illustrate leading trends in cancer incidence, survival, and mortality in Nevada. NCCR has made great strides in data quality and completeness attributed to process improvement activities and recognized the need to obtain updated vital statistics data on previously reported cases in the registry database. This is particularly useful when cases have moved out of the NCCR's catchment area between the time of diagnosis and death since they would not be identified through annual linkage with the state's vital statistics system. Linkage with the National Death Index (NDI) can help to avoid misclassification and potential duplication of cases that are diagnosed with cancer in one state and die in another state.

### CHALLENGE

Nevada Central Cancer Registry never linked registry data with the NDI and needed assistance with the process of conducting the data linkage.

### SOLUTION

Chris Johnson from the Cancer Data Registry of Idaho and CDC provided training sessions to review the process and step-by-step instructions. NCCR performed a data quality review of death-related variables, finding important missing data items, many of which were resolved by the linkage with the death file. Most of the resolved data items were for records with a diagnosis date prior to 2010. Registry data was linked with NPCR-CSS Social Security Death Index (SSDI) data files from the NPCR-CSS document server to update demographic information prior to linkage with the NDI. Necessary documents were completed, and special utilities prepared the data to be send to NDI.

### RESULTS

NCCR performed linkage between Dx-year 1995-2017 (263,630 records) file and State Deaths file 1995-2017.

Results:

- Records w/ Vital Status Dead (0) = Race1-5 recovered= 205
- Spanish Origin in same vital status = 305
- Records w/Vital Status Dead (0) and Cause of Death 7777 or 7797 (Unknown) = 139
- Birthplace Country recovered, same status = 2,455
- Occupation text Information, same status = 2,032
- Social Security number = 648
- Vital Status Dead and DIFFERENT Cause of death, were changed to cause 7777 = 1,334 to send to NDI

The Cancer file was linked with the annual SSDI files 1995-2017.

#### Results:

- Date of Death missing recovered = 468
- Birth Date missing recovered = 126

The file sent to NDI, was extracted from NDIPrep and ALL errors were corrected by Registry Personnel (CTR's) using the NDIPrep, Edits vs16.

- Number of records sent to NDI for linkage 1995-2017
  - Records with Vital Status Alive = 115,345 and Alias records =108
  - Records with Cause of Death Unknown = 3,865---No Alias records

#### NDI-NV CANCER FILE LINKAGE RESULTS

- Vital Status Alive and Cause of Death 0000 = 5,501, including 88 matched records with cause of death unknown (7797)
- Vital Status Death and Cause of Death 7777 or 7797 (Unknown) = 1,664, including 1,291 with valid cause of death and 373 still unknown cause of death.
- Overall, 20,312 tumors and 30,532 abstracts were updated in the registry database.

#### SUSTAINING SUCCESS

The NDI linkage is a vital tool to improve the quality and completeness of cancer data. NCCR plans to link data at least every other year to update results on vital status and cause of death in the registry database.

#### REGISTRY CONTACT INFORMATION

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