

Linking Central Cancer Registry Data with National Death Index (NDI) Data



Central cancer registry (CCR) files are linked with the National Center for Health Statistics' National Death Index (NDI) data to obtain updated vital statistics data on previously-reported cases in the registry database. Periodic linkages with NDI allow registries to improve the completeness of their follow-up data and survival. This is particularly useful when cases have moved out of the CCR'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 NDI can also help to avoid misclassification and potential duplication of cases that are diagnosed with cancer in one state and die in another state. Including the follow-up data from NDI linkages in annual calls for data allows national organizations to compile more complete and accurate population-based data on cancer survival.

NPCR-NDI Application: The NPCR-NDI application can be used by all cancer registries (NPCR and SEER) and allows for the following:

- Release of NDI information (e.g., fact and date but not cause of death) to reporting sources such as ACoS-approved hospitals.
- Case sharing with other central cancer registries to identify potential duplicate cases (e.g., Death Certificate Number (DC#), fact, date, and State but not cause of death).
- In the event that a cancer registry allows the release of identifiable or potentially identifiable data to researchers, the cancer registry may include the release of NDI-obtained death information (fact, date, and cause of death) to approved researchers after formal review and approval by the cancer registry. NDI assumes that cancer registries have a formal process by which researchers may obtain such information and will respect the process by which a cancer registry makes such data available to researchers. However, each year, the registry must provide NDI with information regarding the release of such data (i.e., researcher name, organization, study title, date). This log is available on the NPCR-CSS/Utilities/NDI page.
- Release of NDI information (fact, date, and cause of death) may be included in the annual data submissions to approved parties (CDC, SEER, NAACCR).
- Both NPCR and SEER have negotiated a flat fee for the use of the NDI by their respective cancer registries. We encourage all cancer registries to take advantage of the opportunity to obtain follow-up information via the NDI. Both programs track usage of the NDI by cancer registries.

Additional Resources for Vital Status Information: You are also encouraged to search the NPCR-CSS Social Security Death Index (SSDI) website. You will need a separate login and password to access the SSDI website or download the SSDI data files. If you do not have a username and password, please contact support@npcrcss.org to request access.