



Cancer Registry Linkages

American Indian and Alaska Native communities and Tribes often lack adequate cancer statistics. Tribes need accurate Tribe-specific cancer incidence data in order to plan and provide appropriate cancer prevention, screening, treatment, and survivorship services to their communities and to obtain and allocate funds where they are most needed.

While statewide and regional cancer data include some tribal data, cancer registries around the nation recognize that cancer statistics for American Indian and Alaska Natives under-estimate the burden of cancer in these communities. This is due in large part to racial misclassification, where American Indian and Alaska Native individuals are reported as white by their doctors. A study conducted by Johnson et. al. found that during a span of ten years, over 80% of tribal members were reported as non-AI/AN to one state cancer registry (AJPM 2009). The under-estimation of AI/AN cancer burden in state and national statistics is problematic for Tribe, State, and nation-wide cancer surveillance and public health programs.

Tribe-State Cancer Registry Linkages

Data linkages may be performed between a State cancer registry and a Tribe's enrollment roster or Indian Health Service patient registration data, which aims to identify records in separate files that represent the same person. Individuals initially recorded as white in the State's cancer registry may be identified through this process as tribal members; their data may then be corrected within the State's cancer registry, ensuring that AI/AN individuals are counted in state and national statistics. The resulting Tribe-specific cancer data may be used by the Tribe to conduct cancer surveillance and provide appropriate health care services to the community. Mortality data linkages may also be performed with vital statistics files, death certificates, and cancer registries as well.

Process

The Tribe may want to establish a team of individuals from within the Tribe, State cancer registry, and Indian Health Services to work together. Each agency may have specific approval processes that the team will need to follow and often data sharing agreements are created to specify how the data will be handled and used, including confidentiality.

The Indian Health Services and the Centers for Disease Prevention and Control worked together to create a free software program (Registry Plus™ Link Plus) to conduct these linkages. The process of linking datasets may take several days to complete, depending on the size of tribal enrollment.

Ideally, the Tribe would have the following enrollment information on their members in electronic form: Social Security number; date of birth; first, last, middle name; gender; and street address.

The linkage may be conducted on the Tribe's computer, accessing the registry's dataset from an external hard drive. Once this is done, the team of State and Tribe staff review all possible matches to ensure that



Resources for Tribe-State Cancer Registry Linkages

Software:

- Registry Plus™ Link Plus
- The Link King
- LinkSolv

Documents:

- Link Methods Protocol
- Data Sharing Agreement
- Memorandum of Understanding
- Confidentiality Pledge
- IRB Protocol
- Cancer Linkage Report

Websites:

CDC National Program of Cancer Registries

Council of State and Territorial Epidemiologists: Tribal Data Linkage Toolkit

they make sense. Next, the team pulls cancer information for all of the individuals that linked and then delete all of the identified fields (all of the fields listed above, except sex), producing a de-identified Tribe-specific dataset that includes cancer site, stage at diagnosis, histology, laterality, age at diagnosis, and year of diagnosis for all Tribe members diagnosed during a specified time frame available within the State's registry.

Analysis of Data

The team may perform statistical analyses on the de-identified dataset using a statistics program such as SAS or SPSS. The types of data analyses performed will depend on the size of the dataset. Data analysis may be limited by the number of links made - i.e. if only three individuals are identified with stomach cancer from 1985-2005, the statistical analyses may not be reliable and therefore may not be used to compare with the rates of larger populations for that particular site, in this case, stomach cancer.

Through tribal linkages, a variety of data may be identified:

- Most prevalent primary sites for each sex and combined sexes
- Number of cases that occur each year included in the linkage
- Number of cases by age group
- Most prevalent primary sites (cancer types) by age group and year.

If the Tribe's population data are available (e.g. number of alive enrolled members by year and sex), annual cancer incidence may be calculated for the Tribe and compared with the all-races rates for the State and Nation.

Mortality data linkages may also be performed, which identifies:

- Tribe-specific causes of death by most common causes of death
- Death cases by year and sex
- Deaths per age group

Use of Outcome Data

The more Tribes pursue tribal data linkages, the better over-all quality of tribal community data across regions. Tribe-specific data and aggregated data are not only useful for cancer prevention and control planning, but also for other health programs. This information may also aid in preparing grant applications for funding of cancer and other health programs.