2019 NPCR MAINE SUCCESS STORY

Maine Cancer Registry: Kim Haggan and Denise Yob

The Importance of Linking Registry Data with Other Sources to Improve the Quality and Completeness of Data Collection

NATIONAL PROGRAM OF CANCER REGISTRIES
SUCCESS STORY

SUMMARY: A data quality check involving a comparison across sources using Maine Cancer Registry (MCR) data gave us the opportunity to identify a procedural gap in our post linkage processes (counts) and identify ways in which different programs calculate American Indian/Alaska Native (AIAN) rates (population).

When reviewing Maine cancer incidence rates by race using MCR SEER*Stat database, staff found different counts and rates among the AI/AN race when compared to results generated by NAACCR Fast Stats and the U.S. Cancer Statistics. Our immediate question is why Maine AI/AN cancer counts and rates differ across sources. Each is based on identical data (the annual NAACCR/NPCR Maine submission), therefore, the incidence data for Maine reflected in national datasets are expected to match the results produced by our MCR dataset. Our dataset produced counts and rates lower than what other sources display.

CHALLENGE: Using the MCR dataset for the five-year period of 2011-2015, the All Site age-adjusted cancer incidence rate of the AI/AN population is 407.2/100,000. Rates from the U.S. Cancer Statistics Data Visualization Tool and NAACCR Fast Stats are 464.6 and 572.4 respectively. The MCR epidemiologist needed to explain the variation in rates between sources. The question addressed is, "Are the rate differences due to population definitions or counts?" The answer turned out to be both.

After reviewing all technical notes in each data source, she determined that the differences in results between the NAACCR Fast Stats and the USCS are population differences and can be explained by NAACCR's case restriction of the AI/AN population to residence at time of diagnosis in a contract health service delivery area (CHSDA) county. As of 2015, three of Maine's sixteen counties were designated as CHSDA (now referred to as purchased/referred care delivery area – PRCDA).

After accounting for differences in population definitions, differences in counts persisted. When she looked at AI/AN All Site incidence counts for the five-year period, MCR data shows there are 189. The USCS file shows 217 for the same timeframe. After reviewing additional technical notes, the difference in counts were explained by USCS and NAACCR Fast Stats using a race recode algorithm based on the results of our annual Indian Health Service (IHS) data linkage.

SOLUTION: Maine has a predominately white demographic. The 2010 U.S. Census showed that the state's total population is 1,328,361, the AI/AN population of the state was 8,568 (0.6%) of the total. The MCR does linkages with IHS annually and updates the "IHS Linkage" field as required by NAACCR and NPCR. We had identified no specific NAACCR/NPCR instruction to guide cancer registries to either create a modified "Race Recode" field or to update any of the primary race fields; historically because the overall number of linked records are small and did not appear to impact epidemiologic analysis, race had not been recorded in our existing database. Until our recent comparison of MCR results with other sources, we had not considered the impact of this decision. We sought to determine the impact of changing the MCR protocol to update registry data to best use IHS linkage results.

Among the individuals who were not initially classified as AI/AN by the MCR among cased diagnosed in 1995-2017, a recent IHS Linkage located 136 individuals that matched with IHS records, resulting in a 28% increase of AI/AN individuals. We determined that our cancer incidence rates among the AI/AN population in Maine based on our previous practice of excluding non-AI/AN records that linked with the IHS data file were significantly lower than when these cases were included in the analysis.

The epidemiologist working with the MCR data presented her findings in June 2019 at the NAACCR annual conference. While there she talked with other registry programs about how they handled the results of IHS linkages since we had identified no specific instruction for cancer registries to follow. One state, Utah, was able to share an email exchange with CDC about the IHS linkage and race variables. The NAACCR data dictionary includes this statement about the IHS linkage field: "The goal is to include incidence data for American Indians in the United States Cancer Statistics by use of this variable as well as the race variable." We are considering leaving the NAACCR race variables as originally reported and using the linkage results to create a new modified race variable. Our next step is to determine how to use this new race field while creating our SEER*Stat database so that it can used to generate cancer incidence rates.

RESULTS: The Cancer Registry can get a better understanding of the cancer burden among American Indians in Maine by more fully using the linkage data which we receive from Indian Health Service. The IHS linkage results in an increased case count of nearly 30% of AI/AN people in the full registry database 1995-2017. Because AI/AN race has been demonstrated to be under-reported in administrative and clinical data sources, the IHS linkage results in more complete data, improved data quality and a better understanding of cancer incidence among populations and regions in Maine. From 2011-2015, the linkage results increased our incidence by 28 cases. The exclusion of these 28 cases underestimated Maine's age-adjusted rate to 407/100,000 compared to 464/100,000 using a recoded race.

When trying to understand diversity as it pertains to cancer it is important to base our analyses on accurate incidence data. After the next linkage with IHS, the linkage results will be added in the database into a newly created field. This analysis of the differences in rates among sources has proven that it is important to have the race recode variable available for future analysis.
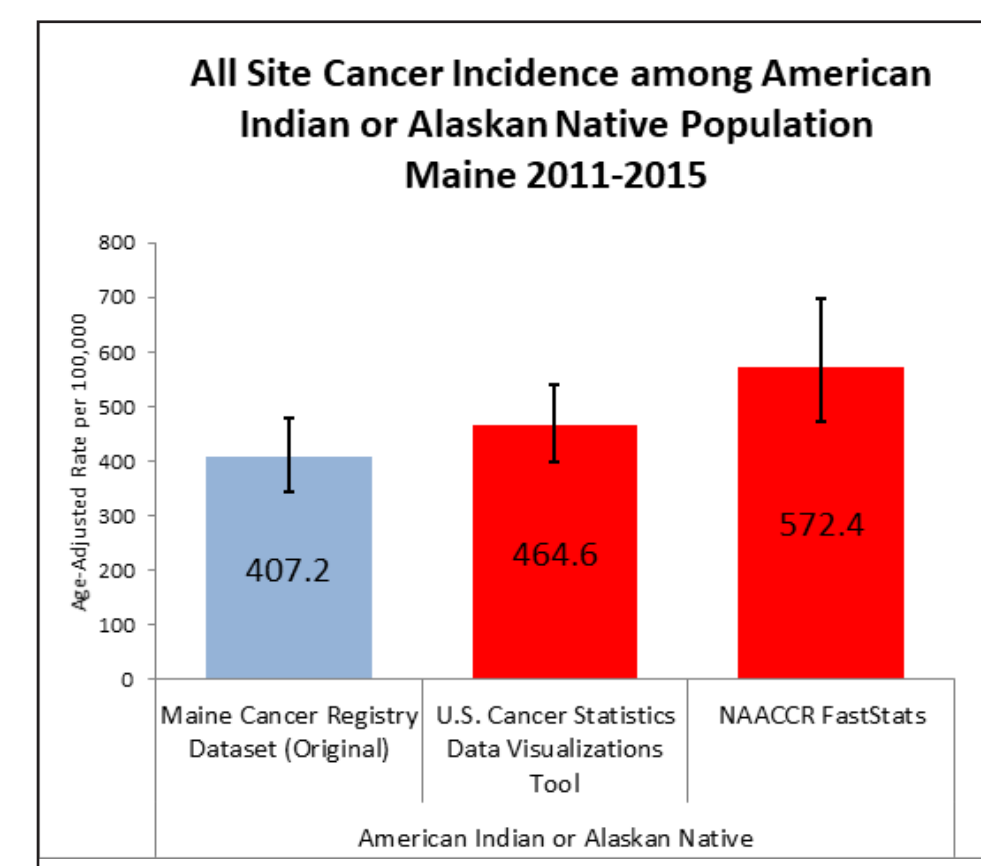
Three Maine counties are designated as PRCDA counties where four Native tribes reside, representing 19% of Maine's population, 45% of the AI/AN population in Maine, and 49% of the malignant cancers among the AI/AN population in Maine. We analyzed AI/AN cancer incidence rates and compared rate differences among Maine AI/AN total population, the AI/AN population whose residence was within a PRCDA county at time of diagnosis, and the AI/AN population whose residence was not within PRCDA county at time of diagnosis. We calculated proportions and rates for all invasive cancers combined (all sites cancer) and for several common cancer sites: colorectal, lung, female breast, and prostate. Presenting Maine cancer incidence data for all Maine counties versus restricting to cases to those residing in a PRCDA county at time of diagnosis significantly impacts cancer incidence rates, with rate differences observed by sex, age, and cancer site. This analysis provides a structure for discussions on how to approach disseminating cancer findings by race in Maine, while recognizing the heterogenous needs of stakeholders, policy-makers, and program managers.

SUSTAINING SUCCESS: An important take away is that linkages can be very beneficial in improving data quality. NPCR guidance states that "The central cancer registry should utilize linkages to address gaps identified in data quality and completeness or to improve the utility of the data." Small numbers on the surface may seem to have little impact to the overall database but when dealing with relatively small populations to start with these differences can be significant. It is important that data be recorded accurately as these data are integral to advancing public health and improving population health and ensures inclusiveness and respects for the individuals.

CONTACT INFORMATION:
Telephone:207-287-5272
Website: http://www.maine.gov/dhhs/mecdc/public-health-systems/data-research/vital-records/mcr/

All Site Cancer Incidence among American Indian or Alaskan Native Population Maine 2011-2015

All Site Cancer Incidence, Maine 2011-2015			
American Indian or Alaskan Population	AA Incidence Rate	5 Year Count	5 Year Population
Maine Cancer Registry Dataset (Original)	407.2	189	53,828
Maine Cancer Registry Dataset with **Updated** Race Recode	464.6	217	53,828
U.S. Cancer Statistics Data Visualizations Tool	464.6	217	53,828
NAACCR Fast Stats **Limited to 3 CHSDAs**	572.4	139	NA[+]
Maine Cancer Registry Dataset with **Updated** Race Recode **Limited to 3 CHSDAs**	572.4	139	27,032
Maine Cancer Registry Dataset (Original) **Limited to 3 CHSDAs**	475.8	116	27,032

NPCR
NATIONAL PROGRAM of CANCER REGISTRIES
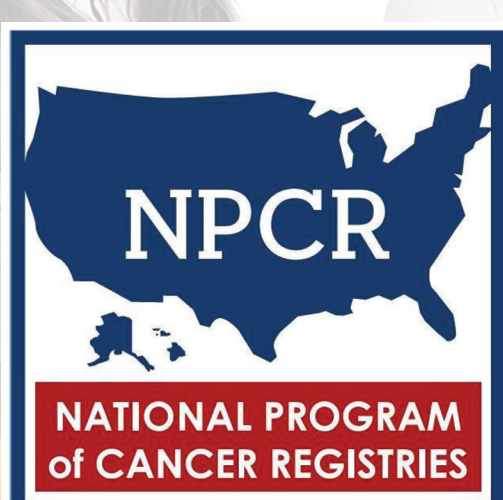
Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention and Health Promotion