

Understanding nuances when presenting Native American data for your cancer center or cancer registry catchment area

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Background

Accurate incidence, mortality, and survival statistics are critical to identifying disproportionate cancer burdens across racial and ethnic populations within a catchment area and setting priorities.

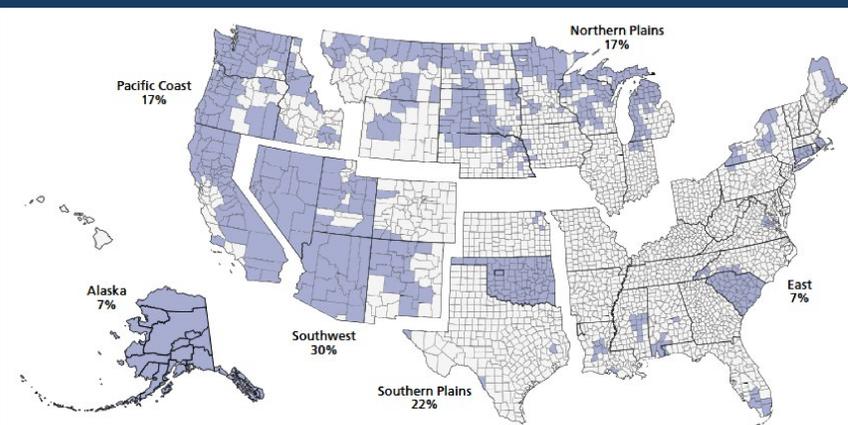
A known data limitation for the Native American population is the ongoing racial misclassification of American Indian and Alaska Native (AIAN) people within the cancer registry system, which results in artificially depressed rates.

Current Methods

Current methods to address misclassification of AIAN race in the central cancer registry system include:

- Linkage to the Indian Health Service (IHS) patient registration
- Restriction of analyses to include only AIAN people resident in Purchased/Referred Care Delivery Areas (PRCDA) – counties in which are in or adjacent to Tribal lands, and in which AIAN people are eligible for IHS care.

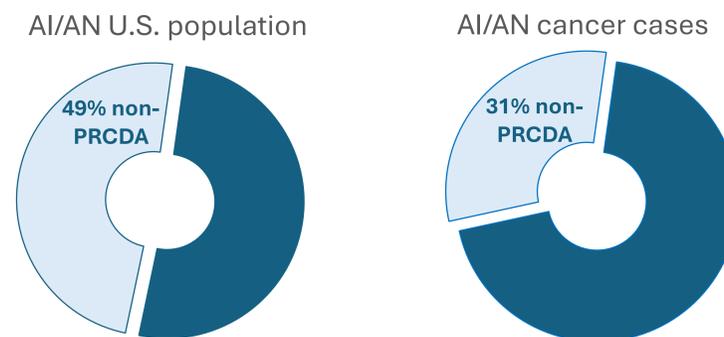
These methods have *critical limitations* that must be understood when analyzing and presenting cancer burden data for AIAN peoples.



Map of Purchased/Referred Care Delivery Area counties serviced by the IHS (given in blue), stratified by IHS region. Source: 2022 American Cancer Society Facts and Figures Special Section on Cancer Among AIAN peoples.

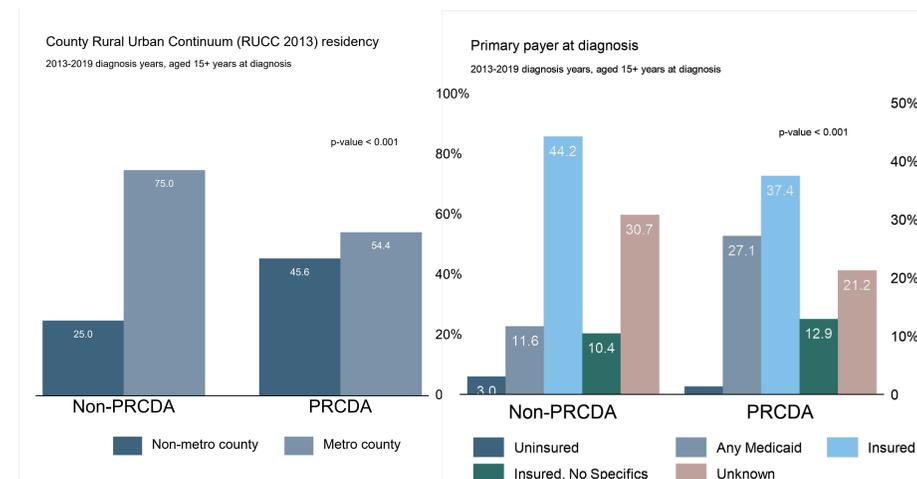
Limitations of Current Methods

1: Limiting to PRCDA areas excludes a large proportion of the AIAN population from national cancer statistics

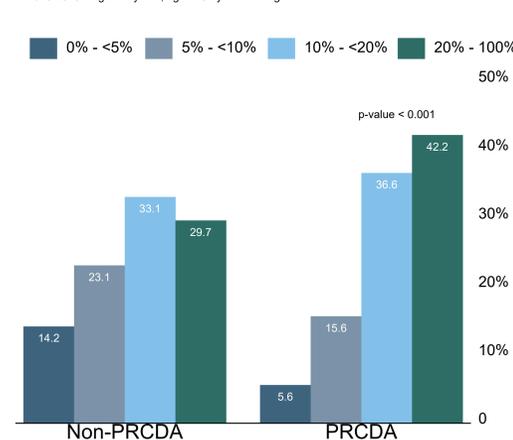


Morawski et al. In review

2: Differences in sociodemographic, economic context between those that are included and those that aren't



Households Living Below Federal Poverty Level (%)



Morawski et al. In review

AIAN people living in PRCDA areas who have cancer are more likely to live in rural, high poverty areas, and be supported by Medicaid, compared to those living in non-PRCDA areas. These data indicate a selection bias in who is and who is not included in national cancer statistics for AIAN people.

Potential Solutions

The North American Association for Central Cancer Registries Cancer Surveillance Data for Native American People Taskforce has been exploring potential solutions to address this critical issue:

- **Alternative methods to improve racial misclassification**, including statistical methods (quantitative bias analysis), and linkage to Tribal Roll.
- **Recommendations for the use of non-PRCDA AIAN cancer cases in analyses**, acknowledging current data limitations while inclusively representing AIAN people with cancer in national statistics.

Discussion

Cancer registries, Cancer Center COE programs and researchers interpreting Native American population cancer surveillance data need to understand the nuances of the methods used to reduce racial misclassification of AIAN people, which result in:

- the exclusion of substantial portions of the AIAN population; and
- data that may not be generalizable across all geographic regions.

Ongoing, Tribally-engaged work is needed to improve racial misclassifications methods and ensure the inclusion of all AIAN people diagnosed with cancer in cancer surveillance statistics and research.

Acknowledgements

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