

2024 NPCR SOUTH DAKOTA CANCER REGISTRY SUCCESS STORY

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Addressing Racial Misclassification Statistics in Cancer Data

SUMMARY

The South Dakota Cancer Registry (SDCR) has collected data and reported on cancer incidence in South Dakota since 2001. The South Dakota Cancer Registry (SDCR) has implemented a comprehensive partnership network and systematic verification process to reduce racial misclassification in cancer data, particularly for American Indian and Alaska Native (AIAN) populations. This improved accuracy enables better-targeted cancer prevention and control efforts through collaboration with Indian Health Service (IHS), tribal organizations, and multiple healthcare partners.

CHALLENGE

- American Indians and Alaska Natives have the highest racial misclassification rate in health data of any group, according to the American Cancer Society
- Racial misclassification in cancer registries has historically led to underreported cancer rates in tribal communities
- Underreporting previously resulted in inadequate funding for cancer programs in the Northern Plains region
- AIAN populations have a higher burden of major cancer risk factors and are more likely to be diagnosed at later stages
- Accurate racial classification requires coordinated effort across multiple organizations
- Careful attention is needed at every step of data collection and verification

SOLUTION

- Developed reporting from out-of-state pathology laboratory used by South Dakota IHS medical facilities
- Implemented annual linkages with IHS data
- Established partnerships with Great Plains Tribal Leaders' Health Board, Registry Partners Inc., and Breast and Cervical Cancer Early Detection Programs (BCCEDP), such as All Women Count!, Honor Every Woman, and the Cheyenne River Sioux Tribe's Women's Health
- Established systematic death clearance processes with Office of South Dakota Vital Statistics

RESULTS

- Case finding of AIAN cancer cases diagnosed at IHS medical facilities
- Case finding of AIAN cancer cases during patient linkages with BCCEDP
- Achieved 100% accuracy for racial data elements in the 2024 CDC National Program of Cancer Registries Data, Quality, and Evaluation

- IHS linkage results are consistently < 0.10% racially misclassified
- Cancer registry database is updated with IHS linkage results
- Created a multi-partner verification system throughout the data collection process
- Developed comprehensive case consolidation processes across multiple data sources

SUSTAINING SUCCESS

- Maintaining and expanding partner relationships with healthcare entities and tribal organizations
- Conducting regular linkages, data quality checks and verification processes
- Supporting improved initial documentation at healthcare facilities

STORY QUOTE

"I did complement [the SDCR] very much. How low [the racial misclassification rate] was and how successful it is compared to other states... having that lower percentage is just really a shout out to a lot of the work that's done, a lot of the efforts." - Richard Mousseau, Great Plains Tribal Leaders' Health Board

REGISTRY CONTACT

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