

2019 NPCR ARIZONA SUCCESS STORY

Arizona Cancer Registry: Georgia Yee

Collaborations with Federal Facilities

NATIONAL PROGRAM OF CANCER REGISTRIES SUCCESS STORY

SUMMARY: Arizona is a unique state with 22 American Indian Tribes, three VA Health Care Systems, with many military outpatient ambulatory facilities, and several Indian Health Service and tribally-operated health care facilities that serve tribal communities. Working with our federal partners is essential for understanding the cancer burden and its impact on our communities. Since Arizona cancer reporting regulations do not impact federal facilities, we have used various approaches to address cancer reporting and to also foster relationships. One such example is creating tribal specific reports. As told by a tribal program director– “the report will be helpful for providing education, understanding the trends, and opportunities for screening and education.”

CHALLENGE: Federal facilities are not required to follow state law and regulations. This is a challenge with the federal demographics as described above when the registry is tasked to identify all cancer cases that occur in the state.

SOLUTION: Networking and persistence with our federal partners allow for opportunities to collaborate.

RESULTS: The Arizona Cancer Registry (ACR) collaborates with our federal partners in various methods; the following is a description of those projects.

Tribes

- The ACR is part of a three-way data exchange agreement with the Indian Health Service and the New Mexico Tumor Registry (NMTR) to share cancer case information. The NMTR is the designated registry that collects cancer cases from IHS and several tribally-operated health care facilities and is able to forward the cancer cases to ACR due to this exchange.
- The ACR participates in the Arizona Tribal Collaborative Conference each year. This Tribal Collaborative is a result of the work started by the Well Woman HealthCheck Program and the work they have done with tribes. This conference has helped the registry increase our understanding and knowledge of tribes, identify opportunities for improved collaborations, and identify how we can support each other in the work we do. The ACR is able to share American Indian data and discuss the purpose and results of the yearly linkage with Indian Health Service.

- The registry has two separate data sharing agreements with the Navajo Nation Breast and Cervical Cancer Prevention Program and the Hopi Cancer Support Services. The data linkages allow the programs and the ACR to share information on women that have been diagnosed with cancer through the screening programs.
- The ACR also collaborates with tribes to create tribal specific reports that are only shared with the tribe. We work together to determine the content of the report and discuss cases to include in a tribal report (e.g., on reservation, off reservation). The data are used to educate tribal cancer stakeholders regarding cancer priorities.

VA Health Care Systems

- The registry has not received VA cancer data for several years. Our focus was to chip away at each VA individually to obtain data. Internally, we had to verify we met VA standards related to encryption and items contained within the Data Use Agreement. After several years of back and forth with two of the VA facilities, we finally had one sign the DUA and have received data. With the other major metropolitan VA, we are very close to having a signed DUA.
- What we learned through this process is to always maintain a relationship with the VA registrars by inviting them to trainings, meetings, and including them in emails that contain the latest updates and changes to standards.

SUSTAINING SUCCESS: The ACR has already built upon relationships developed and projects implemented. These activities are incorporated into the timelines of registry activities. As we continue to network at meetings, we will continue to educate and inform about the cancer burden.

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