



3, 2, 1 GO!

PRACTICAL SOLUTIONS FOR ADDRESSING CANCER CARE DISPARITIES:

Findings from The Arizona Clinical Oncology Society

INTRODUCTION

American Indians have the highest kidney cancer incidence and death rates of any race and ethnicity. Research has proven that American Indians have less knowledge of cancer screening and are less likely to have a particular place to receive medical care when compared to non-Hispanic whites (NHWs). The screening rates for colorectal cancer, a highly treatable disease with early detection, is alarmingly low for American Indians. Arizona has the eighth highest percentage of American Indians in the U.S. While many of them live on federally designated reservations, over 75 percent do not. Federal Indian Health Service provides in-patient and ambulatory care services for individuals living on or near federal reservations. For those living off reservations and without access to the Indian Health Service system, finding high-quality cancer care poses significant challenges.

This report, created in collaboration with The Arizona Clinical Oncology Society (TACOS) and The Center for

Community Solutions, details and identifies gaps in cancer care service delivery and access for the American Indian population living off reservations and outside of the Indian Health Service in the state of Arizona. Currently, surveillance of this specific population is substandard and is made worse by the fact that more American Indian cancer patients are incorrectly classified as members of another race than patients in other racial groups.¹ Additionally, according to the U.S. Centers for Disease Control and Prevention (CDC) American Indian people are more likely to get certain cancers, including lung, colorectal, liver, stomach and kidney cancers, compared to non-Hispanic White people in the United States.² Because of this, it is imperative that individuals in this demographic have access to screening, preventive health care services, and programming to help decrease the incidence rate of cancer. This report provides information regarding the current landscape of healthcare delivery as well as recommendations to address disparities.

METHODOLOGY

To adequately understand the current state of cancer identification and care for American Indian patients living off reservation in Arizona, TACOS members² on the Association of Community Cancer Centers' (ACCC) Health Equity and Access Committee are participating in the education program: **3, 2, 1 Go! Practical Solutions for Addressing Cancer Care Disparities**. As part of this work, the Committee

is tasked with aggregating three "go-to" resources to advance equity in cancer care, make two recommendations to eliminate disparities in care, and identify one major gap in care to address. The Center for Community Solutions (CCS) was contracted to facilitate two virtual focus groups for community input, one with patient advocacy organizations, and the other with multidisciplinary providers.

FINDINGS

Participants from both focus groups supported the development of the following recommendations to help eliminate cancer care disparities among American Indian patients. This is not an exhaustive list, but the gaps, recommendations, and resources herein, offer a starting point to provide better care and support to American

Indian patients in Arizona. There are more gaps and recommendations than what the framework has outlined to provide opportunities for prioritization as the work moves forward. CCS will work with ACCC to facilitate a prioritization process.

GAP TO BE ADDRESSED (1)

Challenges in continuity of care, lack of integrated care teams

Both groups spent considerable time discussing the challenges around continuity of care for the American Indian population. Fragmentation of care is an immense barrier for patients who did not have a "medical home" prior to a cancer diagnosis and are often seeking education and care from multiple sources at different times. This is also a challenge for family members, typically sons and daughters, who are often tasked with translation, transportation, and more, as well as figuring out next steps at any given time.

One individual from the provider group asserted that a deficiency of integrated care teams is contributing to fragmented services and a lack of continuity of care. They noted that physicians do not always trust other members of the integrated care team because they do not see the benefit of their nonclinical work. While many cited patient navigators as being instrumental in supporting patients as they navigate their cancer screening and care as they spend far more time with patients and families, they are often looked down upon and doubted. Patient navigators are

known for meeting patients where they are, which can entail going into homes, learning culture, talking through diets and routes to the grocery store and can help to bridge gaps caused by language isolation.

Data

Both focus groups agreed that a critical piece of care coordination is improving data collection and surveillance. An example was provided by one of our group participants from a Federally Qualified Health Center. When patients decline screenings, it is documented. Data can be collected on number of screenings declined. This has implications for future interventions, education, and resources. Additionally, data access and data entry should be broadened to strengthen integrated care teams which improves coordination.

Lack of Community Based Settings

The challenges of getting American Indians screened for cancer and getting newly diagnosed patients treated for cancer was an equal concern among the focus groups. When asked what has worked to get individuals

screened and treated for cancer, the provider focus group turned their attention to the issue of trust which led to discourse on settings. One provider indicated that hosting community events that feature vendors, incentives, and even providing dinner has worked in building relationships with American Indian communities. The patient advocacy group also indicated that screening programs and

resources need to meet American Indians where they are. One participant suggested that American Indian casinos, for example, should be a place where screenings are offered, for free. Clinics can be difficult to navigate and make populations that historically struggle with medical mistrust feel unwelcomed.

RECOMMENDATIONS TO ELIMINATE DISPARITIES IN CARE (2)

Walk-in screenings with community connection, when and where possible

During the focus groups, it became clear that caregivers play a critical role in managing the care for cancer patients, often tasked with making and keeping appointments, following up with clinicians, interpreting guidance and ensuring services are provided in a culturally competent manner. The patient advocacy focus group indicated that many providers leave it up to patients to make and keep appointments. Many providers do not consider the social determinants of health that affect patients who do not show.

Regular opportunities for walk-in screening clinics in the region can alleviate the burden of an appointment for both parties. Providers could consider shifting schedules for an "access clinic" to enable this kind of service. TACOS could also explore ways to augment the engagement of families and enable more opportunities for geographically convenient services, where possible. This could include forming a statewide patient advisory group comprised primarily of family members of American Indian patients who can help answer questions and facilitate improvements in an ongoing fashion.

Pursue additional training in cultural competency specific to American Indians, focused on privacy

Routine cancer screenings are essential to detecting and treating cancer early when treatment is more likely to be successful. Accessible and culturally competent screenings for the American Indian population residing on or off

reservation in Arizona is key to ensuring they regularly occur. While accessibility and cultural competency may mean different things to different tribes, it is important that they are considered in screening discourse, and American Indian-specific equity and inclusion consultants could be contracted to provide an ongoing series of provider-specific plenaries for TACOS members.

Another barrier to screening and treatment that each group presented was stigma and perceived lack of privacy. Because of this, those tasked with screening should be well-versed in confidentiality and should work with families to ensure an awareness of privacy practices and individual security are addressed. This can include ensuring that the language being used to communicate throughout the screening process is plain and easy to understand and this issue should be included in any potential contract with an American Indian-specific consultant.

Appreciate the totality of American Indians living off reservation and those living on

While TACOS intended to focus strictly on American Indians living off reservation, both groups struggled to distinguish the two groups in their comments. While American Indians are not a monolith, it was easier for the groups to discuss American Indians as a whole and not in parts, despite different tribes, traditions, and language. Since much of this population living off reservation has the same social determinants of health as those living on, it did not feel necessary to separate them from one another when seeking to address systemic issues.

RESOURCES TO ADVANCE EQUITY IN CANCER CARE (3)

Bag it

An individual from Bag It took part in one of the focus groups. “Bag It” is a customizable guidebook and compendium of treatment-related resources, available in multiple languages online and via a bag, to help patients and their care team keep information organized and easily accessible. This tool, which aids in the navigation of services and treatment supports, enables patients and caregivers to better understand the continuum of cancer-related services available. While more languages should be added, this is a useful resource that can be seen as a best practice in Arizona.

Cancer Support Community Arizona

Cancer Support Community Arizona supports individuals impacted by cancer, including family, with no-cost supportive services and programs to help individuals undergoing

treatment. Services include healthy lifestyle supports (e.g., art therapy and nutrition consultation), education, social connections, and resource navigation. While there are specific programmatic supports for the Hispanic population, participants indicated the organization is developing relationships with American Indian communities.

Ending Well Patient Advocacy

Ending Well Patient Advocacy collaborates with individuals on their end-of-life planning and management needs. While this organization provides traditional advanced care planning, there are additional, inclusive services such as end-of-life doula availability, professional surrogate and medical Power-of-Attorney surrogacy, and direct patient advocacy through facilitated conversations with providers at key decision points in the delivery of care.

CONCLUSION

While CCS did not survey focus group participants on their age, sex, gender identity, race or ethnicity, observations indicate that between the two groups there were only two non-white participants and zero male participants. It's imperative in any instance of terminal or life-threatening disease that the care team is well informed on existing supports and resources to help communities, especially historically underserved, underrepresented, and marginalized communities with their navigation journey.

TACOS' main challenge stems from the historical and valid mistrust of the American Indian community towards institutional medical systems and providers, which often

lack resources to accommodate the cultural and logistical needs of the population. In this way, nearly every issue identified by the groups are tied to the need for developing resources which center the preferences and experiences of the patients through the creation of culturally appropriate materials, improved access for medical services through decentralized delivery and better inclusion of community-based navigators and non-clinical patient supports.

REFERENCES

1. <https://www.cdc.gov/cancer/dcpc/research/articles/cancer-AIAN-US.html>bid.
2. TACOS is the largest oncology professional organization in the state of Arizona. TACOS membership is limited to licensed

physicians and allied health professionals including but not limited to registered nurses, nurse practitioners, clinical nurse specialists, pharmacists, physician assistants, administrators, social workers, and office managers.

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Founded in 1991, **The Arizona Clinical Oncology Society (TACOS)** is the largest oncology professional organization in the state of Arizona. TACOS membership is limited to licensed physicians and allied health professionals including but not limited to registered nurses, nurse practitioners, clinical nurse specialists, pharmacists, physician assistants, administrators, social workers, and office managers. As a Chapter Member of the Association of Community Cancer Centers (ACCC) and a State Affiliate of the American Society of Clinical Oncology, TACOS members receive valuable educational content and tools designed to respond to national challenges and trends. For more information, visit acc-cancer.org/state-societies/Arizona. Follow us on Twitter @OSSatACCC or LinkedIn @Oncology State Societies at ACCC.

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