

Listening Session Summary: Cancer Prevention Research Among American Indian and Alaska Native Populations: Research Priorities and Dissemination

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**NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS**

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Background

The Center for Disease Control and Prevention's (CDC) Division of Cancer Prevention and Control formed the Cancer Prevention Across the Lifespan (CPAL) workgroup as a division-wide effort to foster innovative public health approaches to primary cancer prevention to address cancer risk and protective factors at each phase of life. In previous years, the CPAL workgroup collaborated with external partners to conduct reviews of the literature and experts to identify factors that influence cancer risk and promote strategies to address these factors during every phase of life. This project used the information gained from this previous work and applied it to the development of innovative resources to empower public health practitioners to put evidence-based cancer prevention strategies into action in their communities using a lifespan approach. More information about the previous work of the CPAL workgroup is available on the [CDC website](#).

Due to the COVID-19 pandemic, the in-person meetings that were planned for year 4 of this project were canceled. Instead, the National Association of Chronic Disease Directors (NACDD) and partners used a virtual platform to convene team and sub-committee meetings, interviews with subject matter experts (SME), and webinars.

Earlier in this five-year project, a CPAL strategic planning meeting led to the identification of four areas of focus:

- Opportunities to reduce cancer risk among American Indian and Alaska Native (AI/AN) populations
- Opportunities to reduce cancer risk among Hispanic and Latino populations
- The role of the chronic disease prevention field in addressing adversity and toxic stress in childhood
- The Impact of Environmental Chemicals on Cancer Risk.

A variety of activities supported these workgroups during year 4, including SME interviews, a literature search, webinars, and briefs. This brief summarizes key themes of a listening session convened on July 25, 2022, with select leaders in American Indian health. The participants in this session agreed to have their names listed as participants; however, participants wished to maintain anonymity regarding their specific thoughts and ideas.

American Indian and Alaska Native people and communities' cancer experiences occur in a unique and diverse cultural context, as sovereign nations representing more than 570 federally recognized tribes. Mainstream models and approaches to research and engagement can be a poor fit for tribes and Alaska Native communities and people. Existing Indigenous principles and approaches to research are unique and differ from traditional Western approaches. To better inform the CPAL project team and CDC staff, a listening session on Cancer Prevention Research Among American Indian and Alaska Native Populations: Research Priorities and Dissemination was conducted in partnership with consultants from the [International Association for Indigenous Aging](#).

Themes

Cancer Research Priority Challenges

Populations are small and disbursed. Data is tribe-specific and may not be generalized for all AI/AN populations. Small populations lead to small data sets that are sometimes not considered “high-quality research” due to a lack of sample size.

Agreements between agencies such as State Health Departments, Indian health, CDC, National Cancer Institute (NCI), death records, and others can take time and coordination to set up and red tape can be a barrier.

Communities want research and intervention that is directly beneficial to them but waiting for the entire scientific process is frustrating. Additionally, people often have to travel far distances to participate in research, and there is no support for travel or accommodations.

Challenges in Seeking Funding

The application process is complicated, and the credentials required for the researchers often limit who can apply for funding. Without more credentials, the funding options are small opportunities that have to be pieced together, and each opportunity comes with different priorities. There needs to be an additional consideration to assess expertise and ability. “We have to validate our knowledge and existence for everything we do.” Academic partnerships have pros and cons. Sometimes academia offers a different level of expertise and can alleviate some internal tribal processes; however, it is also patronizing. It is viewed that the research done within the native system isn’t “good enough” or equal to university research.

Each community has different characteristics; each funding opportunity in a new community is like starting over. Success for AI/AN communities would look like having a funder that prioritizes providing the funding and letting the community have the freedom to address solutions that are culturally appropriate for their community. Use the funding and data to make it useful in a translatable message. Western research wants a defined hypothesis, but AI/AN want data to get engaged in research and want a result that impacts them.

There are opportunities for pilot funding, but there are delays and processes to get the funds. Many tribes are too small and do not have the budget to fund the project while waiting for funding to go through. For a year-long project, a tribe has to wait four-to-five months for the funding to be deposited, losing time in the one-year project timeline for the pilot.

The lead time for a funding opportunity is not always conducive to how the tribe works. The tribal community and bureaucracy take many steps and reviews to ensure the project is in the best interest of the tribe. A three-month notice for an opportunity will most likely be missed because some tribes only meet twice yearly to review. In addition to the lead time, the application process is cumbersome. Extensive legal documentation and signatures are required of people who potentially can't read or write. The process is modernized for some, but other tribes still need multiple paper copies and do not use email. This takes a lot of time and processing.

Lack of personnel is an issue in accessing funding opportunities. Staff or leadership turnover is the first issue. The tribe has to educate new people on the "direction" of the project for support. Additionally, the academic model of full-time employee (FTE) requirements doesn't align with tribal employment. Allotting a 1.0 FTE is challenging and requires advanced planning yet, assigning a 0.5 FTE is also challenging because the tribe has to employ the other portion of the position. The lack of access to a full grant writer makes just the proposal process challenging. Many people hold multiple roles and functions, and grant writing is only one of their jobs.

Disseminating Findings

The decision of "whose knowledge is important" really determines what you can publish. Partnerships are vital in disseminating information, and additional relationships must be established in the community as researchers. The community should be involved in sharing the research they went through. Create a plan for students and research partners to be part of the dissemination.

Information should be disseminated in the tribe through youth, families, and lived experience. When kids tell their stories, leaders listen. Data that is collected through traditional public health assessment is a data story, but not a story. Translating the data into a story for the people we serve is critical. The need has to be presented in a culturally based solution that allows for trust. There is still the idea that "the people that took it away from us still control how we get the funding."

How we interpret and use the data to talk about our communities is essential. Currently, it's deficit-based and not always positive. The perception is biased because medicine is often harmful and measured by what is missing or what is a risk factor. Change the way the information is presented to look at positives and provide information and health processes that are useful.

Peer Reviewed Journals

Often the deliverable for a research project is to be published in a peer-reviewed journal. AN/AN researchers are doing the work for their community, not just to

justify western academics. Our research only validates the information for people who aren't part of our community. The biomedical model does not understand the people. Showing up for the community first to ensure their needs are met should be a priority over publication. Make sure that community dissemination is part of the plan.

Findings in Action

The research done with AI/AN communities should have an outcome and a policy change or it shouldn't be done. The goal is to improve health. For example, the testing of fecal matter was used to screen for disease. The results were presented to leadership and the testing was implemented in the clinical practice of the tribe.

Research Priorities

More community-level research and practice is needed. Most research is done on individual screening, care, and treatment, and not enough on the community. Biological research shouldn't be the only area that receives funding. For example, there is not enough emphasis on palliative care which is a disservice. Tax money that goes to government agencies for research should be better divided at the community level.

Continue to grow Community Based Participatory Research (CBPR). Researchers lack CBPR skills, but it is growing and very effective.

Closing Thoughts

Through the process of 'compacting', Tribes in the U.S. have taken over authority to operate and oversee the health of their customer/owners. Could this be applied to federal research funds, such that Tribes could have more control of how research funds were spent and be in a stronger position to determine who and which academic institutions to partner with.

Look at options to make research easier on people by partnering with travel entities like hotels or transportation to provide accommodations when traveling to research-based medical appointments.

It comes back to relationships and communities. Look at the whole person and where they live, not their risk or their disease.

If you were to ask your grandparent, "If we were to do cancer research, what should the priority be?" What would they say? The best way to reach our community is by having individual discussions. Talk with families. "Remember your mom? She had cancer last year; what is your story?" When you talk with your own family about health, they aren't using data; they talk about what they

went through. They talk about what it took to get through the situation. They talk about dying and what is next. “What we do in this life will carry forward into the next one.”

Participants

Facilitator

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I am Chiricahua Fort Sill Apache, a registered nurse and a Research Scientist at the Pacific Institute for Research and Evaluation in Albuquerque, New Mexico. My research is guided by the health and wellness priorities of the Native American partners with whom I collaborate. I have published in peer-reviewed journals on cancer pain management and decision-making, telehealth and video conferencing, complementary and alternative therapies for pain management, issues in racial misclassification, and national trends in premature mortality. I always focus my research efforts on the interests of Native Americans and Alaska Natives. I have worked with Indigenous groups throughout New Mexico to address social justice and health equity concerns. I most recently completed a health impact assessment with the urban Native American community in Santa Fe, investigating the health implications of chronic underfunding of the Indian Health Service. She is a frequent speaker at local, tribal, state, regional, and national meetings on Native American health, particularly related to cancer prevention, palliative care, and health promotion. Dr. Haozous received her undergraduate degree in music from the University of California, Santa Cruz, and a master's and Ph.D. in nursing from Yale University.

Participants

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Carol Goldtooth-Begay is a citizen of the Navajo Nation; her Maternal Clan is Kinyaa'aanii (Towering House People); Paternal Clan is Biih bitoodnii (Deer Springs People); her Maternal Grandfather's Clan is Tl'izi Iani (Manygoats People); Paternal Grandfather's Clan is Tl'aashchi'i (Red Left Hand People). Carol is currently the outreach program coordinator at Northern Arizona University (NAU) for the Partnership for Native American Cancer Prevention (NACP). NACP is a collaboration between NAU, the University of Arizona Cancer Center (UACC), funded through the National Cancer Institute (NCI) Partnerships to Advance Health Equity U54 mechanism. NACP's mission has been to alleviate the unequal burden of cancer among Native Americans (NA) of the Southwest through research, training, and community outreach programs in

collaboration with the communities they serve. Carol's public health interests and work have focused on NA health and related disparity issues for over 20 years. She received her BS in Microbiology from NAU and an MPH from the University of Arizona.

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Diana Redwood, PhD is a Senior Epidemiologist at the Alaska Native Tribal Health Consortium. She has worked in the Alaska Tribal Health System since 2004. Her expertise is in public health and epidemiology, with a focus on cancer screening and prevention. She conducts research into novel methods of colorectal cancer screening outreach and new screening methods for the Alaska Native population. Her research has focused on use of the stool DNA test (Cologuard) for improving screening, including Cologuard effectiveness, patient and provider perspectives on the test, and its cost-effectiveness within the Alaska Tribal Health System. Her current R01 work is a randomized controlled trial of Cologuard in rural/remote Alaska Native communities. Dr. Redwood is an Alaska representative to the National Colorectal Cancer Roundtable and is a passionate advocate for improving the health of Alaska Native people through decreasing the burden of colorectal cancer.

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Dr. Timothy Thomas is a medical epidemiologist who currently serves as Director of Research Services Department in the Division of Community Health Services, Alaska Native Tribal Health Consortium (ANTHC). He worked as a Family Practice doctor in Kenya, Bethel and Anchorage, Alaska in the 90's and then completed training in epidemiology with the CDC. He has subsequently been primarily engaged in research back in Kenya working on HIV and more recently in Alaska. He joined ANTHC in October 2011 in his current position overseeing the department that operates on a budget of \$4-5 million and has a staff of 30. Staff are engaged in multiple research projects including liver disease and hepatitis, cardiovascular and rheumatologic diseases, diabetes, tobacco cessation, colon cancer, pediatric respiratory illness, water and sanitation, HIV stigma, and oral health. For the last ten years, Dr. Thomas has been a member of the Alaska Area IRB. He currently serves as a Technical Advisor on the NIH Tribal Advisory Council.

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Sydney Martinez, PhD, MPH is a Cherokee Nation citizen and an Assistant Professor in Epidemiology in the Department of Biostatistics and Epidemiology at the University of Oklahoma Health Sciences Center (OUHSC). She received her PhD and MPH in Epidemiology from OUHSC and a Bachelor's of Science from OU in Health and Exercise Science. She currently studies the intersection of commercial tobacco and diabetes and works towards improving the implementation and delivery of smoking cessation interventions for patients with diabetes in primary care and in tribal health care settings. Dr. Martinez also aims to recruit and train the next generation of scientists engaged in health equity research. She is the Co-Director of the OU Health Stephenson Cancer Center Cancer Research Immersion Summer Program in partnership with Cherokee Nation and Oklahoma State University to provide mentored research experiences for undergraduates and medical students. She also serves as the Director of Indigenous Research at the Society for Research on Nicotine and Tobacco University, curating online content related to international Indigenous commercial tobacco research.

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Wyatt Pickner is an enrolled member of the Crow Creek Sioux Tribe in South Dakota. Mr. Pickner is currently the Research Manager at the American Indian Cancer Foundation. In this role, he works with Indigenous communities to design and implement research projects that assess the burden of cancer and potential contributing factors with the aim to identify culturally relevant solutions. He received his undergraduate degree in American Indian studies and health sciences from the University of South Dakota and earned an MPH in community-oriented public health practice from the University of Washington. He has a decade of experience working with tribes, tribal organizations, and American Indian-serving organizations at local, regional, and national levels on research projects, capacity building, training, and community engagement.

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