In Research and Cancer Care, Indigenous Representation Matters

Fred Hutch/University of Washington Cancer Consortium works to reduce risk, inequities and access to care for Indigenous communities.

December 22, 2021 By Diane Mapes at the Fred Hutch News Service

---

Dornell Pete's grandparents were both diagnosed with lung cancer, although neither of them smoked.

"My grandfather worked in the mines, inhaling the uranium in the air, then came home where my grandmother would wash his clothes, so she was also exposed," said the University of Washington Navajo (Dine') doctoral student, who grew up in Shiprock, New Mexico, on the Navajo Nation.

Pete experienced health inequities firsthand growing up: shortages of clean water, fresh healthy foods and reliable health care for those living on reservation lands. Later, as a college undergrad and caretaker for her aging grandmother, she learned how to push back, ensuring the U.S. government would compensate her grandparents (uranium mines were built on tribal lands and Navajo mine workers were routinely exposed to harmful levels of the toxic metal without knowledge, consent or protective gear).

"There were many differences in education and resources growing up," she said. "Some people had things and other people didn't."

These lived experiences are what led Pete to pursue advanced degrees in public health and epidemiology. Her goal: to get to the heart of the health issues the Navajo people faced — issues like diabetes, mental health, suicide, infectious diseases and cancer — and help turn things around through community-engaged research.

"In the Navajo teachings this is something you do," she said. "You give back. You come back to the family and the community."

Pete and other Native American advocates, researchers and scientists within the Fred Hutch/University of Washington Cancer Consortium are giving back to science and public health as well, conducting research with American Indian/Alaska Native individuals and communities that could lead to longer and healthier lives for all.

‘Walking in both worlds’

“Representation is really important; it plays a vital role in cancer prevention and research,” said Craig Dee, also a member of the Navajo (Dine’) Tribe, and a community health educator with the Cancer Consortium’s Office of Community Outreach & Engagement.

But it’s not just representation within the health care system, he said.

“There also needs to be representation at the research level, at the principal investigator level in cancer and prevention research,” said Dee, who is pursuing a master’s degree in public health at UW. “The community needs to see commonality and your understanding of the lived experiences that stream from historical trauma and colonization. This helps with the trust.”

Originally from the Four Corners region, Dee focuses on urban American Indian and Alaska Natives, which he terms an “often-overlooked population.”

Like Pete, who recently received a large grant from the National Cancer Institute to study stomach cancer risk among the Navajo people, Dee works to connect two communities — academic and Indigenous.

“My work is to walk in both worlds,” he said. “To build relationships and create internal and external educational opportunities, but lately more so to support the scientific community to better understand and acknowledge the significant value of Indigenous relationality in cancer research.”

Dee said strengthening the health of American Indian and Alaska Native peoples means recognizing research and data evaluation as Indigenous values that can be used to tackle the health disparities they face.

“American Indian and Alaska Natives have been observational researchers since time immemorial,” he said. “A lot of our traditional medicines, ones that were used thousands of years ago to treat infection, relieve pain and other things, are still being used today.”

Storytelling and science

Information about these medicines was passed along — not through scientific publications — but oral storytelling, which still provides value today.

Listening to people’s stories is how Pete learned of the cancer burden in her community, including the fourfold rate of stomach cancer in Navajo people compared to the surrounding population.

“As an epidemiologist, your training is to find out how much of a burden there is and that starts with stories, with people talking about cancer,” she said.

“Stomach cancer was one no one expected. But among Native people in the Southwest and also among the Alaska Native population, the stomach cancer disparity is high.”

As principal investigator of the Assessing the Gut Microbiota and Individual Diet (or ‘ABID study — “Abid” is the Navajo/Dine’ word for stomach), Pete hopes to find the root of this disparity and is gathering data on the prevalence of infections with the bacterium H. pylori, a strong risk factor for stomach cancer.

“Prevention is where my heart is,” she said. “And most people don’t realize there’s a link between infectious disease and cancer.”

Done in collaboration with Hutch researcher Dr. Amanda Phipps, it’s one of only a few studies to look at this risk factor among members of the Navajo Nation.

And it wouldn’t have happened without Pete.

“Working with Dornell has been hugely educational,” Phipps said. “She’s very much attuned to the needs of the community and also how things are done. You don’t just walk into Navajo Nation and expect to conduct research without support and buy-in. She talked with community leaders, with folks from the IRB [the Institutional Review Board, which governs research] and the health care systems on the Navajo Nation to hear from them what the challenges were. She made sure all of them had their voices heard in the research process.”

Representation and collaboration, Phipps said, are crucial for effective cancer prevention.

“Public health includes the public in it,” she said. “It is a science that involves the public and should not be removed from the people we’re hoping to serve with the science we produce.”

And public health has long been part of American Indian/Alaska Native cultures, Dee said.

“Indigenous people have always been involved in public health,” he said. “One of the things we’re taught within my community is if there’s an elder who needs help, then you help that elder like she’s your own grandmother, like a blood relative. That’s a shared teaching and value among Indigenous communities. We look out for the community and looking out for the community is public health, making sure our elders, our children, our women, our community are safe.”

A higher burden of disease

And there is much to keep these communities safe from, particularly in the realm of cancer.

Data from the National Cancer Institute shows that American Indian/Alaska Native populations have the lowest survival rates for nearly all types of cancer of any subpopulation in the U.S., possibly because these cancers are often detected late, when they are harder to treat. National data from the Centers for Disease Control and Prevention tell us:

- American Indian/Alaska Native people are more likely to get liver, stomach, kidney, lung, colorectal, and female breast cancers than white people in most regions.

- American Indian/Alaska Native men have higher rates of myeloma and liver, stomach, kidney, colorectal and lung cancers than non-Hispanic white men.
- American Indian/Alaska Native women have higher rates of liver, stomach, kidney, colorectal and cervical cancers than non-Hispanic white women.
- Additionally, the federal government's Office of Minority Health has found that American Indian/Alaska Native men are twice as likely to die from stomach cancer once they're diagnosed and American Indian/Alaska Native women are 2.2 times more likely to die from liver and bile duct cancer once they're diagnosed.

In Washington state, Fred Hutch/UW Cancer Consortium data show American Indian/Alaska Native people are diagnosed with breast cancer at 1.6 times the national rate and blood cancers at nearly twice the national rate.

Before vaccines became available, COVID-19 hit Indigenous communities harder, as well.

"Rates of COVID-19 for American Indian and Alaska Native communities were 3.5 times higher than they were for non-Hispanic whites," Dee said, adding that the numbers do not account for racial misclassification.

'Tobacco companies have exploited tribes' sovereignty from smoke-free laws with promotional strategies. And lack of access to cessation treatment (due to costs and living remotely) is a major barrier that keeps smoking rates high.'

— Fred Hutch behavioral psychologist and public health researcher Dr. Jonathan Bricker

Trauma, abused trust, and toxins

What leads to the higher rate of disease in Indigenous people? According to research, it's multifactorial. And as with African Americans, much of it starts with persistent racial inequity and trauma, historical and otherwise.

"Seven out of 10 American Indian/Alaska Native people live within large urban areas," said Dee. "This is due to either moving or being forced to relocate because of government policy, lack of economic and educational opportunities, and/or limited access to health care and other services."

Additionally, over decades, tens of thousands of Indigenous children in the U.S. and Canada were separated from their families and forced to live in residential schools designed to "kill the Indian … save the man." Subjected to enforced assimilation, they had to abandon their language, clothing, food and customs and were routinely beaten, abused, sickened by disease and worse.

Many Native families and individuals still carry trauma from this. And it's hardly ancient history. The practice didn't end until passage of the Indian Child Welfare Act of 1978. There is ongoing trauma, as well, including that from the high numbers of missing and murdered Indigenous women and girls in the U.S. and Canada.

Other contributing factors include inadequate medical facilities on reservation lands, shortages in health care providers and lack of access to preventive screenings.

"Cancer screenings are low in Indigenous people," Pete said. "The Navajo Tribe does have a breast and a cervical cancer screening program, but screenings for other cancers like lung and colorectal need improvement. With cancer, it's about access to care. It's about who gets access to screening, clinical trials and good therapies, including effective cancer prevention programs."

Environmental exposures from polluted air, water and soil and/or toxins from manufacturing plants and mines built on or near tribal lands, like the one Pete's grandfather worked in, have increased health disparities. Ditto for isolation and lack of transportation.

"My grandfather was advised not to treat his lung cancer because of his age," Pete said. "But it was also that we couldn't travel two hours to get treatment and surgery and then come back and follow up with his care. There are geographic problems and lack of specialty care. We have to seek care off the reservation and in particular environments, racism is present in terms of our treatment."

Language barriers can also impede care.

"A lot of people speak their tribal language, so there may be a lack of understanding between provider and patient," she said. "There's no word for cancer in our tribal [Navajo/Dine'] language."

Another complicating factor is tobacco use.

"It's high and a problem in our catchment area [the 13 Puget Sound counties that the Fred Hutch/UW Cancer Consortium serves]," said Ursula Tsosie, program manager and tribal liaison for the Indigenous health promotion program at Seattle Cancer Care Alliance, the Hutch's clinical-care partner.

"American Indian and Alaska Natives smoke twice as much as other people," she said. "In non-Indigenous people, prevalence is like 15%, but for our Native groups, it's like 32%. They have a high number of quit attempts, but also high relapse. So they're trying to quit; it's just hard. What we've found in our conversations with communities is that it's about trauma. It's about coping."

Working with tribes to cut tobacco use

Hutch public health researcher and behavioral psychologist Dr. Jonathan Bricker, who just published a study on smoking cessation in American Indian and Alaska Native people, said the high rates of cigarette use in this population is a combination of internal and external factors.

“There’s historical trauma, which is the psychological wounding of a group across generations, there’s racism, and there’s also the ceremonial use of tobacco in certain tribes,” he said. “Tobacco companies have also exploited tribes’ sovereignty from smoke-free laws with promotional strategies. And lack of access to cessation treatment (due to costs and living remotely) is a major barrier that keeps smoking rates high.”

Bricker’s study included American Indian/Alaska Native participants from 31 states, with 70% of them in urban areas and 30% residing on reservation lands. Funded by the NCI with additional help from the local Snoqualmie Tribe, his findings showed that a digital intervention with the ICanQuit smartphone app, using Acceptance and Commitment Therapy, was twice as effective in helping this population quit smoking as compared to a standard NCI quit-smoking app.

“ICanQuit shows exceeding promise in effectively addressing these causes and barriers to treatment," he said.

And it’s not the only program designed to help Indigenous people kick cigarettes.

SCCA established the həliʔil Program (pronounced haa-lee-eel) in 2019 to promote lung cancer screening and cessation of commercial tobacco products in Indigenous communities. The name “həliʔil” (a Lushootseed word meaning “to become well and heal”) was also gifted to SCCA by the Snoqualmie Tribe.

Tsosie, also a member of the Navajo (Dine’) Tribe, said the program is developing a culturally appropriate lung cancer screening navigation program. They also offer trainings to SCCA staff and providers in order to better serve patients who identify as Indigenous.

’American Indian and Alaska Natives have a high number of quit attempts, but also high relapse. So they’re trying to quit; it’s just hard. What we’ve found in our conversations with communities is that it’s about trauma. It’s about coping.’

— Ursula Tsosie, program manager and tribal liaison for the Indigenous health promotion program at Seattle Cancer Care Alliance

Navigating cancer care

SCCA also has its own Indigenous patient navigator, Lenora Starr, who serves American Indian/Alaska Native as well as Native Hawaiian populations.

“I‘m very grateful that SCCA has been able to hire Indigenous persons to work on both the prevention and the navigation side of cancer,” Starr said. “I like to think we’re making a difference in being able to identify and reach out to people, whereas before, they might slip through the cracks.”

A member of the Confederated Tribes of Warm Springs in Oregon, which represents a handful of Northwest tribes, Starr has also experienced health inequities over the years. Her former partner, for instance, repeatedly saw doctors about gastrointestinal issues but was never helped. Instead,

he was told he wasn't able to eat because of anorexia.

"He actually had colon cancer," she said. "But it wasn't found until he was stage 4. There was a huge delay. He died shortly after he was diagnosed."

As patient navigator, Starr meets with newly diagnosed patients and families who identify as Indigenous, assisting them with whatever services or comforts they may need, whether it's connecting them with transportation, lodging, counseling services or financial resources; or teaching visiting relatives how to use Seattle's bus system. She's even brought a homesick coastal patient some canned salmon from her pantry.

"Some people will say they don't want help or they'll say they're okay, but then when they find out I'm Indigenous they'll open up more," she said. "When I tell them it's part of my job to look for grants and financial assistance for patients, they're more receptive."

Starr also works with Indigenous patients and communities to help them understand the important difference between ceremonial and commercial tobacco use (ceremonial tobacco has no chemical additives).

'A silver lining'

Despite the challenges in Indigenous health and research, Pete, Dee and the others are not at all discouraged.

"The pandemic shined a light on the inequities across all systems, especially for people of color," Pete said. "But there's a silver lining. It's made us more passionate. COVID has put a fire in us to look at the data and see the disparities and go after the funding and research to change it. And to get more education about disparities back to our people."

Outreach efforts during the pandemic made a huge difference in vaccination uptake, the researchers said. At this point, American Indian/Alaska Native people are leading the U.S. in vaccination rates. Dee said he believes the Indigenous values of protecting communities was a large factor.

"I think it's a matter of our tribal communities being diligent about caring for the people and caring for our elders, the knowledge-keepers," he said.

In the future, Pete said she hopes to use technology and other tools in similar ways to disseminate information on cancer and cancer prevention and to demystify cancer screenings.

"I'm very interested in getting out of the ivory towers," she said. "There are other populations that can benefit from this research and this work."

Dee couldn't agree more.

"It's critical that we share this knowledge and engage with the research and academic communities on behalf of our people and relatives," he said. "This is what representation looks

like.”

RESOURCES AND INFORMATION

- Cancer Among the Navajo Report
- Cancer Health Equity NOW podcast on “Grief, Intergenerational Trauma, and Healing Among Indigenous People.”
- Cancer Health Equity NOW podcast on “Building Trust and Relationships Among Indigenous Communities”
- Cancer Health Equity NOW podcast on “Representation Matters”
- Cancer Health Equity NOW podcast on“Indigenous Relationality in Research, Pt. I”
- Urban Indian Health Institute
- Seven Directions Center for Indigenous Public Health

Diane Mapes is a staff writer at Fred Hutchinson Cancer Research Center. She has written extensively about health issues for NBC News, TODAY, CNN, MSN, Seattle Magazine and other publications. A breast cancer survivor, she blogs at doublewhammied.com and tweets @double_whammied. Email her at dmapes@fredhutch.org. Just diagnosed and need information and resources? Check out our patient treatment and support page.

This article was originally published by the Fred Hutchinson Cancer Research Center on December 6, 2021. It is republished by permission.

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.realhealthmag.com/article/research-cancer-care-indigenous-representation-matters