Nothing about us, without us: Learning from both good and bad research in Indian Country

Many tribal and urban Native communities are familiar with the long history of abuse of American Indian and Alaska Native (AI/AN) peoples in health research and evaluation. In this document, we provide examples of this harmful research. These abuses often took place in direct violation of ethical guidelines or because researchers lacked understanding and respect for AI/AN culture and values. These historical abuses played a role in informing a new generation of research that abided by ethical and cultural norms and respected AI/AN communities. To contrast these harmful examples, we also provide examples of respectful research. These respectful research projects were often conducted by AI/AN people or under the direction of AI/AN people. They offer valuable lessons in how to approach and conduct research with AI/AN communities in a good way.

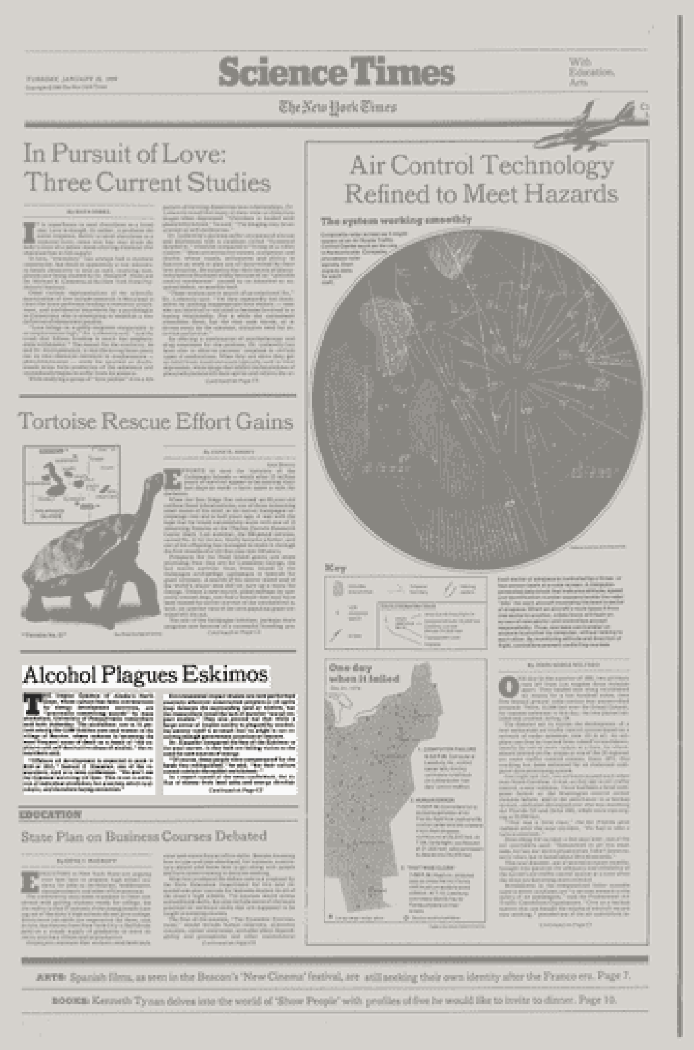
Harmful Research Examples

Barrow Alcohol Study (1979)

Often called the Barrow Alcohol Study, in this study non-native researchers surveyed alcohol use in the small Arctic Circle town of Utqiaġvik. Native leaders in the community had invited the researchers after they expressed concerns about drinking and associated problems they were seeing in their community. After completing the study, researchers shared the findings with the press before sharing results back with the local community. The results ended up published in the New York Times and portrayed the community as an “alcoholic” society of Iñupiats “facing extinction”. Researchers blatantly disregarded the wishes of the community and it resulted in an insulting portrayal on a national level. Additionally, some banks stopped lending to the community because of the study results leading to both emotional and financial hardship for the community. The researchers broke trust with the community by failing to share the results with the community first and allowing them to comment on and interpret the results. This incidence led to distrust between many Alaska Native communities and researchers for decades to come.

Relevant resources:

Foulks, E. F. (1987). Social stratification and alcohol use in North Alaska. Journal of Community Psychology, 15(3), 349–356.



Science Times

With Education, Arts

The New York Times

In Pursuit of Love: Three Current Studies

Air Control Technology Refined to Meet Hazards

The system working smoothly

Tortoise Rescue Effort Gains

Alcohol Plagues Eskimos

EDUCATION

State Plan on Business Courses Debated

ARTS: Spanish films, as seen in the Beacon's 'New Cinema' festival, are still seeking their own identity after the Franco era. Page 7.

BOOKS: Kenneth Tynan delves into the world of 'Show People' with profiles of five he would like to invite to dinner. Page 10.

New Yorks Times article sharing the results of the study without permission from the community and with an offensive and harmful framing

Source: New York Times

Havasupai Tribe DNA abuse by Arizona State University (1990s)

Researchers from Arizona State University (ASU) obtained blood samples from Havasupai Tribal members to study DNA linkages to diabetes to help see if they could predict diabetes or works towards developing cures and treatments for it. Diabetes was a health concern among Havasupai Tribal members and so a group consented to allow the researchers to use their blood to study this disease to hopefully find results that could benefit their community. But the researchers also used the blood samples to study mental illness, inbreeding, even migratory patterns that contradicted Havasupai traditional belief- all without the consent of the tribal members the blood samples belonged to. One tribal member expressed the following sentiment when they found out all the studies their blood was used for “that angered me because I was not properly informed nor did I sign any consent form or fully explained to what my blood was being used for. And it was benefiting different people in the university levels as professors have been obtaining their doctor's degrees and undergraduate students that were graduating with master's degrees while our people down here, first of all, were not informed of all of those studies but was also lied to from the beginning...” In this case, researchers completely disregarded the process of informed consent and violated both ethical and cultural norms. Community members were betrayed, and this harmful research eroded trust between the Havasupai Tribal community and researchers.

Relevant resources:

Sterling, R. L. (2011). Genetic research among the Havasupai: A cautionary tale. AMA Journal of Ethics, 13(2), 113–117.

Headlee, C. (2014, April 25). 'Blood Victory' In Medical Research Dispute. Retrieved August 13, 2020, from https://www.npr.org/2014/04/25/306832661/blood-victory-in-medical-research-dispute

Lack of informed consent in Iodine 131 thyroid research among Alaska Natives (1957)

The Arctic Aeromedical Laboratory (AAL) in Fairbanks, Alaska conducted unethical and horrifying experiments in the late 1950s where they administered radioactive iodine 131 to Alaskan Natives to investigate the role of the thyroid in cold acclimatization. This research offered no prospect of medical benefit to the participants. In the 1990s that the ethics of this study formally came into question and those reviewing the ethics of this work wondered if the large number of Alaskan Natives who participated in the study gave true informed consent. Some of those involved in the study participated more than once meaning they received higher levels of radiation and some of the participants were pregnant or lactating during the study. Many of the Alaskan Natives included in the study did not speak English at the time and it was unclear how the AAL established communication with those participants during the experiment. Some participants came from a village that suffered from semi-starvation the year prior and trusted the researchers because they were also medical doctors that would treat the ailments of community members when they visited. This study offered no prospective benefit to any of the participants, it was simply the researchers putting Alaska Native people in a potentially harmful situation to further their research agenda and not the health and wellbeing of the community. This research also shows how power dynamics can affect research when a community is underserved and previously depends on those researchers for essential services like health care. Therefore, it is likely many participants felt pressured to participate because the same doctors administering the study were the only medical doctors the community had access to.

Relevant citations:

National Research Council. (1996). The Arctic Aeromedical Laboratory's thyroid function study: a radiological risk and ethical analysis. National Academies Press.

Chapter 12: The Iodine 131 Experiment in Alaska. (n.d.). Retrieved August 18, 2020, from https://bioethicsarchive.georgetown.edu/achre/final/chap12_4.html

Forced Sterilization of Native American Women by IHS (1970s)

Multiple accounts and studies accuse the Indian Health Service (IHS) of sterilizing at least 25% of Native American women between the ages of 15 – 44 in the 1970s. Those affected said the IHS failed to provide the women with the appropriate information about sterilization, coercing women to sign the consent forms, improper consent forms, and lack of waiting period between signing the consent and the procedure. These accusations were later confirmed in an official government accountability office report. The American government targeted American Indian women for family planning because of their high birth rates in the 1970s. By the 1980s the birth rate among American Indian women would be about 60% lower than it was the prior decade (1.3 children per woman vs. 3.29 children per women). Many of these sterilizations were not for medical reasons. A study conducted by the Health Research Group found that most of these doctors were white males who thought they were benefiting society by limiting the number of births in low-income minority families. Some stated that they didn’t believe minority women were intelligent enough to properly use other forms of birth control. These sterilizations affected the health and wellbeing of native women- their relationship with their families and spouses, many marriages ended in divorce and victims turned to self-medication with substances to deal with the shame and guilt. Forced sterilization contradicts the sacredness of women's roles as child-bearers and the ancestral knowledge that Native American women had already used for generations to prevent unwanted pregnancies. This example is a horrific violation of human rights that impacted generations of Native women and Native families.

Relevant resources:

Lawrence, J. (2000). The Indian health service and the sterilization of Native American women. American Indian Quarterly, 24(3), 400–419.

U.S. Government Accountability Office. (1976) Investigation of Allegations Concerning Indian Health Service. HRD-77-3.

CDC withholding COVID-19 Data from Tribal Epidemiology Centers (2020)

During the coronavirus (COVID-19) pandemic, the Centers for Disease Control and Prevention (CDC) repeatedly denied tribal epidemiologists' multiple requests for raw coronavirus data—even though state health departments could freely access the information. Under the Affordable Care Act, tribal epidemiology centers (TECs) are considered public health authorities just like state health departments and federal agencies such as the CDC. The refusal of the CDC to share coronavirus data severely limited the ability of TECs to track and address the public health needs of American Indians and Alaska Natives (AI/AN). This refusal to share critical information that TECs are entitled to by law demonstrated a disrespect for tribal sovereignty. It also served as a manifestation of continued settler colonialism, potentially widening already existing health disparities due to historical trauma and structural racism against AI/AN community. Only after significant publicity about the issue did the CDC eventually provide TECs with its coronavirus data—which, while limited, indicated disproportionate COVID-19 incidence and severity in AI/AN populations.

Relevant resources:

Tahir, D., Cancryn, A. (2020). American Indian tribes thwarted in efforts to get coronavirus data. Politico. https://www.politico.com/news/2020/06/11/native-american-coronavirus-data-314527

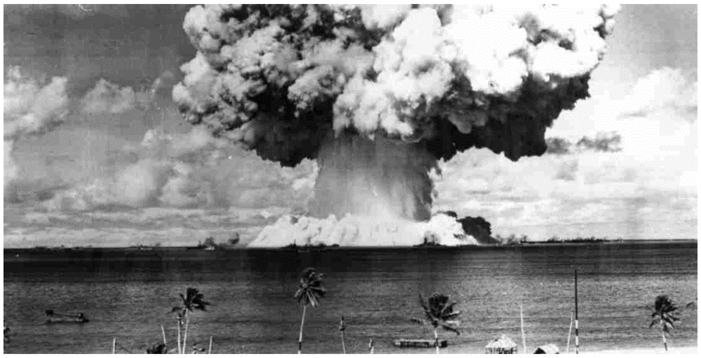
Hatcher, S.M., Agnew-Brune, C., Anderson, M., et al. COVID-19 Among American Indian and Alaska Native Persons — 23 States, January 31–July 3, 2020. (2020). MMWR Morb Mortal Wkly Rep. ePub: 19. DOI: http://dx.doi.org/10.15585/mmwr.mm6934e1external icon

Nuclear testing in the Pacific leads to evacuation and radiation of Marshallese (1946-1958)

After World War II, the United States selected the Marshall Islands as the site of the Pacific Proving Grounds for testing nuclear weapons. Between 1946 and 1958, the US conducted 67 nuclear tests in the Marshall Islands—exiling people from their homes only to later promote resettlement on the lands still contaminated with nuclear fallout. This exposure to the nuclear fallout caused long-term adverse human and environmental health impacts from radiation exposure. While the US government provided medical care for the exposed population, researchers also saw this as an opportunity to study the long-term effects of lingering radiation on the human body. According to the Advisory Committee on Human Radiation Experiments, the tension from combining research with patient care, lack of informed consent, transparency, and collaboration, as well as insensitivity to language and cultural differences led to deep distrust and the Marshallese peoples' criticism of being used as "human guinea pigs" for a radiation experiment. Instead of focusing on the care of a population, the US government had knowingly poisoned, researchers started to treat the Marshallese population like a science experiment. For the Marshallese people, this just deepened their mistrust of the US government and scientists who continued to ignore their humanity.

Relevant resources:

The Marshallese. Bioethics Archives. Georgetown University. https://bioethicsarchive.georgetown.edu/achre/final/chap12_3.html



The second atomic bomb test at Bikini Atoll on July 25, 1946 in the Marshall Islands

Anonymous/AP

Nuu-chah-nulth blood used and shared without consent (1980-2000)

In the early 1980's the Nuu-chah-nulth people on Vancouver Island, BC participated in a study hoping to address the high incidence of various forms of rheumatic disease in their community. The study was funded by the Canadian government and directed by a genetic researcher from University of British Columbia, Richard Ward. At the time it was to be the largest-ever genetic study of a First nations Population in Canada. They interviewed and surveyed thousands of Nuu-chah-nulth people and collected blood samples from 833 participants in hopes of find out whether there was a genetically inherited aspect to the rheumatic diseases. One participant in the study recollects "[The researcher] said the disease was very common within the Nuu-chah-nulth people and that he was going to work on it so we could get help, people with arthritis will do anything to get help, and that was the understanding they got from the doctors was that this was really going to help us." So in hopes of helping their community address this debilitating disease over 800 Nuu-chal-nulth people signed consent forms for their blood to be used to look for genetic markers for rheumatic diseases.

But after four years of active fieldwork, lab work and research, everything seemed to have stopped. Though researchers found no genetic marker they did not share that information back to the Nuu-chah-nulth people. Then Richard Ward continued to use the blood samples collected in that study for other un-related studies. The blood that the Nuu-chal-nulth people gave for a specific cause has traveled from the west coast of Vancouver Island to the labs at U.B.C., the University of Alberta in Edmonton, The University of Western Washington in Seattle, the University of Utah in Salt Lake City, and the University of Oxford in England, to name only a few. Data from those blood samples are frequently borrowed by researchers from GenBank in Maryland, and incorporated in studies around the world.

Yet, after 15 years of waiting, many Nuu-chah-nulth people are now discovering that the blood they volunteered to help find a cure for rheumatic diseases has traveled the world, and has been used in a variety of genetic anthropology studies; outside the boundaries of the consent forms they signed.

Relevant resources:

Wiwcha, D. (2013) Genetic researcher uses Nuu-chah-nulth blood for unapproved studies in Genetic Anthropology. Ha-Shilth-Sa. https://hashilthsa.com/news/2013-07-22/genetic-researcher-uses-nuu-chah-nulth-blood-unapproved-studies-genetic

CBC News. (2000) B.C. natives demand their blood back. CBC News Website. https://www.cbc.ca/news/canada/b-c-natives-demand-their-blood-back-1.206834

Ha-Shilth-Sa

Canada's Oldest First Nations Newspaper - Serving Nuu-chah-nulth-aht since 1974

Vol. 31 - No. 25 - December 16, 2004 hašiltsa "Interesting News"

Nuu-chah-nulth blood returns to west coast

Newspaper clipping celebrating the return of Nuu-chah-nulth bloof from the Ha-Shilth-Sa Newspaper

Source: Ha-Shilth-Sa Newspaper

Examples of respectful research

Though there are many examples throughout our history of AI/AN people being exploited by western institutions in the name of science there has been an increasing number of non-native and native researchers speaking up against the harmful ways research was conducted in the past. As a result, some of these researchers are intentionally approaching their work with and for AI/AN communities in a good way. The examples shared below share one or some of the following characteristics:

- Honored the relationship between AI/AN communities and the land they are of
- Took a strength-based approach to recognize the inherent gifts present in the community
- Centered the AI/AN community in decision making (e.g. AI/AN researchers and/or communities had power/control over and throughout all stages of the project)
- Used decolonizing methods (methods that challenge or push standard western research conventions)
- The research directly benefits the AI/AN community
- Respects and/or strengthens tribal sovereignty
- Centered culturally relevant frameworks, design, and methods

Developing Indigenous Health Indicators

Many health assessments by government agencies, industry, and researchers outside of the Indigenous community fail to include Indigenous definitions of health and as a result, produce questionable or inconsistent results. These Indigenous definitions of health can include more "intangible" aspects of AI/AN community health such as social connection, cultural knowledge, and access to traditional land. This research describes a collaborative community-based approach to develop a set of Indigenous Health Indicators (IHIs) to be used and adapted to identify more context-specific Indigenous health risks and impacts. They can also be tools for evaluating Indigenous health priorities. The six IHIs (community connection, natural resources security, cultural use, education, self-determination, and resilience) reflect a strengths-based perspective and draw attention to the connections between community members, and community members' relationships with the non-human world. The IHIs contribute to the development of an improved, more comprehensive Indigenous health assessment framework, whose measures can be modified to fit the health practices, beliefs, and values of AI/AN communities—ultimately helping to increase Indigenous control over research and evaluation projects, and contributing to more impactful outcomes for AI/AN communities.

Relevant resources:

Donatuto, J., Campbell, L., & Gregory, R. (2016). Developing responsive indicators of indigenous community health. International journal of environmental research and public health, 13(9), 899.

Poster about clams as a traditional food from the Swinomish Community Environmental Health Program

Source: Myk Heidt

Native women reconnecting to body, health, and place

This research project applied principles of wilderness experience programming and traditional AI/AN knowledge in a novel intervention designed to address health disparities in a tribal community. It is a wonderful example that centers community knowledge, connection to the land, and ancestral experiences through an innovative and culturally-grounded model for health promotion. Drawing upon historical trauma frameworks, tribal members re-walked the Trail of Tears to consider its effect on contemporary tribal health. Qualitative data from tribal members suggest that engagement with place and experiential learning, particularly the physical and emotional challenge of the Trail, facilitated changes in health beliefs, attitudes, and behaviors. Tribal health leaders and university researchers partnered together to create this community-based participatory research (CBPR) project. All five authors of the article are AI/AN (4 are enrolled members of the tribal community in which the project was done) and were involved in the design of the project. They also walked the trail with other participants.

Relevant resources:

Schultz, K., Walters, K.L., Beltran, R., Stroud, S., & Johnson-Jennings, M. (2016). “I’m stronger than I thought”: Native women reconnecting to body, health, and place. Health & Place, 40, 21–28.

Source: UIHI TONL Photos

Using traditional knowledge to improve therapy for historical trauma

This research centered the community knowledge through documenting therapeutic approaches to historical trauma used by clients and staff in a Native American healing lodge. Researchers identified these therapeutic approaches through interviewing members of this community to identify the strategies community members found most effective at healing historical trauma. Their conclusions provide suggestions for psychologists to better implement culturally sensitive treatment programs that can directly improve the health and wellbeing of Native American communities. This research shows how research can center and honor community knowledge. Additionally, this example shows applicable, practice-based research that is done to increase health and wellness in AI/AN communities.

Relevant citations:

Gone, J. P. (2009). A community-based treatment for Native American historical trauma: Prospects for evidence-based practice. Journal of Consulting and Clinical Psychology, 77(4), 751–762. https://doi.org/10.1037/a0015390

Partnering with tribal leaders to address Vitamin D deficiency

Tribal leadership in Alaska approached researchers with a concern about the incidence of neonatal rickets in their community. Neonatal rickets happens when there is a decrease in calcium and phosphorus in bones that can be caused by insufficient levels of vitamin D. Results from the study found insufficient levels of vitamin D in the population. These findings prompted the community to encourage pregnant women and the mother of newborns to supplement their diets with vitamin D. They also did this through promoting traditional foods rich in vitamin D such as fatty fish. These findings also led to additional research to identify other factors contributing to vitamin D deficiency. The community reviewed study designs, participated in biannual meetings, and approved both presentations and publications resulting from the study. This research exemplifies giving power to community members by designing a study where the community has an active role in decision making about the direction of the research from the very beginning.

Relevant citations:

Singleton, R., Lescher, R., Gessner, B. D., Benson, M., Bulkow, L., Rosenfeld, J., ... & Tiesinga, J. (2015). Rickets and vitamin D deficiency in Alaska native children. Journal of Pediatric Endocrinology and Metabolism, 28(7–8), 815–823.

Fohner, A. E., Robinson, R., Yracheta, J., Dillard, D. A., Schilling, B., Khan, B., ... & Thummel, K. E. (2015). Variation in genes controlling warfarin disposition and response in American Indian and Alaska Native people: CYP2C9, VKORC1, CYP4F2, CYP4F11, GGCX. Pharmacogenetics and genomics, 25(7), 343.

Letting communities lead for Diabetes Prevention Program

Another successful research project with AI/ANs that directly benefitted the community is the Diabetes Prevention Program, otherwise known as DPP. DPP is a randomized control trial that aimed to decrease type 2 diabetes and researchers and AI/AN communities worked together to adapt it to an AI/AN audience. Results of the study showed that DPP decreased type 2 diabetes incidence by 58% through lifestyle intervention. This program engaged several tribes and at least one Urban Indian organization in the study. The DPP included consultation with tribal and Urban Indian community leaders and governing boards. The research team hired AI/AN community members to serve as research assistants on the team. It resulted in the DPP being successfully adapted to AI/AN community to deliver an effective intervention for a health issue that was important to both the community and researchers.

Relevant citations:

Diabetes Prevention Program (DPP) Research Group. (2002). The Diabetes Prevention Program (DPP): description of lifestyle intervention. Diabetes care, 25(12), 2165–2171.

Preventing youth suicide in partnership with AI/AN communities

In 2016 researchers published a paper about a study they conducted with a Midwestern Urban Indian Health Programs to identify resources, challenges, and cultural aspects affecting AI/AN youth suicide prevention. Researchers attended advisory council meetings where AI/AN community members provided project guidance and oversight. Council members participated in funding discussions and assessed which survey questions and measures to include on the questionnaire used in the study to identify resources and support for AI/AN youth suicide prevention. The Urban Indian Health Program director approved the study along with the university partner's IRB. This study offers an example for how to develop a broad Urban Indian community–based research in a respectful way that centers community voices throughout the entire process.

Relevant citations:

Burrage, R. L., Gone, J. P., & Momper, S. L. (2016). Urban American Indian community perspectives on resources and challenges for youth suicide prevention. American journal of community psychology, 58(1–2), 136–149.

Let us move forward in a good way!

We encourage you to keep these lessons in mind and think about how they can apply to your current or future work. This is only a small excerpt of examples and there is much more to learn through your own research and in partnership with the communities you work with. We hope this document serves as a starting point to continue your journey in learning how to do research with Indigenous communities in a good way.

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