

Building on a Solid Foundation: Success Stories – Community Engagement & Evaluation

**Community engagement in research
and dissemination**



Objectives



Community engagement in research and dissemination that will:

- Discuss **strategies to engage** Native American communities in cancer research, screening, and prevention;
- Provide **guidance** about how to navigate tribal approval and cultural humility in research; and
- Discuss **experiences and best practices** regarding challenges and how they were addressed.

Givens



American Indians and Alaska Natives (AI/AN) are sovereign.

5.2M people identify as American Indian or Alaska Native, 1.7% of U.S. population

Median age is 29 years old, 38 for U.S.

Lower life expectancy and more years of potential life lost

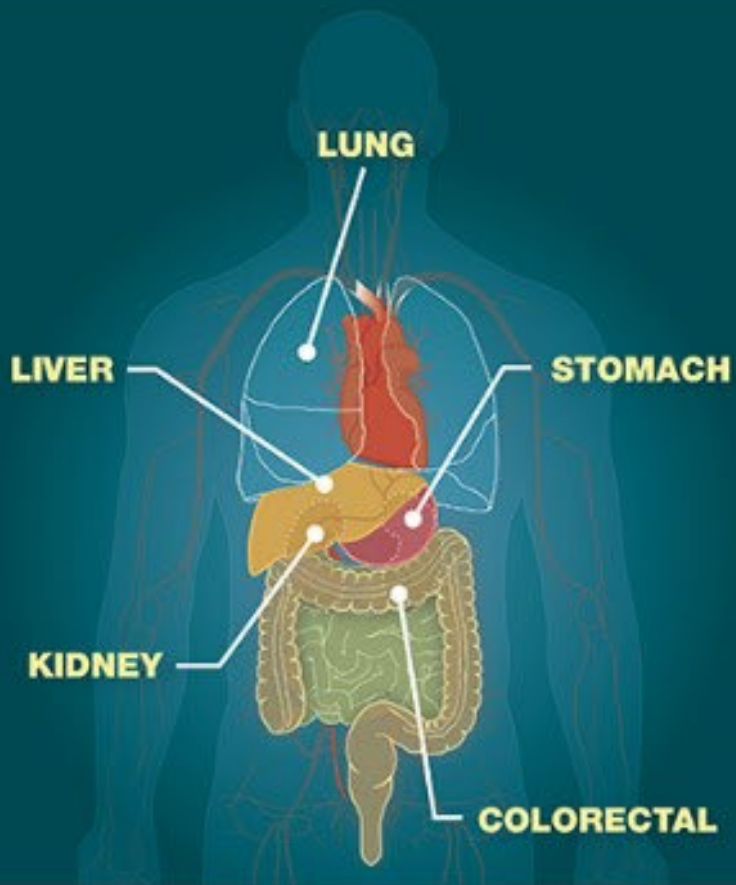
Cancer is the second leading cause of death

AI/AN tend to be diagnosed at younger ages and at later stages of cancer, with lower 5-year survival rates



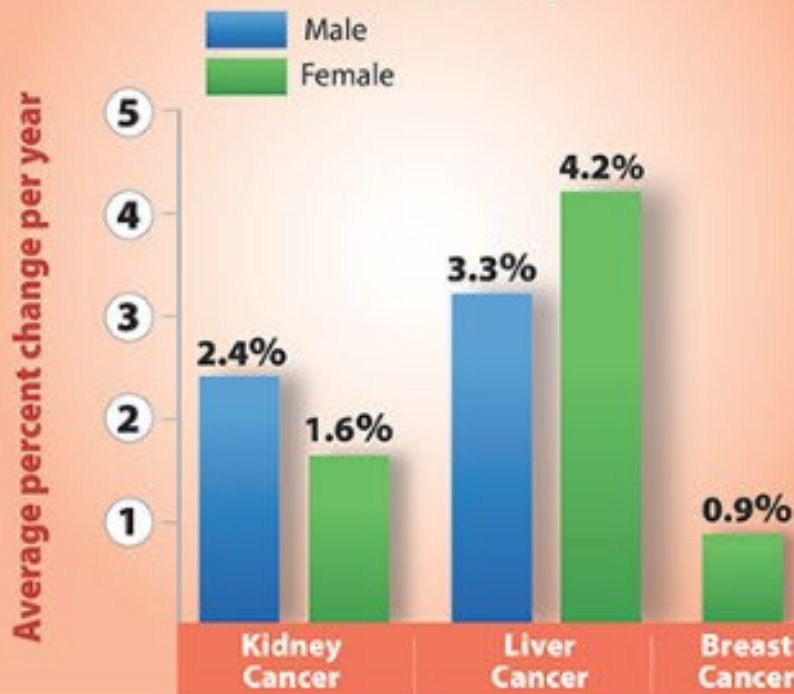
Cancer Disparities in the American Indian and Alaska Native and Alaska Native Populations

CANCERS WITH HIGHER INCIDENCE RATES COMPARED TO NON-HISPANIC WHITES



AMERICAN INDIAN AND ALASKA NATIVE CANCER INCIDENCE TRENDS

Data from 1999 to 2015 showed significant increases in the following



STEPS TO LOWER CANCER INCIDENCE RATES



PROVIDE CULTURALLY APPROPRIATE, COMMUNITY-BASED INTERVENTIONS TO SUPPORT HEALTHY BEHAVIORS



DECREASE EXPOSURE TO CANCER RISK FACTORS, SUCH AS COMMERCIAL TOBACCO AND ALCOHOL



INCREASE ACCESS TO PREVENTIVE HEALTH SERVICES (VACCINES, CANCER SCREENING)

Social Determinants of Health and Institutionalized Racism important contributors.





**Build and
Sustain Trust**

**Equal and
Respectful
Partnership**

**Harms &
Benefits from
Tribal
Perspective**

**To engage Native American
communities in cancer research,
screening, and prevention, understand
them**



Guidance

How to navigate tribal approval and cultural humility in research

- Community-based focus, priority
- Tribal ownership and control
- Transparency and ongoing frequent communications
- Capacity building and sustainability
- Community experiences and expectations



How to Conduct Research in American Indian and Alaska Native Communities

The Partnership for Native American Cancer Prevention, USA4CA143924
Hopli NARCH, 505GM128012

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Contents	This document is a guide for researchers on:
Sovereignty & Government 1	• Tribal Sovereignty;
Cancer Health Disparities 2	• American Indian/Alaska Native Cancer Health Disparities;
Sensitivity & Responsibility 2	• Researcher Sensitivity and Responsibility;
Tribal Research Checklist 3	• Research Checklist; and
Resources 4	• Additional Resources.
References 4	• Respectful research is the first step to maximize benefits of research.

Tribal Sovereignty

There are a total of 573 federally recognized American Indian and Alaska Native (AI/AN) tribes in the United States (US), 22 of them in Arizona. Each one of the federally recognized tribes are Sovereign nations. Hundreds of treaties, executive orders, and laws have been signed to promote federal "trust responsibility" between AI/AN tribes and the US government. This means that tribes have the authority to govern themselves within the borders of the US.

With sovereignty comes the establishment of tribal governments. Each tribal government has the power to determine their own governance structures, and to pass and enforce laws. These governments are essential, because they have the ability to protect each tribe's cultures and traditions. When undertaking research in partnership with an AI/AN community, a researcher should identify whether the target population is located within reservation boundaries and what laws govern research activities.

Research with AI/AN is not the same as working with other underserved, minority or rural populations. It is imperative that researchers follow appropriate reviews and approvals before engaging in research activities.

In this guide, we offer a brief outline of basic items needed to conduct respectful and transparent research in AI/AN communities and list resources for additional detail (pg. 4). This guide is part of a series that the University of Arizona NACP Outreach has created. The other guides in this series are focused on:

- How to Build and Sustain a Tribal RCT, Volume I
- How to Review Research to Benefit Tribal Communities, Volume II
- Guidelines for Researchers, Volume IV

These resources are intended to provide useful and pertinent information to tribes and researchers so that outcomes can benefit tribal members and tribal communities. These guidelines are written specifically for research that would involve people, usually called human subjects. Most of the procedures and policies contained within these guides are based on current federal regulations, called *Code of Federal Regulations* (CFR), 45 CFR 46, for *human subjects protection*.

Suggested Citation: Guichard EC, Meltzer L. How to Conduct Research in American Indian and Alaska Native Communities. WHOI, Tucson, Arizona: University of Arizona, Department of Family and Community Medicine, College of Medicine, February 2019.



Experiences



Individual Tribes



Joint Tribes



Tribal Consortia



Urban Organizations



Descendants

Bryan Newland, a citizen of the Bay Mills Indian Community (Ojibwe) in Michigan, is the Assistant Secretary - Indian Affairs

Best Practices regarding Challenges, How Addressed

No	Conditions	Different Priorities	Training	Capacity Building
Tribes have the right to say no	No Tribal identification No publications No private or sacred information disclosed No secondary uses	Biospecimen use Genetic testing Clinical trials	Primary data collection Data entry and analysis Dissemination and interpretation	Involving trainees Beyond the research

Clinical Trial Issues and Considerations

- Multiple Systems of Care
 - Indian Health Service
 - Tribally-run Health Care
 - Urban Health Care
 - Salish, Tuba City Cancer Centers
 - Referred Care
 - Continuity of care
 - Communications between services
 - Financial coverage
 - Access: distance, scheduling, safety
- Trial Requirements
 - Double-blind
 - Research vs Treatment
- Informed Consent
 - Long, technical documents
 - Lack of advocate
- Biospecimen Use
 - Storage
 - Secondary Uses
 - Destruction
- Burden of Trial Requirements
- Privacy
 - Holistic Approaches
 - Traditional Healing
 - Traditional Medicines

Clinical Trial Issues and Considerations

- Personalized Care
 - Oncologist availability
 - Lay person advocate
 - Beyond Treatment
- Trial Demystification
 - Community-based engagement
 - Ongoing
- Empowering patients beyond CT scope; not just about the research
- Access to chemotherapy medications, not contingent on trial
- More cancer centers regionally
 - Partnerships with IHS, Tribes/Urban
- Investigators and funders invest in trust and care
 - Collaborative partnerships
 - Patient benefit
- Biospecimens in Tribally-owned banks
 - Native BioData Consortium
- Training in clinical trial research
 - Providers
 - Review committees
 - Potential participants and their families
 - Advocates
- Secondary use approval

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