

Engaging Communities in PACHE Research and Dissemination

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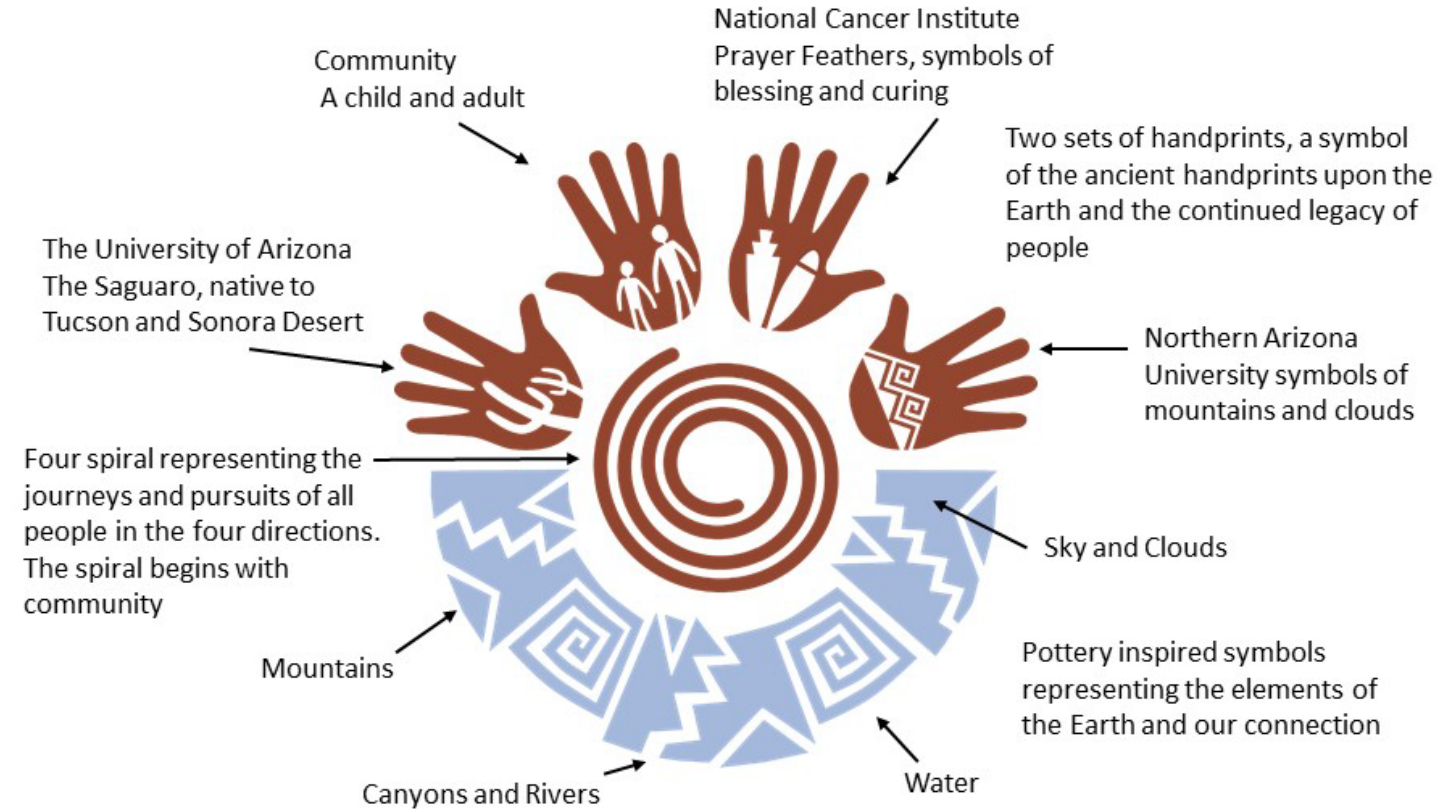


Objectives of Presentation: Supporting Partnership Science

- Current approaches
- Challenges/pitfalls, outcomes
- Future directions/opportunities

The Partnership for Native American Cancer Prevention

Logo Interpretation



Guidelines for Researcher

- Publications developed to assist researchers with working with American Indian/Alaska Native Tribes
 - A Guide to Establishing Effective Mutually-Beneficial Research Partnerships with American Indian Tribes, Families, and Individuals
 - How to Build and Sustain a Tribal IRB
 - Resources found at: <https://in.nau.edu/nacp/nacp-outreach-publications-library/>

Community's Rights

- right to decline participation,
- self-assessment of harms and benefits,
- recognition of community-level harms and benefits,
- (dis)trust of research,
- experience(s) with stereotyping, discrimination or stigmatization,
- preference for ownership of data,
- request for ways to protect participant and tribal privacy, including how identification occurs in presentations or publications,
- preference for how to handle dissemination and implementation,
- preference for how to handle incidental findings,
- requirement to return results in a timely manner, and
- requirement for transparency, especially related to secondary uses of data.

Conducting Research in American Indian/Alaska Native Communities

- Be transparent.
- Get to know the tribal communities and establish relationships.
- Attend meetings and gatherings as a means to develop an appreciation for the history and culture of the tribe and to get to know people in a non-work setting.
- Demonstrate respect for the community and its indigenous expertise through a Memorandum of Understanding.
- Hire members of the community to serve as consultants on various aspects of the research, such as development of research questions, data collection, interpretation and dissemination.
- Recognize and accommodate a tribe's schedule for tribal ceremonies, rituals and annual gatherings.
- Appreciate the community's strengths, assets, and challenges.
- Engage the community in the partnership with respect to tribal culture, language, and values.

Conducting Research in American Indian/Alaska Native Communities

- Discuss data sources, measures, and collection of information with the tribe.
- Discuss intellectual and cultural property rights of the information including tribal data ownership.
- Keep the community fully informed as the study progress through local presentations, newsletters and radio, recognize contributions of community members.
- Discuss study findings with tribal leadership before external dissemination activities.
- Have tribal leaders and key community members review all abstracts, reports, and manuscript drafts.
- Jointly determine how study results will be presented to the community and public, including scientific audiences.

Conducting Research in American Indian/Alaska Native Communities

- Consider sharing the results of the study in a public open community forum.
- Acknowledge and give credit to the community for the scientific results from the study.
- As applicable, consider including key community members as co-authors who participate in writing reports and publications.
- Discuss with the tribal community how they want to be recognized in publications and reports.
- Assist the tribal community in the application or next steps of the research.
- Discuss with the tribe the storage and/or destruction of data, especially place, duration, and access and responsibility for the project materials and data.

Current NACP Outreach Core Approaches

- Elevation of the Community Action Committee to the Community Advisory Board (CAB) providing guidance and oversight at the same level as the Internal Advisory Committee and the Program Steering Committee
- Monthly meetings with the CAB to provide updates and opportunity for dialogue
- Involve the CAB in the call for proposal to provide potential researchers with community cancer concerns
- Monthly newsletter – NACP Insights

Current NACP Research Approaches

- *Helicobacter pylori* and Stomach Cancer Among Native American in Northern Arizona
 - Study conceived through discussions with medical staff from Winslow Indian Health Care Center
 - Engagement of community participants to both understand and increase awareness of current perceptions and risk factors for stomach cancer/*H. pylori* within Navajo Nation communities
 - Navajo patients undergoing endoscopy for symptoms of gastric disease recruited to provide bio-specimens
 - Study reviewed and approved through the Navajo Nation Human Research Review Board

Current NACP Research Approaches

- Improving Shared Decision-Making about Cancer Screening among American Indian (AI) Women Experiencing Intellectual and/or Developmental Disabilities (IDD)
 - Community-based participatory approach, partner with AI women with IDD, their family caregivers, their health care providers, and leaders to culturally adapt an existing breast and cervical cancer education program, Women Be Healthy 2, for American Indian women with IDD
 - Community partners – Hopi Cancer Support Services and the Tucson Indian Center
 - Tribal council approvals and resolutions of support to obtain Institutional Review Board approval

Current NACP Research Approaches

- Viewing Native American Cervical Cancer Disparities through the Lens of the Vaginal Microbiome
 - Developed partnership with the Native Community Action (NACA) clinic in Flagstaff
 - Worked with NACA and Outreach Core on developing and implementing culturally sensitive vaginal sample collection protocols
 - A questionnaire administered to the participants enabling assessment of associations between the vaginal microbiota and human papillomavirus with sociodemographic factors, sexual history, knowledge of safe sex practices and health behaviors

Challenges/Pitfalls & Outcomes

- Challenge - COVID-19 Pandemic
 - Non-COVID related clinic visits came to a halt
 - Community meetings and field work put on hold
 - ✓ Response - *H.pylori* project submitted and funded on a supplement to investigate COVID-19 Impact on Navajo Adults and Healthcare Workers
 - ✓ Response – podcast, videos, and virtual meetings
- Challenge
 - Changes in personnel with community partners
 - ✓ Response – importance of training materials and patience

Future Directions/Opportunities

- Development of Podcasts and Wellness Videos with Community Partners
- Increase outreach and engagement with additional Arizona Tribal communities and agencies to ensure AI cancer-related priorities are being addressed
- Delivery of a Dissemination workshop to expand research teams' strategies for sharing outcome to non scientific audiences
- Engage NACP researchers, beyond NACP funding, to collaborate on future cancer projects and initiatives focused on Native American cancer health disparities

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- Tribal Partners – Navajo Nation, Hopi Tribe, Tohono O'odham Nation, San Carlos Apache Tribe
- Community Partners – Native American for Community Action, North Country HealthCare, Tucson Indian Center, Tuba City Regional Health Care Center, Winslow Indian Health Care Center



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