



Published in final edited form as:

Am J Drug Alcohol Abuse. 2011 September ; 37(5): 333–338. doi:10.3109/00952990.2011.596976.

Research Partnerships between Academic Institutions and American Indian and Alaska Native Tribes and Organizations: Effective Strategies and Lessons Learned in a Multi-Site CTN Study

Lisa Rey Thomas, PhD, Carmen Rosa, MS, Alyssa Forcehimes, PhD, and Dennis M. Donovan, Ph.D.

In honor of Duane Mackey (Santee Sioux Nation)

Abstract

Community Based and Tribally Based Participatory Research (CBPR/TPR) are approaches that can be successful for developing ethical and effective research partnerships between academic institutions and Tribes and Native organizations. The NIDA Clinical Trials Network funded a multi-site, exploratory study using CBPR/TPR to begin to better understand substance abuse issues of concern to some Tribes and Native organizations as well as strengths and resources that exist in these communities to address these concerns. Each of the five sites is briefly described and a summary of the common themes for developing these collaborative research efforts is provided.

Keywords

American Indian and Alaska Native; CBPR/TPR; substance abuse; strengths based research

BACKGROUND

Community-based participatory research (CBPR), “a partnership approach to research that equitably involves... community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision making and ownership” [1], is an increasingly acceptable approach to American Indian and Alaska Native (AIAN) communities for establishing research partnerships. Although CBPR exists on a continuum, most partnerships are built on the fundamental principles outlined by Israel and colleagues; they: 1) recognize community as a unit of identity, 2) build on strengths and resources of the community, 3) facilitate collaborative partnerships in all phases of the research, 4) integrate knowledge and action for the mutual

Correspondence to: Lisa R. Thomas, Alcohol & Drug Abuse Institute, 1107 NE 45th Street, Suite 120, Seattle, WA 98105-4631, lrthomas@u.washington.edu..

Declaration of interest: This research was funded by the National Institutes of Health’s National Institute on Drug Abuse and National Center on Minority Health and Health Disparities.

Contributors in alphabetical order:

California/Arizona Carmen Masson Ethan Nebelkopf Michael Shopshire James Sorensen

Ohio Valley Frankie Kropp Maurine (Orwa) Lilleskov Duane Mackey (Santee Sioux Nation) Eugene Somoza

Oregon/Hawaii Joe Bray (Choctaw) William Lambert Dennis McCarty Traci Rieckmann Paul Spicer Birdie Wermly (Cheyenne-Arapaho)

Pacific Northwest Dennis Donovan Sandra Radin Lisa Rey Thomas (Tlingit)

Southwest Michael P. Bogenschutz Meredith Davis Ray Daw (Dine’ - Navajo) Kevin Foley (Rappahannock) Alyssa A. Forcehimes Kamilla Venner (Athabaskan) Eric Willie (Navajo - Tódích’íí’níí & Tábaahí) Navajo Nation Human Research Review Board

National Institute on Drug Abuse Carmen Rosa Harold Perl

benefit of all partners, 5) promote a co-learning and empowering process that attends to social inequalities, 6) involve a cyclical and iterative process, 7) address health from both positive and ecological perspectives, and 8) disseminate findings and knowledge gained to all partners [2]. Tribal Participatory Research (TPR) approaches are viewed as particularly ethical and respectful of research partnerships with sovereign Tribal nations [3, 4]. Such partnerships allow research to be responsive to community needs, culturally appropriate, and strengths-based while being mindful of the unbalanced and often harmful research previously conducted in AIAN communities as well as the unique status of federally recognized Tribes as sovereign entities. [5, 6, 7]. Although it is beyond the scope of this paper to address the appropriateness of CBPR approaches for non-AIAN communities, see LaVeaux and Christopher [8] for a more thorough discussion of how CBPR principles can be contextualized and effectively applied with AIAN communities.

NIDA's National Drug Abuse Treatment Clinical Trials Network (CTN) funded five exploratory/developmental projects ("Methamphetamine and Other Drugs in AIAN Communities – MOD") in order to develop mutually beneficial collaborative research partnerships with AIAN communities. The overall goal of these partnerships was to begin to better understand issues regarding substance use/abuse and community driven initiatives that appear successful in preventing substance abuse and supporting recovery [9, 10].

OBJECTIVES

This paper briefly describes the *process* followed by each of the five sites or "Nodes" as they developed their research partnerships with AIAN communities and presents lessons learned and recommendations for others interested in ethical research with AIAN communities. There is a lack of current, accurate documentation regarding methamphetamine and other drugs or community-based, culturally grounded prevention and treatment strategies and programs that are working in Native communities. It is hoped that these research partnerships and their findings will lead to future rigorous, community-based, and culturally appropriate epidemiological and clinical research. Not all studies have been completed nor do we have Tribal permission to report data; therefore the current paper will not present data from any of the Tribal communities. It is possible that site-specific data will be presented in future manuscripts.

METHODS

The five CTN Nodes that participated in the MOD project are: California/Arizona, Ohio Valley, Oregon/Hawaii, Pacific Northwest, and Southwest. Each of these nodes partnered with AIAN communities and/or organizations in its region, including Tribes (reservation and urban), treatment agencies, health consortiums, and/or urban health centers. In most cases the academic researchers initiated contact with potential research partners and in many cases the presence of pre-existing relationships with community members facilitated the willingness of Tribes and Tribal organizations to participate. Academic and community research partners from the five Nodes met monthly via teleconference as the study was developed. Initially we had planned to develop or adapt standardized protocols across all sites; however, it became clear that this would not be possible. There are more than 560 federally recognized Tribes in the U.S. and although there are some similarities between Tribes, there exist more differences with regards to health disparities, access to resources, geography, culture, tradition, exposure to post-colonial trauma, and issues related to substance abuse and sobriety. Due to the uniqueness and variability of the Tribal partners, "one size does not fit all"; therefore, the sites developed protocols appropriate for and in conjunction with their partnerships in order to be respectful of these differences and maintain scientific rigor. Steps common to each site are described below followed by brief

descriptions of each site and their partners as well as any unique characteristics of the research partnership and/or process.

Common Steps

Tribal Council and/or other Tribal leadership approval, including Memoranda of Understandings and Data Sharing and Ownership Agreements were negotiated at all sites. These documented the roles, privileges, responsibilities of the research partners and guidelines for all aspects of the data including data ownership and use. Developing understanding, trust, and support for the MOD projects was an ongoing process given changes in Tribal Council memberships and clinical and program staff over time. Community Advisory Boards (CABs) comprised of key stakeholders were identified and convened to guide the MOD projects in many of the partnering communities. Both qualitative and quantitative methods were deemed important, particularly at this early stage of the research. The Community Advisory Boards provided meaningful input into the development and implementation of the research protocols. The degree of participation of the Community Advisory Boards varied due to community time and resources, readiness and capacity of the community with regard to research, and ability of the academic researcher to spend significant time in the communities,

University and, as appropriate, Tribal and/or Indian Health Service Institutional Review Board approvals were obtained. Some AIAN communities and agencies obtained their own Federalwide Assurances in order to regulate research activities by delegating IRB authority as deemed appropriate by them. A Certificate of Confidentiality was obtained in order to further protect research participants and communities

A set of principles, found in Table 1, was crafted and followed to insure that our research partnerships were ethical and respectful of the unique status of our AIAN partners as sovereign entities.

All sites conducted focus groups; additional data collection included key stakeholder interviews, telephone surveys, Addiction Severity Index (ASI) information, and/or client record reviews. The next sections provide brief descriptions of each Node and its research partners; we obtained permission to mention specific Tribes, communities, or agencies below.

California-Arizona Node

The California-Arizona CTN Node worked with an American Indian tribe in Arizona and an urban AIAN urban treatment program in the San Francisco Bay Area. When initially approached about conducting research, neither the Tribe in Arizona nor the urban AIAN treatment program was willing to conduct research due to skepticism and past research missteps. Therefore, initial efforts focused on building and strengthening working relationships resulting in relationships with key contact persons with both partners rather than the collection of data. This careful attention to being responsive to the needs and readiness of the research partner was critical and as a result a conference was organized on historical trauma. The conference brought together both American Indian researchers and clinicians. The conference was held in San Francisco on July 1, 2008 and titled "Historical Trauma: Healing Approaches in Native American Communities." The steps taken by the CA/AZ Node and their partners has laid the groundwork for potential research partnerships in the future.

Ohio Valley Node

The Ohio Valley Node (OVN) worked with Northern Plains American Indians since 2007 to explore the possibilities of collaborating in clinical research. During this period, staff from the OVN Regional Research and Training Center (RRTC) developed close relationships with the Aberdeen Area Indian Health Service Department of Behavioral Health, with members of the Aberdeen Area Tribal Chairmen's Health Board (AATCHB), with the South Dakota Division of Alcohol and Drug Abuse Agency, and with health centers serving Native American populations in urban areas. Approximately 104,000 AIANs living in rural areas of the Indian Health Service Aberdeen Area in North and South Dakota, Nebraska, and Iowa are faced with daily struggles of poverty, limited access to health care, and minimal educational and employment opportunities. The role that alcohol and drug abuse plays in the health disparities, including suicide, among AIANs in the Aberdeen Area is well-documented [11,12, 13]. Focus groups were conducted and ASI and client intake data were gathered from AIAN clients at the partnered sites.

Many complexities must be addressed when preparing for research in the Aberdeen Area. Regulatory issues with the Tribes require extra time to pass through the multiple layers of authority. Study efforts may be impaired by the region's extreme winter weather. Other factors such as the geographic remoteness of the reservations and seasonal cultural activities must also be taken into consideration when planning for study approval and implementation.

Oregon- Hawaii Node

The Oregon-Hawaii Node partnered with the Northwest Portland Area Indian Health Board (NPAIHB) to assess drug use patterns among AIs seeking addiction treatment. The partnership included two large reservations, one in Oregon and one in Washington State, university investigators, NPAIHB staff, and clinicians and administrators at an urban health center. Mixed method data included Addiction Severity Index interviews and focus groups assessing drug use, treatment services, and the health, legal, financial, and social impacts of alcohol and drug use.

Pacific Northwest Node

The Pacific Northwest Node initiated and developed partnerships with four Tribal communities in Washington State and with a Native health organization in Alaska; these communities ranged from relatively urban to remote or isolated. Communities chose semi-structured, qualitative individual interviews and focus groups with community members and key stakeholders to gather information about the prevalence of substance use/abuse; impact or consequences; existing and desired prevention and treatment efforts; existing and desired role of culture in prevention and treatment; and community strengths and resources.

Southwest Node

The SW Node developed collaborations with AIAN Southwestern tribal entities and treatment programs, in and around New Mexico, in order to explore the epidemiology of methamphetamine use and co-occurring problems. The SW Node conducted focus groups, telephone surveys with treatment providers, and reviewed client Addiction Severity Index files. While the distance between University of New Mexico and sites and the lengthy travel time required to attend meetings was not necessarily unique, the community partners required regular attendance in person rather than interacting primarily by phone or email and generally required that most of the academic team attend the meetings. Another unique component to the Southwest Node was the presence of the Navajo Nation Health Research Review Board which provides strict and ongoing authority over all research conducted in this area with AIAN communities.

RESULTS

As described earlier, the purpose of this paper is not to report data but rather to share the common themes in the process of developing and maintaining respectful, ethical, and effective research partnerships between American Indian/Alaska Native Tribes and organizations and academic researchers. The following points are important considerations for research in collaboration with Tribes and AIAN organizations.

(1) It is critical that the focus of the research be driven by the community. (2) The uniqueness of each AIAN community/organization may require similar but distinct research protocols. (3) Researchers historically have focused on substance use problems, tending to pathologize both AI individuals and communities. Our Native research partners indicated that they want the strengths and resources that exist in their communities identified and documented and to collaborate on research regarding cultural practices that are effective in prevention and treatment. (4) The processes for developing collaborative, trusting research partnerships with sovereign Tribal Nations and subsequently obtaining approval for specific research activities are very complex and often require a great deal of time and negotiations. (5) “One size does not fit all”; each Tribal community or AIAN agency may have a unique process for if and how research is to be conducted. It is the researcher’s responsibility to learn, understand, and follow Tribal processes as well as those required of their own academic institutions. (6) Similarly, each Tribal community or organization may have multiple levels of Institutional Review Board approvals needed; coordinating among multiple IRBs can often take many months with some only meeting monthly due to weather conditions, cultural and spiritual times in the communities, or standard practice. (7) It is critical to negotiate Memoranda of Understanding and Data Sharing and Ownership agreements early in the process to document specific roles and responsibilities as well as attend to data use and ownership. (8) Many AIAN communities are in geographically diverse, isolated, and remote locations, resulting in travel challenges. Developing and implementing research protocols can be greatly affected by weather and other conditions “out of our control,” e.g. power outages, road closures, etc. Such logistical issues make community-based research in the field considerably more challenging and time consuming than other types of more conventional research. (9) Many AIAN communities are small and under-resourced, resulting in some community members operating in a number of roles in the community including service provider, Tribal leader, cultural leader, member of an extended family, etc. Academic researchers must be aware of these multiple roles and the impact that participating as a research partner may have for the community partner as well as the impact on the scientific integrity. (10) While AIAN communities are grateful for those non-Native investigators who are allies and trusted partners, many still state that they are most comfortable and trust is often more easily established when AIAN investigators are part of or leading the research teams. (11) Spiritual ceremonies and subsistence activities must be considered in the research processes. Therefore, data collection may not be possible during these ceremonial times. Nevertheless, these times offer important opportunities for cultural training for researchers as well as relationship building. (12) Academically based research teams often require training and time to acquire new skills needed to successfully implement these approaches.

CONCLUSIONS

All of the teams working on these projects are honored to have the privilege and opportunity to work collaboratively with AIAN research partners. We are committed to this work and see these projects as developmental and an essential foundation for a long-term process that requires a great deal of time and effort in order to develop trust, understanding, knowledge, and true partnerships that will guide research that is rigorous as well as ethical, effective,

and culturally appropriate. Critical to the success of these partnerships is the willingness of the academic researchers to *go to* the communities, *spend time* in the communities, be *present* in the communities, and *listen*. While the timeline varied greatly for each site and for each partnership, it was very apparent that to engage ethically and effectively in research partnerships between academic institutions and AIAN Tribe, communities, and organizations can take considerably longer than lab-based or conventionally designed research. In most cases it took a minimum of one year to negotiate data sharing agreements, convene Community Advisory Boards, obtain IRB approvals, and proceed with implementation of the protocols; some took considerably longer.

In order to move forward with these types of research partnerships, it is recommended that proposed studies acknowledge the need for these critical timelines and that researchers incorporate them into the research plans and proposals and that funders recognize and accept the need for them.

While the writing of this manuscript was done by the academic partners, the community partners participated in the more general process report [14] and are included in the contributors list.

SCIENTIFIC SIGNIFICANCE

American Indian/Alaska Native research partners frequently refer to research with AIAN communities as “helicopter research”; outside researchers come in with pre-determined research questions and protocols, collect data, and leave the community without ever reporting back any results – “never to be heard from again”. Tribal communities believe that such research rarely results in any benefit to them and, in fact, often results in harm to the community. The history of these abusive research practices has led to reluctance, and sometimes outright refusal, on the part of AIAN communities to agree to participate in research protocols. However, as AIAN communities become increasingly sophisticated partners in, and consumers of, research, CBPR and TPR are emerging as effective, ethical, culturally appropriate, and acceptable approaches. This can serve to improve the science we engage in with AIAN communities, add to the scarce literature regarding AIAN communities, and better serve AIAN communities in addressing health disparities and improving health.

Finally, we are grateful to NIDA for understanding the importance of this long term commitment and we are especially grateful to the American Indian/Alaska Native communities for welcoming us and allowing us to partner with them.

Acknowledgments

The authors also acknowledge the generous and crucial contributions of the participating communities and organizations. Please see last page for a full list of contributors.

REFERENCES

1. Israel, BA.; Eng, E.; Schulz, AJ.; Parker, EA., editors. *Methods in Community-Based Participatory Research for Health*. First ed. Jossey-Bass; San Francisco: 2005.
2. Israel BA, et al. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*. 1998; 19:173–202.
3. Fisher PA, Ball TJ. Tribal participatory research: Mechanisms of a collaborative model. *American Journal of Community Psychology*. 2003; 32(3-4):207–216. [PubMed: 14703257]

4. Thomas LR, Donovan DM, Sigo RLW. Identifying community needs and resources in a Native community: A research partnership in the Pacific Northwest. *International Journal of Mental Health and Addiction*. 2010; 8(2):362–373.
5. Caldwell JY, Davis JD, et al. Culturally competent research with American Indians and Alaska Natives: Findings and recommendations of the first symposium of the work group on American Indian research and program evaluation methodology. *American Indian and Alaska Native Mental Health Research*. 2005; 12(1):1–21. [PubMed: 17602391]
6. Jacklin K, Kinoshameg P. Developing a participatory aboriginal health research project: “Only if it’s going to mean something”. *Journal of Empirical Research on Human Research Ethics*. 2008; 3(2):53–67. [PubMed: 19385745]
7. Holkup PA, Tripp-Reimer T, Salois, Weinert. Community-based participatory research: an approach to intervention research with a Native American community. *ANS: Advances in Nursing Science*. 2004; 27(3):162–75. [PubMed: 15455579]
8. LaVeaux D, Christopher S. Contextualizing CBPR: Key principles of CBPR meet the Indigenous research context. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*. 2009; 7(1):1–26.
9. Allen J, Mohatt GV, Rasmus SM, Hazel KL, Thomas LR, Lindley S. The Tools to Understand: Community as Co-Researcher on Culture-Specific Protective Factors for Alaska Natives. *Journal of Prevention & Intervention in the Community*. 2006; 32(1-2):41–59. [PubMed: 17000601]
10. Ball J, Janyst P. Enacting research ethics in partnerships with indigenous communities in Canada: “Do it in a good way”. *Journal of Empirical Research on Human Research Ethics*. 2008; 3(2):33–51. [PubMed: 19385744]
11. LeMaster PL, Beals J, Novins DK, Manson SM. The prevalence of suicidal behaviors among Northern Plains American Indians. *Suicide and Life Threatening Behavior*. 2004; 34(3):242–254. [PubMed: 15385179]
12. Olson LM, Wahab S. American Indians and suicide: A neglected area of research. *Trauma, Violence & Abuse*. 2006; 7(1):19–33.
13. Shore JH, Beals J, Orton H, Buchwald D. Comorbidity of alcohol abuse and dependence with medical conditions in 2 American Indian reservation communities. *Alcoholism: Clinical and Experimental Research*. 2006; 30(4):649–655.
14. National Institute on Drug Abuse. [Retrieved March 6, 2011] Methamphetamine and other drugs (MOD) in American Indian and Alaska Native Communities (CTN-0033*): Preliminary report on the process of MOD research partnerships between community and institutionally based researchers. 2010. from <http://www.ctndisseminationlibrary.org/display/440.htm>

Table 1**The Methamphetamine and Other Drug Research Group Ethical Principles**

Each of the participating nodes and partnering communities from the NIDA Clinical Trials Network will ask at least one community stakeholder to join the project conference calls and local discussions with those implementing the MOD project. Embracing Community-Based Participatory Research and Tribal Participatory approaches, the team working on this project is committed to community-based decisions and solutions that reflect each tribe's ability to identify and address its community concerns. Thus, the stakeholders are asked to engage in our discussions and review our materials and methods to ensure that:

- 1 Any research project conducted will have the goal of improving the quality of life of American Indian/Alaska Native people;
- 2 Our work is responsive to tribal community needs and desires;
- 3 There is ongoing, meaningful, and equal participation and collaboration from tribal community members;
- 4 Tribal community members are full partners during the entire research process, from conception to dissemination;
- 5 Our work reflects and respects cultural knowledge;
- 6 Our work encourages and reflects indigenous ways of knowing;
- 7 Our work reflects and respects cultural values and community priorities in the generation of research questions and processes;
- 8 The project is built from culturally appropriate processes and oversight, clear communication, and appropriate terminology;
- 9 Appropriate attention is given to tribal research codes;
- 10 Critical documents and materials are obtained, such as Tribal Council resolutions that authorize the research, Memoranda of Understanding that clearly state the roles and responsibilities of the research partners, and Federalwide Assurances if indicated;
- 11 Data are jointly owned by the tribal community and the research institutions; (this statement applies to all study sites except the Southwest Node. The Navajo Nation retains full ownership of the data and the right to review all materials prior to publication or presentation);
- 12 The tribal community reserves the right to review and approve all proposed publications and presentations;
- 13 Continued attention is given to the validity, reliability, and utility of the project findings, from both academic and indigenous perspectives;
- 14 Collaboration exists around decisions about what research questions are analyzed, how findings are interpreted, and how research is disseminated.
- 15 Dissemination strategies to American Indian/Alaska Native communities will be in a language and manner of sharing research findings that is culturally appropriate.
