

Chapter 9

COMMUNITY-BASED PARTICIPATORY RESEARCH IN INDIAN COUNTRY: DEFINITIONS, THEORY, RATIONALE, EXAMPLES, AND PRINCIPLES

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American Indian and Alaska Native children, youth, and families experience some of the most appalling health disparities of any minority group in our country. Research to address these health disparities has often been less than effective and has, at times, resulted in harm to Native communities. Community-based participatory research and tribal participatory research (CBPR and TPR) are two approaches that have been quite successful in developing research partnerships between academic and tribal/Native communities to improve health and mental health status. This chapter provides the definition, theory, rationale, and principles of in Indian Country and provides a brief case example.

“We’ve been researched to death and it doesn’t even benefit us.”

“Researchers are like mosquitoes; they swarm in, take what they want, and swarm out.”

“We’ve been doing these things for thousands of years; it’s just that nobody wrote it down.”

“We’ve always done ‘research’; we just called it ‘common sense.’”

These quotes come from numerous discussions with community members from tribes that the authors have had the privilege to work with. The

quotes represent the tension between most research projects that have been conducted to date *on* tribal communities (rather than *with* tribal communities, as described later) and the need to respect and build on thousands of years of indigenous science through true research partnerships.

This chapter is focused on community-based participatory research and tribal participatory research (CBPR and TPR) approaches and how these innovative research partnerships are improving the health status of American Indian and Alaska Native communities. As communities become increasingly sophisticated consumers of, and collaborators in, research, it becomes evident that we have the opportunity to substantively advance the field of mental health research. This will occur only by acknowledging that tribal communities have expertise and knowledge that is equally critical to the conduct of rigorous science as that of more academically trained researchers. In addition, as more American Indian/Alaska Native communities, as sovereign entities, regulate the research that is conducted with their members, it is our obligation as ethical research partners to educate ourselves about the principles of CBPR and TPR.

We begin with a brief discussion of the history of research in American Indian/Alaska Native communities, as well as definitions of and theory behind CBPR/TPR approaches. Next, we provide quotes and themes from interviews we've conducted with community-based research partners in the Pacific Northwest who have varying degrees of experience with CBPR/TPR. These quotes address the principles found in the literature but also include fundamental values that are critical to achieving these principles, such as the importance of trust and the necessity of academic partners being willing to spend time in the partnering communities. We then use a case study of a research partnership between an academic institution and two federally recognized and sovereign tribes to provide some context and to illustrate how the principles of CBPR/TPR may be implemented in "real life." This case example provides important lessons learned and recommendations for successful research partnerships to develop community-based and culturally grounded interventions that can nurture the health of American Indian/Alaska Native communities. Finally, we close with comments from two of our community-based partners on CBPR/TPR partnerships from the communities' perspectives.

BACKGROUND, DEFINITIONS, AND THEORY

For some time, and with a variety of communities and ethnic groups, there has been a "disconnect" between academic research and the communities in which, for which, and with which it has been conducted

(Goldberg-Freeman et al., 2007). To a large extent this disconnect is related to basic differences between research institutions and the “researched” communities. Edwards and colleagues note, “The fundamental dichotomies that exist between academic and community partners range from their agendas for research, the power differentials in partnerships, to ownership of and identity with the research project,” (Edwards et al., 2008, 189). This has been particularly true in research between academic institutions and American Indian/Alaska Native communities, where prior experiences of tribal communities with academic research often have not been positive, with the research not addressing primary concerns of the community and thus failing to provide benefit to their members (Caldwell et al., 2005; McKennitt & Fletcher, 2007). These efforts were not collaborative and more often were conceptualized by academicians with minimal input from the targeted communities. Research studies and protocols have been formulated, implemented, and evaluated with limited knowledge of community strengths, traditions, and values, or active participation of community “researchers” or those individuals in the communities who have indigenous knowledge that can better shape questions in the context of tribal history and culture (Cochran et al., 2008; Thomas et al., 2010). These experiences, including a lack of understanding and failure to include communities in the research process, have led to mistrust of academic researchers and have raised questions among American Indian/Alaska Native communities about the value of participating in research with academic partners (Edwards et al., 2008; Goldberg-Freeman et al., 2007). At worst, research conducted in this unethical manner has resulted in much harm done to American Indian/Alaska Native communities (Foulks, 1989). In a special volume of *American Indian and Alaska Native Mental Health Research*, Foulks describes an alcohol study conducted on (rather than with) a remote Alaska Native village. The data were misinterpreted and presented the village as being plagued by extremely high rates of alcohol abuse as a result of revenue from oil and gas production. The researchers published a news release on the front page of the *New York Times* with the title “Alcohol Plagues Eskimos,” (Sobel, 1980). In addition to the harm to the reputation of the village and the members of the community, the village subsequently lost contracts with gas and oil companies, resulting in a harmful loss of revenue.

COMMUNITY-BASED PARTICIPATORY RESEARCH

CBPR (Minkler, 2005; Minkler & Wallerstein, 2008; Wallerstein & Duran, 2003) has been promoted as one approach to help overcome the “disconnect” between researchers and communities (Goldberg-Freeman et al., 2007); as a

means of addressing issues of health disparities in disadvantaged communities (Wallerstein & Duran, 2006); and as a method of developing, implementing, and sustaining effective behavioral health interventions (Bogart & Uyeda, 2009). CBPR has been defined as a “collaborative approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute unique strengths and shared responsibilities to enhance understanding of a given phenomenon and the social and cultural dynamics of the community, and integrate the knowledge gained with action to improve the health and well-being of community members,” (Israel et al., 1998, 177). There is a commitment that there will be an ongoing, collaborative process that determines the proposed focus of the research, the research process, and the data collection methodology. Involving community members in data analysis and interpretation of results enriches insights and findings through the context of the community’s understanding of them (Cashman et al., 2008). There should also be joint involvement in dissemination of the findings. Most importantly, the goal of the research is to benefit the community; it should be conducted “only if it’s going to mean something,” (Jacklin & Kinoshameg, 2008). The meaningfulness is based not on researchers’ prior evidence and/or theory, but rather on relevance of the research to the community and addressing its areas of concern.

CBPR has been described as an approach that serves as a bridge between these two cultures, academia and community, translating knowledge derived from academic research into community-relevant interventions and policies by combining collaborative research methods and community involvement and capacity building (Viswanathan et al., 2004). This requires an ongoing balancing act between scientific rigor and empiricism on the one hand, and the use of local cultural knowledge on the other. Unlike other approaches, CBPR focuses on conducting research *with* communities, not just *in* or *on* communities; communities and their members assume an active role as collaborators and co-investigators in the research process (Edwards et al., 2008 ; Viswanathan et al., 2004). It views indigenous knowledge as being as valuable and valid as that derived from scientific methods and believes that it helps shape and guide the research process (Caldwell et al., 2005; Cochran et al., 2008).

Such an approach focuses less on career-building of academic researchers, which often has involved relatively short-term projects in the context of the “publish or perish” atmosphere of the academy, and increasingly on the longer-term commitment involved in engaging and benefiting American Indian/Alaska Native communities (Mitchell & Baker, 2005). Together, researchers and community members work to

assess strengths, resources, and needs of the community; select an issue of particular concern; and adapt and implement available “evidence-based” interventions or potential solutions derived from the community to address the identified concern (Minkler et al., 2008). Since the evidence base for most medical and behavioral health interventions is based on selective and ethnically restricted samples, adaptation is important to make them culturally relevant and acceptable. “Culturally supported interventions” that emerge from a community’s traditions, values, and indigenous knowledge capitalize on the strength and resources of the community (Duran et al., 2008). The CBPR approach is based on a set of basic principles that foster collaboration and equity in the working relationship and partnership between researchers and communities (Israel et al., 2005; Israel et al., 1998; Minkler & Wallerstein, 2002; Minkler & Wallerstein, 2008; Wallerstein & Duran, 2003). These have been articulated and elaborated recently by Jacklin and Kinoshameg (2008). The principles are found in table 9.1 They include the development of a partnership that involves the community in the planning and conduct of the research; a focus on empowering the community

Table 9.1
Eight Principles of Appropriate Community-Based Participatory Research

<i>Principles</i>	<i>Research Philosophy</i>	<i>Specifics</i>
Partnership	Local involvement and participation in planning and implementation	<ul style="list-style-type: none"> • The project should be conceived by the community • The methodology should include mechanisms for community representatives to participate in research design, process, and outcomes • Communication should be continuous throughout the process
Empowerment	Research as a process that enhances community empowerment and moves toward self-determination	<ul style="list-style-type: none"> • The project incorporates and values local knowledge and experience • The project meets the political/policy needs of the community • Community participation guides the research process • Capacity is developed in the community

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Table 9.1 (Continued)

<i>Principles</i>	<i>Research Philosophy</i>	<i>Specifics</i>
Community Control	Community maintains ownership and control of research process and outcomes	<ul style="list-style-type: none"> • The tools developed, the results, and the planning belong to the community, not the researchers • There is a process for the community to review, comment on, and approve the tools, methods, findings, reports, publications, etc.
Mutual Benefit	Working in partnership with and for the community for a mutually beneficial outcome	<ul style="list-style-type: none"> • There are tangible benefits to the community • Process allows for skills and knowledge transfer • Academic outcomes (dissertations, publications, presentations) reflect community needs
Wholism	Use and production of holistic knowledge	<ul style="list-style-type: none"> • Value is placed on all forms of knowing: spiritual, cultural, local, and academic • Knowledge transfer is two-way • Local knowledge is respected
Action	Knowledge produced is used for action	<ul style="list-style-type: none"> • Holistic knowledge to be used for action is the result • Cycle of knowledge to action is continuous
Communication	Commitment to communication, dissemination, and knowledge translation of research and results	<ul style="list-style-type: none"> • Local colleagues, participants, and community members are aware of the study, its progress, and the results • Data is readily available and accessible to community members • Knowledge produced is communicated to participants, community members, policy developers, government officials, and academics
Respect	Respect for local research philosophy and culture	<ul style="list-style-type: none"> • A research philosophy that respects and is compatible with local teachings and culture is maintained • Local ethical standards are respected and attended to

From Jacklin and Kinoshameg, 2008. Used with permission of the author and publisher.

through the research process, its findings, and policy implications; community control and ownership of the research process, outcomes, and data; working in partnership toward mutually beneficial goals and outcomes; the production of holistic knowledge; that this knowledge be used for some positive action to benefit the community; a commitment to communicate throughout the research process, as well as in the dissemination/translation of findings; and a respect for the community's traditions, values, and culture.

While these general CBPR principles apply to many populations and communities, it is important to contextualize them to be more specific and culturally appropriate in their application (LaVeaux & Christopher, 2009). This has been the case in particular in the use of CBPR with American Indian/Alaska Native populations (Burhansstipanov et al., 2005; Caldwell et al., 2005; Christopher, 2005; Holkup et al., 2004; Mail et al., 2006; Norton & Manson, 1996). The resulting approach is tribal participatory research (TPR) (Fisher & Ball, 2002, 2003).

TRIBAL PARTICIPATORY RESEARCH

TPR embodies the general principles of CBPR and extends them into specific recommendations for doing research with American Indian/Alaska Native communities (LaVeaux & Christopher, 2009). This coincides with tribal communities assuming a more active and proactive role in the development of community-university partnerships and in conducting research in their communities. A fundamental principle underlying TPR is that American Indian/Alaska Native tribes and their communities are sovereign nations whose rights must be respected and reflected in the research process. TPR indicates that research should involve continual tribal oversight of the process and project. Such oversight is often provided through tribal research review committees, tribal council review, and/or by a community advisory board whose function is to help guide research development; ensure that the research is consistent with and respects community values, tradition, and culture; and ensures the community's safety and benefit. This includes the development and implementation of tribal council resolutions to support the intended research, and the development of memoranda of understanding to define the roles, responsibilities, and parameters of the community and academic partners, as well as agreements about ownership of data and the right to review and approve project-related information prior to dissemination.

Research in American Indian/Alaska Native communities may be regulated by the community and may also involve tribal research review boards,

tribal research codes, and possibly tribal institutional review boards (IRBs) to ensure ethical behavior on the part of researchers, including appropriate respect of the culture, traditions, and values of the particular tribe. In fact, there has been an increased focus on ethical issues in the conduct of research with American Indian/Alaska Native, First Nation, and Aboriginal communities (Ball & Janyst, 2008; Ethics Office of the Canadian Institutes of Health Research, 2007; Jacklin & Kinoshameg, 2008; Letendre & Caine, 2004; Van der Woerd & Cox, 2006). A number of tribal research codes are being, or have been, developed in many tribal communities to better protect tribal interests (American Indian Law Center, 1999; Brugge & Missaghian, 2006; Martin-Hill & Soucy, 2005).

These steps, which are not involved in many approaches to research but are integral to CBPR and TPR, are crucial to the development of a truly equitable and collaborative partnership between researchers and communities that increase the likelihood of community buy-in, engagement, and benefit from research. Further, these steps, which involve researchers spending time in the communities with which they work as a means of gaining the trust of their partners, are necessary to ensure that they “do it in a good way,” (Ball & Janyst, 2008) and “only if it’s going to mean something,” (Jacklin & Kinoshameg, 2008).

Clearly, CBPR and TPR offer ethical, respectful, and rigorous approaches to develop research partnerships between American Indian/Alaska Native communities and academic institutions to engage in research that is collaborative, equitable, mutually beneficial, and involves clear, transparent communication in a manner that ensures a balance of power and control over the research process. The next section provides quotes from interviews conducted with American Indian/Alaska Native community-based research partners that illustrate both principles and underlying values and practices that are essential for successful collaborative CBPR/TPR partnerships.

CRITICAL VALUES AND PRACTICES FROM THE COMMUNITY PERSPECTIVE

In the course of developing a user-friendly manual for CBPR/TPR research partnerships (not released yet), we conducted interviews with academic and community-based research partners, as well as with individuals with experience and expertise with regards to ethics in American Indian/Alaska Native health research, and in the use of IRBs that review American Indian/Alaska Native health research protocols. The quotes and themes that follow represent some of the key underlying values as well as practices that American Indian/Alaska Native community-based research

partners feel are critical to CBPR/TPR research partnerships. The voice of community partners is often missing in the literature; therefore, we felt it was critical to include our partners' voices in this chapter. We have organized them under the eight principles identified in table 1: partnership, empowerment, community control, mutual benefit, holism, action, communication, and respect. For the sake of brevity, we offer two or three quotes for each principle.

For *partnership*, community-based research partners had the following thoughts: "We had the university come over to the reservation and have face to face meetings with us and other native Americans that worked on the project were part of the team, or community members, and cultural co-op committee. They ranged from tribal council chairman, to a grant writer, to someone who worked in the computer lab with the kids, and youth services people, and janitorial staff. It wasn't just who you'd think would be involved in this sort of thing; there was an assistant cook who worked with the youth who was involved. Very much the community involved in all these types of processes. Those people were the people who were able to teach the people from the university"; and "They were very happy to have help from the university to get the project going so that alcohol in the end might be prevented and all the bullying in children. So they were very happy to have the help of the university to start something to prevent both alcohol and suicide. We already had a group and we're always doing this and that to prevent all this. That is why they were ready to accept help from the outside." There were similar thoughts expressed by all the community-based researchers interviewed: the community must be ready, it is important that the university-based researchers come to the community, and all must recognize and build on the successful practices and community-based interventions that exist in the community.

For *empowerment*, community-based researchers shared the following two quotes with us: "I think the more CBPR that are conducted in Indian country will lead through the process to more community empowerment. Having the research review board for our tribe has been really empowering to our tribe, our people. We have a radio show; we have a brochure out there. We have had a couple of research summits on what the research review board is all about. We are also holding the researchers accountable that after the research is done and they have some data to present, that they present it in the community at our annual research conference where they rotate area to area giving the same information and feedback and allowing the community people to ask questions or make suggestions"; and "I just really think that respect and humility is so powerful in this community. Like, 'We're coming forward and this is what we have to offer that is

something you're interested in,' rather than a big sales pitch, because it never felt like that. It felt like, 'How can we do this together? What is it that you guys want us to help with? Can we do that? We've got these ideas, but that doesn't mean they're set in stone and we can't change them.'" The themes in the interviews focused on respect for tribal sovereignty and authority, as well as a commitment to an equal partnership.

For *community control*, community-based partners shared the following: "Well, I would hope that we can give them a little bit of education about the uniqueness of our community. One of the things—I'm sure somebody like Lisa knows this—but in the past, with others, that we've dealt with before, some tend to think that all tribes are alike. That's just not right. We're all unique communities and, for instance, us and the Port Gamble S'Klallam Tribe are 12 miles apart, but probably couldn't be more different in many respects. And there are actually a lot of relations between the two tribes, intermarriage or whatever, but still the basic reservations, the way we do things, the size of the community and where the community is situated, are all different and unique. We've been more of an identifiable community for a lot, lot longer. So I guess I would say that the partners need to get up to speed fairly quickly, and that would be what we'd have to help them to learn about the community"; and "I'd reiterate get involved with the Elders first and ask questions and, of course, explain the program to them so you can find out who could help you the most as far as the Elders are concerned, different aspects of learning here. That's definitely where we'd start. Of course, you'd have to have the approval, should have the approval of the tribal council on what you're trying to do. That'd probably be the first thing, get involved with the tribal council and ask them what the program is and ask them how they could help, and get involved with the Elders, of course." These two quotes illustrate critical components of CBPR/TPR partnerships with tribes and Native communities. First, while there may be similarities between tribes/Native communities, they are actually more unique than similar and it is the responsibility of the researcher to acknowledge this and inform themselves. Second, each community has a unique process for gaining approval, trust, and for implementing the research plans that include tribal councils, existing committees, and specific groups such as elders. Once again, it is the responsibility of the academic researcher to acknowledge this and become informed about how to work respectfully with each community.

For *mutual benefit*, the community-based researchers shared the following: "One thing I think it has brought is an understanding of the academic, social, political networking that can occur. It really kind of has brought that out. It has kind of broken new ground in the community in providing that.

So it has given people that opportunity. Also, just the new relationships and the pride in being able to talk about this project in a public manner too is important for us as well”; and “I want to go back to the university. I think the fact that they’ve helped us with curriculum. They also provided resources such as supplies and equipment which we don’t always have that opportunity to have available They also invited another partner from the University of Washington which was very beneficial. The partnership was a health partnership, but it also involved the media and so, in that manner, was a positive, because by adding in the media component we learned a lot more. And so were able to gain additional skills and the individual trained our staff person in the use of video cameras, so the training was done on-site here with students and with staff. And so they were able to build skills at the same time.” Themes in this section focused on the benefits of research to the participating communities and the importance of supporting skill building and capacity at the community level.

For *holism*, community-based partners offered the following: “So the process with that was we met with community people. So we met with the tribal historian, members of the canoe family, the teachers in the community, Elders in the community. So we met with a group of people, and talked about sections of the curriculum and asked their opinion about adapting, how they would adapt it. What stories could we use? And so they would give their suggestions and we would incorporate it into the manual. So we used the same kind of framework of the manual, but we just incorporated the stories and values of the community”; and “We revised the curriculum to fit the culture and traditions of the Suquamish Tribe. This was done with the help of Tribal Elders, Members, Youth, Cultural Co-op and the Tribal Council”; and “Really, I think that it’s important that an understanding of culturally responsive and respectful health initiatives that have occurred in the community or ways that they can occur in the communities is important to understand prior to even coming into the community.” Themes here reiterate the importance of incorporating the knowledge, skills, and wisdom of the community members, both in research protocols and in designing interventions.

For *action*, community-based research partners shared the following: “I think the other part is that people really see this project as they really helped create it, and there were things in our needs and resources assessment. One person had said, ‘I definitely think youth substance abuse is a problem, but I don’t think it’s the biggest one, and I want to shine the light on sexual assault in the community.’ So our project didn’t end up focusing on sexual assault, but what we were able to do was note that somebody had said that and when a grant opportunity came along for a sexual assault

prevention and treatment program, I made sure that that grant went to this person. I said, ‘Hey, this is available’; and ‘‘We as tribal council members would like to see the community be a better place to live and we know that that challenge today is just like it is in a lot of communities that the youth and everyone have the same opportunities that they do everywhere and drugs and alcohol are part of that. And making this a better place to live means in part doing things to steer our members away from harmful things that they might get engaged in. So I would hope that our project will make a difference in the community in some way in that regard.’’ The themes expressed about *action* focus on the research project bringing positive change to the communities and also providing resources and increased capacity for community members to address other issues of concern.

For *communication*, community members shared the following: (In response to a question about what works best to develop a research relationship) ‘‘One on one for one thing. You have to communicate. That’s true in anything we do, and it’s very important to be up front and be knowledgeable about what you’re trying to do, and being respectful of the community and how you approach them in a friendly manner and explaining everything involved with the program. I think that’s real important’’; and ‘‘I listen. I’m listening and trying to listen to what individuals say and behavior of individuals I watch. Interactions. Behaviors. Because that’s important to me. By listening I mean I’m listening for things like information, consistency with information, communication styles—are individuals able to move from different communication styles as well? And I think that’s it for me. Communication styles ... I’m always looking at communication styles and really listening to what individuals are saying, but also observing at the same time. And then also another piece is shared responsibilities. Do we share; do we clarify with one another? I’m always looking for clarity’’; and ‘‘They need to be visible in the community. They need to develop the collaboration. And that takes so much time. They need to create that relationship. And that starts with small meetings, including more people, and explaining who you are, and what you’re doing there. I think that’s just one part of it, that’s relationship building, and that takes a lot of time and effort and that has to be the university people that do it. You might have someone in the community, but they’re part of the community. It needs to be many more people in the community that the university people talk to and collaborate with. They should know the tribal structure. They should know the political structure of the community because each tribe sets it up differently.’’ Themes related to *communication* focused on the need for transparency, sharing knowledge, and the importance of face-to-face communications and the researchers spending time in the community.

For *respect*, community members shared the following: “Everything I think about and everything I work on, the first thing that comes to mind is respect, and that can be in many aspects, culturally, socially. Respect is the first thing and that comes to my mind”; and “Knowing the culture and traditions of the community you will be working with and being respectful of it”; and “Just the partnership deal already with the Alcohol and Drug Abuse Institute staff at the University of Washington. I feel that I can trust them. I feel already that I can respect and trust them and that’s huge. And I think once everyone else gets to meet them and to know them I think they’re going to be well-received in our community.” Themes related to *respect* focused on the importance of academic researchers learning and respecting the unique culture and traditions of the community, as well as the importance of the community members being able to trust and respect academic researchers.

The quotes represent a very small part of the rich and important data that community-based researchers have shared with us. Successful research partnerships can be established when the principles of partnership, empowerment, community control, mutual benefit, holism, action, communication, and respect, are discussed and acknowledged by community and academic research partners. In particular, learning and attending to the perspectives and expertise of community partners is critical to ethical and effective collaborations. We offer a case study below to illustrate how these principles may be implemented, as well as lessons learned.

THE HEALING OF THE CANOE: A CASE STUDY OF CBPR AND TPR

The Healing of the Canoe Project began as an informal discussion between community members from the Suquamish Tribe and a Native research scientist from the Alcohol and Drug Abuse Institute (ADAI) at the University of Washington. The Suquamish Tribe Wellness Program administrator invited ADAI staff to discuss partnering on a project to improve the health of the members of the Suquamish Tribe and community. We obtained approval from the Suquamish Tribal Council (STC) to seek research funds. STC appointed the Suquamish Cultural Cooperative (SCC) to be the community advisory board for our partnership. The SCC is a standing committee that oversees all activities in the Suquamish community that relate to culture, thereby an indication to the academic researchers from the very beginning that the research would need to be community based and culturally grounded and appropriate.

Not long after our research partnership began, the National Institutes of Health’s National Center on Minority Health and Health Disparities

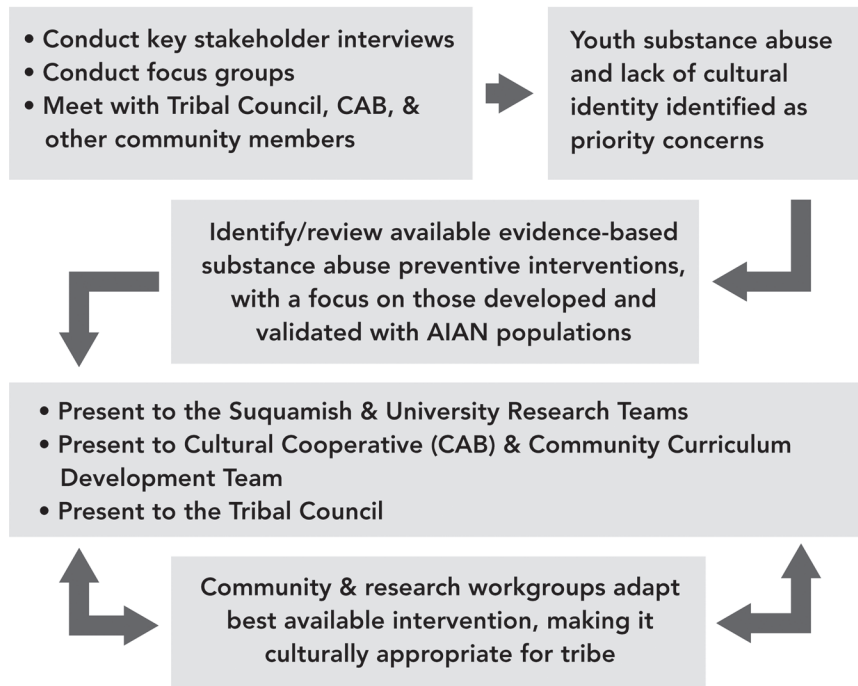
(NCMHD) issued a request for applications (RFA) to propose a project using CBPR approaches to address areas of significant health disparities. Tribal and university-based researchers worked together to craft a proposal to submit in response. This process allowed the community to have meaningful input in every aspect of the proposed research project, and it resulted in having a community member as a co-investigator and a significant portion of the budget allocated to community-based research partners who would be responsible for much of the development and implementation of the research.

We were successful in obtaining a three-year exploratory and developmental grant and began working as full research partners in 2008 on the Healing of the Canoe: The Community Pulling Together Project (HOC) (5R24MD001764-03, Donovan, PI). This was a unique opportunity, as the RFA required that the first year be devoted to developing a research partnership to: a) build and nurture a respectful collaborative effort that was based on trust, b) conduct a needs-and-resources assessment to identify research priorities of the community, as well as the strengths and resources that already existed in the community to address the issues of concern, c) adapt or develop and pilot an intervention to address the issues of concern to the community, and d) engage in bilateral training and capacity building. Figure 1 demonstrates the iterative process of phase one of HOC.

As you can see from this figure, community guidance, input, contribution, and approval was an integral component to phase one and significantly contributed to the success of the phase one project aims. Prior to starting any “official” research activities, university-based project staff began spending time in the community, and in particular the co-investigator, a Native investigator (from a different tribal community), served as the liaison between the two partners. Although all university-based staff spent time in the community, the liaison spent considerable time getting to know the community and, more important, allowing the community to get to know her. This requires that a great deal of time be spent in the community in non-project-related activities and community events. In general, this time is not supported by grant funds and much of it results from the values and commitment of university-based staff to be a true partner to the community.

Before any research activities began, we also met regularly with the SCC for guidance in developing research protocols that would be effective as well as respectful of potential participants and the community as a whole (Thomas et al., 2009). Academic IRBs play an important role in protecting individual participants in research; however, when working with American Indian/Alaska Native communities, protection of the entire community is critical and the local community advisory board is

Figure 1. Developing the HOC Intervention: An Iterative Process



the most appropriate body to ensure this protection. The academic IRB for our institution has been very committed to adhering to the most rigorous standards and policies and procedures for the protection of research participants, while also recognizing that academic institutions may have some important training and capacity-building needs in order to meet the more rigorous standards for the protection of individuals and communities, particularly when the community is a sovereign entity such as a federally recognized tribe. (See Thomas et al., 2010, for a complete description of the early HOC phase one partnership development and a more complete description of the needs-and-resources assessment).

The collaborative research team determined that the community readiness model (Jumper-Thurman et al., 2004; Jumper-Thurman et al., 2001; Thurman et al., 2003) was the most appropriate model for the needs and resources assessment. This innovative model was developed at the Tri-Ethnic Center at Colorado State University and has been used effectively by researchers working with American Indian/Alaska Native communities.

The CR model uses interviews with key community members and cultural experts to assess the level of a community's awareness of a particular issue of concern and what resources and potential solutions currently exist in the community. Most importantly, interviews are also designed to assess the community's level of readiness to make changes to address the issue.

The team worked collaboratively to adapt the questions for the Suquamish community, and community-based project staff conducted key stakeholder interviews and follow-up focus groups to identify the issues of most concern to the community, as well the strengths and resources that existed in the community to address them. These qualitative data were summarized and presented to the STC and the SCC to ensure their accuracy. With guidance from STC and SCC, the summaries were then presented to the Elders and to the community in general at a community meeting hosted by the project. The community determined that the prevention of youth substance abuse was the most important issue in the community, and that this could best be done by working with the youth to support their identity as tribal members and their sense of belonging to their community. The community determined that the Suquamish culture, youth, and Elders were the most important strengths and resources in preventing youth substance abuse and supporting tribal identity and a sense of belonging.

The project team did a literature search and selected a curriculum developed by the Seattle Indian Health Board and the University of Washington Addictive Behaviors Research Center, *Journeys of the Circle* (LaMarr & Marlatt, 2005; Marlatt et al., 2003), to be adapted by HOC as the intervention. The project team worked with community volunteers over a period of five months to adapt this curriculum to address the needs as identified by the Suquamish Tribe and build on the strengths and resources of the tribe. The resulting curriculum was named "Holding up Our Youth" by the Suquamish elders, and has been piloted with middle school and high school students from the community and will be rigorously evaluated in phase two. This curriculum is an eleven-session prevention program, plus an honoring ceremony incorporating evidence-based components with Indigenous knowledge, traditions, and values. The "Holding up Our Youth" curriculum provides Native youth the skills needed to navigate through life without being pulled off course by alcohol or drugs, with tribal culture, traditions, and values as compass and anchor.

Throughout this process the community was involved and informed via regular presentations to the STC and the SCC, as well as to the Elders and the community in general via community meetings hosted by the project. In addition, the project provides updates in the monthly

Suquamish newsletter, which goes to all Suquamish Tribe members. Finally, the project has an “open-door” policy and any and all community members are welcome to stop in to the project office to ask questions, obtain more information, or just chat. Transparency in the research partnership has been a key component to building and maintaining trust.

The HOC project successfully competed for phase two funding and the Port Gamble S’Klallam Tribe agreed to join the research partnership. Tribal members from each of the two communities serve as co-investigators on the NIH/NCMHD grant and as principle investigators on the subcontracts to the tribes. This allows for maximum community ownership, engagement, and cultural appropriateness, and will also support sustainability. The Suquamish Tribal School has invited the Suquamish HOC team to implement the curriculum as a part of their high school curriculum. The SRT will be engaged in testing the curriculum intervention over the coming year; the hope is that this community-based and culturally grounded curriculum will become a best practice and serve as a template for other American Indian/Alaska Native communities who are committed to improving the health of their members. The Port Gamble S’Klallam research team (PGSRT) is engaged in the needs-and-resources assessment for their community, which will inform the adaptation of the intervention curriculum to ensure that it incorporates PGSRT traditions, values, and practices while adhering to the evidence-based life skills components that form the core of the curriculum.

There are three notable points in our current HOC partnership. First, the partnership has remained committed to regular and bi-directional training. Community-based research staff receive training in research methods and approaches and also participate as coauthors on manuscripts and copresenters at professional meetings. University-based staff engage in monthly cultural training to better understand sociopolitical and health disparity issues in American Indian/Alaska Native communities in general, and the specific history and culture of the two tribal partners, as well. Second, we are collecting data on the nature and quality of our CBPR/TPR partnership. Many academic researchers engage in CBPR/TPR partnerships, but the quality of these partnerships varies and is generally not measured. By collecting data on the quality of our partnership we can engage in ongoing evaluation of what is working and also identify and address any issues that may arise. This data will also allow us to contribute to the literature about successful strategies for research partnerships between American Indian/Alaska Native communities/tribes and academic institutions. Finally, in addition to the overall research partnership of HOC (Suquamish Tribe,

Port Gamble S’Klallam Tribe, and ADAI/UW), the two tribal partners support and learn from each other as research partners engaged in health research, in a manner that we, as the academic research partner, are not able to do. It is incumbent on us, the academic researchers, to practice cultural humility and step back as our community partners emerge as leaders in the CBPR/TPR process.

VOICES FROM OUR AMERICAN INDIAN/ALASKA NATIVE COMMUNITY PARTNERS

Community research partner/co-investigator #1: “The Healing of the Canoe Project embodies the essence of community-based participatory research (CBPR). It is in every sense a true collaboration. The relationship is based on mutual respect for the expertise of all partners from the teenage youth worker to those with high level degrees and ‘prestigious reputations’. There is an overall goal that what we do will be beneficial to the tribal communities and we operate under the oath of ‘First Do No Harm’.

This mutual understanding guides all decision making and is evident through our continued and increasing community support from the tribes, universities and funders. Many of the Suquamish Tribal Members have commented that they thought that university staff member, Lisa R Thomas, worked for Suquamish because ‘she is at everything.’ This level of commitment and respect has made this project one to be emulated and should set a standard for tribal research partnerships.

That being said, there is a need to caution other tribes that not all research projects are created equal and that CBPR is a spectrum. Healing of the Canoe is on the far margins and may be unique in its ability to embrace each hand of its partners and gently, skillfully cherish the tribal communities it serves.

Therefore, it is with caution that tribes should enter into any research partnership. Some examples of helpful knowledge and skills to access would include obtaining Human Subject training and to require several references of potential academic researchers and cultivating relationships with other tribes who have healthy research partnerships.”

Community research partner/co-investigator #2: “As a Tribal Member I feel that the University of Washington ADAI staff have really made important steps in protecting, valuing and respecting our S’Klallam families. I feel very privileged to work with this institution as it strives to better our Tribal Communities by acknowledging our indigenous knowledge and expertise in knowing what works best to address our unique

needs and respect our ways of using our tribal customs and culture as the foundation to build a network of approaches to improve our health and well-being. I appreciate Lisa, who is a strong AIAN Woman who understands and works hard to promote cultural respect and competence. As an AIAN person she has an innate sense of understanding and knowing what is acceptable when working with our Tribal Families. She is a ‘protective factor’ for us. I do need to stress still that just because a person is AIAN does not mean that they will work well with a tribal community. It is a very unique blending of professional experience and cultural history with a heart committed to serving the people that makes for a leader in CBPR.”

CONCLUSION

CBPR and TPR can be effective approaches for effective, respectful, and engaged research partnerships between academic institutions and American Indian/Alaska Native communities when based on the principles of partnership, empowerment, community control, mutual benefit, holism, action, communication, and respect. Consistent themes from our community partners include: 1) the community must be ready for and guide the research process; 2) it is critical for university-based staff to spend time in the community to build trust and respect; 3) research must be strengths based; 4) tribal authority and approval must be obtained; 5) the partnership must be based on equity in all aspects; 6) tribes and American Indian/Alaska Native communities are unique, with unique research engagement processes, and it is the responsibility of the academic researcher to learn these (again, by spending time in the community); 7) local knowledge, expertise, and traditions must inform research protocols and be incorporated into research interventions; 8) research should benefit the community and support capacity development in the community; 9) training for working with American Indian/Alaska Native communities and Tribes as sovereign entities is needed by academic researchers and their institutions; 10) the research process must be transparent and include clear and consistent communication; and 11) face-to-face communication is very important, rather than relying on emails and telephone communication.

We cannot emphasize enough the importance and value of trust and respect in CBPR/TPR partnerships between American Indian/Alaska Native communities/tribes and academic institutions, as well as the importance of recognizing the community members as the experts with regards to research in their own community. As one tribal elder said, “We told them what to do and they did it!”

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