“Indigenist” Collaborative Research Efforts in Native American Communities

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What a fascinating thing life is! I have survived the many, many stories of how I think, what I know, and who I am—all told by those who are well meaning, well dressed, and well ignorant of the deeper sides of my cultural epistemology.
Manulani Aluli Meyer (2001, p. 124)

It was nearly 2:00 AM and we were still cutting potatoes and browning buffalo meat. In 12 hours, we were hosting a kick-off feast for our new research project and were expecting 150 community members and tribal leaders. As we chopped and cooked, one of the team members wondered aloud how many faculty at non-Native projects expended this sort of effort to develop, nurture, and honor community partners. Given the state of research training, very few, we figured. In Native communities,

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the aunties or uncles would be calling if Native researchers did not conduct themselves properly, as this type of personal involvement is expected to nurture meaningful partnerships and, ultimately, achieve the health and healing that our research efforts are all about.

Alas, despite good intentions, research in Native communities sometimes is not beneficial and may even have iatrogenic effects. Native communities and other communities of color have experienced research exploitation and, in some cases, cultural and economic devastation at the hands of even well-intentioned researchers. Developing and sustaining community-based partnerships with Native communities, who have endured colonization, historical trauma, genocide, and racism—as well as histories of exploitation by academics—is difficult, even for researchers from the very communities they are hoping to engage.

This chapter addresses some of the challenges in building community-based research partnerships with indigenous communities, illustrating potential conflicts and possible solutions. To inform these efforts, we introduce eight “indigenist” community-based participatory research (CBPR) principles. We refer to the HONOR Project, a national study of lesbian, gay, bisexual, and transgender Natives to illustrate the process of developing a working partnership. Although much of this chapter focuses on Native-specific experiences, the lessons translate with some specific tailoring to other racial/ethnic minority groups as well.

Research in Indian Country

Indigenous communities are reclaiming rights to their own knowledge production and to science, which has been part of their communities for millennia (Castellano, 2004; Holkup, Tripp-Reimer, Salois, & Weinert, 2004; James, 2001; Meyer, 2001; Norton & Manson, 1996; Tuhiwai Smith, 2005). The advanced engineering projects of the Incans in South America and the sophisticated agricultural systems of the Haudenosaunee in North America suggest that indigenous peoples have long employed sophisticated techniques honed by research methods. For example, the ancient city of Cahokia in Illinois was an urban metropolis from the eleventh to twelfth centuries, with an estimated population of 20,000 to 50,000 (larger than London or Paris at that time). It contained sophisticated pyramidal structures, one of which (the Monks Mound) was the third largest structure in the Americas (Nader, 2001).
Part of the colonization process is to render invisible the successes of indigenous science and knowledge while simultaneously infusing public discourse with images of Indians as intellectually inferior. For example, the ancient mound structures were considered too sophisticated to have been produced by indigenous populations (Nader, 2001). Lay persons as well as anthropologists attributed the mounds to others, including the Vikings, Chinese, Lost Tribes of Israel, and lost civilization of Atlantis (www.answers.com/topic/mound-builders-2). Prevailing anthropological theories in the nineteenth century postulated that the mound builders had died off or had been annihilated by barbaric Indian tribes.

More recently, the media, in books and films such as *Chariots of the Gods*, have gone as far as to suggest that similarly complex architectural structures must have been constructed by aliens from other planets, presumably because Natives could not possibly have built them (Von Däniken, 1968). As Maori scholar Linda Tuhiwai Smith (2005) noted,

The Western academy which claims theory as thoroughly Western...has constructed all the rules by which the indigenous world has been theorized...[as a result] indigenous voices have been overwhelmingly silenced. The act, let alone the art and science of theorizing our own existence and realities, is not something which many indigenous people assume is possible.

(p. 29)

For indigenous peoples, therefore, decolonizing research methods include deconstructing and externalizing the myth of the intellectually inferior Indian, while simultaneously privileging and centering indigenous worldviews and knowledge to promote revitalization of indigenous epistemologies, research practices, and ultimately, indigenous wellness practices.

This call for revitalization and innovation in indigenous science follows the egregious mistreatment of indigenous peoples over the course of modern science. Indigenous peoples have endured generations of colonialism in the form of medical impropriety, abusive experimentation, and lack of protection of human subjects (Lawrence, 2000; Smith, 2006; Udel, 2001). Historically, indigenous peoples have been treated as scientific objects with scant regard to community needs or the potentially harmful implications of research processes and findings; research that communities have deemed as “helicopter” or “drive-by” research. Notably, medical impropriety and experimentation often have targeted
the most vulnerable of our people, our children. For example, a report by the Truth Commission into Genocide in Canada (2001) documented the deaths of 50,000 Native children in Canadian boarding schools and detailed numerous instances of medical experimentation, including the removal of organs and radiation exposure.

Another area of exploitation causing concern for indigenous peoples is the seemingly relentless campaign to carry out genetic research on indigenous peoples. Genetic research all too often has been conducted without the approval of indigenous subjects. Researchers, for instance, have taken blood samples from earlier health studies and used them to carry out genetic research without tribal consent or consultation. An infamous example occurred recently among the Nuu-chuh-nulth people in British Columbia and is detailed at length by Schmidt (2001). As he reported, in the late 1980s a study was conducted to investigate the high incidence of arthritis in the Nuu-chuh-nulth community. The lead researcher collected 833 vials of blood from donors who signed consent forms allowing for the screening of biomarkers related to arthritis. The researcher was not able to find a gene related to arthritis but soon after used the samples to conduct further genetic research and shared them with other researchers without tribal knowledge (Schmidt, 2001). Such violations continue to occur, sometimes with federal government approval. For example, Schmidt also reported that the U.S. government filed patents on DNA cells taken from the Hagahai tribe in Papua New Guinea and the Solomon Islands. These samples were taken without informing participants or the tribe of the study. Alarmingly, the Hagahai cells are now available for purchase from a biomedical company. A more recently publicized case of harmful research involved the Havasupai Tribe who, in 2004, filed a lawsuit against researchers at Arizona State University (ASU) for misusing blood samples taken from tribal members. Specifically, tribal members were told that their blood samples would be used only for a study on the genetics of diabetes. However, their blood samples were also used for studies on schizophrenia, inbreeding, and migration studies of their ancestors. Tribal members reported that the published data from these studies were “humiliating and harmful to them” (Sahota, 2007). A major result of this particular case was tribal mobilization throughout Indian Country, including by the National Congress of American Indians (NCAI), to enact policies to protect tribes from research harm as well as increase tribal control over research in Indian Country (Sahota, 2007).
Being “researched to death” is both metaphor and reality for many indigenous communities (Castellano, 2004). Marlene Brant Castellano, while chairing a research session at the 1992 Royal Commission on Aboriginal Peoples, observed an elder who stated “If we have been researched to death, maybe it’s time we started researching ourselves back to life” (p. 98). In response to this exploitation under the guise of scientific inquiry, indigenous communities are demanding accountability, in some places developing their own institutional review boards as well as guiding principles and protocols for all phases of the research process (Wallerstein & Duran, 2006). Research—by and for Natives—has prompted pipeline initiatives among indigenous communities (e.g., kaupapa Maori research) and universities to streamline indigenous scholars into research careers. As Linda Tuhiwai Smith (2005) noted

Research, like schooling, once the tool of colonization and oppression, is very gradually coming to be seen as a potential means to reclaim languages, histories, and knowledge—to find solutions to the negative impacts of colonialism and to give voice to an alternative way of knowing and being. (p. 91)

The lack of indigenous individuals trained in conducting research has necessitated the development of partnerships with nonindigenous scientists. CBPR approaches as well as participatory action research approaches have guided some of these collaborations.

Community-Based Participatory Research

Research is not just a highly moral and civilized search for knowledge; it is a set of very human activities that reproduce particular social relations of power (p. 88).

—Linda Tuhiwai Smith (2005)

CBPR has emerged over the last few decades as an alternative research paradigm that integrates education and social action to improve health and reduce health disparities. Wallerstein and Duran (2007, p. 312) noted that “CBPR is an orientation to research that focuses on relationships between academic and community partners with principles of co-learning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts.”
CBPR is a way of approaching research that is consistent with social justice and, in the case of indigenous communities, tribal sovereignty. Action research, of which CBPR is one form, includes as well participatory action research, feminist participatory research, and cooperative inquiry (Holkup et al., 2004; Minkler, 2004). The approaches to CBPR are related to two traditions—the action research school promulgated by Kurt Lewin in the 1940s and the liberatory and consciousness-raising approaches of South and Central American scholar-activists such as Paulo Friere. Minkler (2004) noted that Friere, Fals-Borda, and other developing world scholars formulated “their revolutionary approaches to inquiry as a direct counter to the often ‘colonizing’ nature of research to which oppressed communities were subjected” (p. 686). Israel and colleagues (2001) defined CBPR as focusing on

...social, structural, and physical environmental inequities through active involvement of community members, organizational representatives, and researchers in all aspects of the research process. Partners contribute their expertise to enhance understanding of a given phenomenon and integrate the knowledge gained with action to benefit the community involved. (p. 182)

Moreover, CBPR, as an orientation to research, focuses on relationships among research partners with goals of societal and communal transformation (Minkler & Wallerstein, 2003) rather than a specified set of methods or techniques (Wallerstein & Duran, 2006).

Generally accepted CBPR principles recognize the community as a unit of identity and/or analysis; build on the strengths, resiliency, and resources of the community; facilitate co-learning, co-partnering, and community-capacity building throughout all phases of the research project, including dissemination; attempt to strike a balance between research and action; emphasize local relevance and ecological and historical contexts that contribute to multiple determinants; generate systems growth through cyclical and iterative processes; and involve long-term commitment to process and community (Israel et al., 2001; Wallerstein & Duran, 2006). Tribes have added to the list of CBPR principles some of the following mandates: (1) don’t plan about us without us; (2) all tribal systems shall be respected and honored, emphasizing policy building and bridging, not a policy wall; (3) policies shall not bypass tribal government review and approval before implementation; and (4) tribally specific data shall not be published without tribal
authorization (Turning Point Collaboration, Robert Wood Johnson Foundation, 2001). Explicit throughout CBPR implementation in indigenous communities is the recognition of the sovereignty of the tribe or indigenous community to be self-determining; that power and authority rest with the community or tribal entity; and that the process of knowledge exchange is reciprocal and always attentive to the best interests of the indigenous community, the ancestors, and future generations.

Authentic CBPR practice means expanding partnership-building dynamics to include the unpacking of power and privilege, specifically around the areas of racism, ethnic discrimination, and internalization of Western science as the only relevant form of scientific inquiry. For nonindigenous researchers partnering with indigenous communities, we caution that either partner’s assumption of academic expertise may unintentionally hide or silence local voices, overriding traditional understanding of local phenomena. In addition, silence can be mistaken or coercively interpreted as agreement when, in fact, it represents resistance.

To facilitate partnership building and to reformat power dynamics, we promote a stance of cultural humility as opposed to cultural competence (Wallerstein & Duran, 2006). Cultural competence might never be acquired, and it may not even be an appropriate goal (e.g., in the case of spiritual protocols). Cultural humility, on the other hand, refers to a life-long commitment to critical self-evaluation regarding multiple, complex, and simultaneous positions of unearned privilege (e.g., being white and male) to redress power imbalances and nurture deeply respectful partnerships with communities.

Decolonizing Research

If we, as Indian people, are forced to reject our own indigenous knowledge and our ways of thought to participate in science, then we will be that much closer to cultural extinction.
—Cornel Pewewardy (2001, p. 21)

As previously noted, the movement toward developing decolonizing methodologies among indigenous communities is a global struggle to counter hegemony. Indigenous researchers have been actively seeking protocols that disrupt and counter the history of exploitation, trauma, and discrimination in research inquiry and, instead, “privilege indigenous
knowledges, voices, experiences, reflections, and analyses of their social, material, and spiritual conditions" (Rigney, 1999, p. 117).

As Tuhiwai Smith (2005) noted, this type of social movement to counter oppressive research structures is not new to research communities. Other populations, such as sexual minority communities, women, and other ethnic minorities, also have experienced dissatisfying and even exploitative research partnerships. They too are challenging the epistemological basis of scientific paradigms and the relevance to their communities.

For indigenous peoples, a layer is added to countering the hegemonic research imperatives; namely, to decolonize the research process while simultaneously indigenizing it. Tuhiwai Smith (2005) wrote that the decolonization research process involves multiple layers of struggle across multiple sites, including the unmasking and deconstruction of imperialism; manifestations of old and new formations of colonialism; as well as the simultaneous recognition of sovereignty for reclamation of indigenous knowledges, languages, and cultures and, ultimately, for the transformation of colonial relations between the colonizer and the colonized. She explained:

Decolonizing research, then, is not simply about challenging or making refinements...to research. It is a much broader but still purposeful agenda for transforming the institution of research, the deep underlying structures and taken-for-granted ways of organizing, conducting, and disseminating research knowledge. (p. 88)

Decolonizing research practices promotes the ability of indigenous peoples and researchers to theorize their own lives; reconnect with past and future generations; acknowledge and prioritize indigenous ways of knowing and healing; respect and prioritize the community’s role in defining problems, resiliencies, and strategies; and cultivate and build indigenous capacity to engage in both indigenous as well as Western research methodologies.

Indigenist Research Principles

It is our conviction that it is not sufficient to decolonize research; we must go further and indigenize research. To guide the development of mutually beneficial research partnerships with indigenous communities,
we suggest eight principles for decolonizing and indigenizing research: reflection, respect, relevance, resilience, reciprocity, responsibility, retraditionalization, and revolution. Specific strategies for incorporating each principle in research partnerships are discussed subsequently. Note that many of these principles incorporate Tuijawi Smith’s (2005) groundbreaking work on building indigenous research capacity. These guidelines are not exhaustive and should be appropriately tailored. They are a starting point, aimed to instigate further co-exploration of decolonizing and indigenizing approaches in research partnerships with indigenous communities (Figure 8.1).

Before engaging with Native communities, research partners could benefit from careful reflection upon their positionality vis-à-vis community members. Most university-based research partners have a

| Reflection | True partnerships begin with reflection upon the privileged statuses from which most partners operate and the emotionally difficult task of acknowledging the pain of Native communities and developing empathy. |
| Respect | Research partners must value and prioritize indigenous epistemologies, knowledge, cultural protocols, and healing practices. |
| Relevance | The community should contribute to defining research problems and strategies, which should respond to their own self-identified needs and concerns. |
| Resilience | All aspects of the research must acknowledge the community’s strengths and resilience. |
| Reciprocity | The partnership should be collaborative and mutually respectful with knowledge exchanged in both directions. |
| Responsibility | Research partners are obliged to enhance community capacity to conduct Indigenous and Western research, disseminate research findings in culturally meaningful ways, and anticipate the implications. |
| Retraditionalization | Traditional knowledge and methods must be actively integrated into the formulation of the research questions and the process of scientific inquiry. |
| Revolution | Research partners and community members must actively seek to decolonize and indigenize the research process to transform science as well as themselves, their communities, and the larger society for the betterment of all. |

Fig. 8.1 Guiding principles for decolonizing and indigenizing research.
privileged status in society, owing to educational and socioeconomic advantages. If they are members of the dominant racial group in the United States, they have additional advantages based on their White privilege as well. Acknowledging these privileges—not disingenuously denying them—can improve the partnership. Reflection involves an ongoing process of self-awareness of emotional reactions as well. The scale of human misery that Native peoples have endured since colonization and that many continue to confront on a daily basis is difficult to comprehend and accept among non-Natives. A common initial reaction is simply to reject it ("It isn’t that bad") or to fight it with individual exceptions ("I know a rich Indian living very well"). Rejection of the experience precludes empathy. Devoid of context, Native calls for justice and inclusion might be misjudged as inappropriately angry or strident, even militant.

The principle of respect means that research partners must value and prioritize indigenous epistemologies, knowledge, cultural protocols, and healing practices. Indigenous “scientists” and expert knowledge already exist within indigenous communities and should be involved throughout the research partnership. As one medicine man once said to an academic when they were walking together in the woods on tribal lands, “Professor, out here you are my student. Welcome to my university.”

For research partners to achieve relevance, they must actively engage the community from the earliest phases of the research endeavor in conceiving the aims of the project. This might involve meetings with key community members and tribal leaders, community forums and feasts, and extensive outreach to determine what the community itself defines as important to its health and well-being. For example, one young white student was strongly motivated to pursue research in eating disorders such as anorexia nervosa but had trouble gaining access to youth in the local tribal community. She was eventually forced to acknowledge that her own interests did not match the priorities of the tribe. Relevance also extends to the methodology of the research. For example, many tribes understandably balk at participating in trials with no-treatment control conditions. Given the extensive health needs of most communities, designs that involve waiting-list controls or comparison conditions of interventions with equivalent time and attention are more desirable. Of course, these should be developed with the needs of the indigenous community at the forefront.
Research with indigenous communities should acknowledge the community’s strengths and its stalwart resilience in the face of multiple assaults on tribal autonomy and integrity. Much of the early work in Indian country focused exclusively on pathologic conditions, such as alcohol addiction and childhood abuse. Although these topics were serious concerns for tribes, the research was conducted without regard to contextual, structural, and historical factors that contributed to these problems (Walters & Simoni, 2002; Walters, Simoni, & Evans-Campbell, 2002) or to the large majority of tribal members who avoided these problems.

Reciprocity should characterize the research partnership, which should be collaborative and mutually respectful, with knowledge exchanged in both directions. Western and indigenous knowledge should be mutually understood, and respectfully exchanged. Often, communities have excellent ideas and possible solutions and just require some assistance in formulating these into research questions and translating them into fundable proposals.

Collaborators with indigenous communities assume a grave responsibility. They are obligated, first, to enhance community capacity to conduct research. Research endeavors should seek to incorporate youth and students into research activities to stimulate their interest in research and provide experiences to bolster their opportunities for future training. Researchers funded by the National Institutes of Health (NIH) have access to training mechanisms (e.g., F31, minority supplements) to build research capacity within indigenous communities. Creating an indigenous research workforce will help to replace the “Indian experts” with “expert Indians,” observed Beverly Pigman, Navajo Nation Institutional Review Board Chair. These newly minted indigenous scholars will need research infrastructures that support and nurture their work; establishing indigenous research organizations is one way of ensuring they find what they need. Second, research partners have the responsibility of disseminating research findings in culturally meaningful ways. This can mean publishing in tribal newsletters as well as peer-reviewed journals, with community partners acknowledged as co-authors according to their contributions. The dissemination process should involve other forms as well, such as digital storytelling, documentaries, photography and other visual presentation, theater, or community events in which the findings are reported in an accessible fashion. Finally, research partners must be responsible for anticipating the implications of their findings. In one
infamous example, the financial integrity of a tribe was threatened when questionable research findings were released to the press—without the prior knowledge or approval of the tribe. In addition, work that fails to adequately consider the contextual factors and the history of colonization among indigenous communities may lead to reports that inaccurately blame the victim, switching the focus away from the need for policy changes that address structural inequities.

Retraditionalization involves incorporating traditional and ancestral knowledge and methods into the formulation of research questions and the process of scientific inquiry. Building on the principles of respect and relevance, it involves the practice of co-embracing hybridized methodologies while maintaining an indigenous core. Whenever possible, partners and communities should co-develop mechanisms for developing innovative indigenous methodologies or hybrid methodologies that combine Western and indigenous approaches. Retraditionalization is a way to indigenize science. Reframing scientific processes from indigenous worldviews or, rather, reclaiming these processes involves consciously shifting from Western approaches to more holistic approaches in research methodologies. In this fashion, research methodologies become tools and the researcher is the vessel or the vehicle through which the tools come to life. Although some of these tools might contain their own spirit, how the researcher relates to the spirit of these research tools is what matters. In essence, the researcher can be witch or healer, practicing bad or good medicine depending on how he or she works with the spirit of these methods.

Truly indigenist research collaborations involve scientific revolution. Research partners and community members, by actively seeking to decolonize and indigenize the research process, can transform the structure and nature of knowledge production. This can be facilitated by challenging colonial or racist research practices within institutions (Mihesuah &Wilson, 2004). Decolonizing research practices include holding the researchers accountable as well as the institutions where research takes place. This process might involve promoting indigenous science and knowledge within universities, as well greater awareness of the need to recognize tribal sovereignty and treaty obligations. Indigenous peoples have established histories as astronomers, engineers, mathematicians, and physicians and, as a result, “science” and the processes of observing, developing, and testing hypotheses are not new to indigenous peoples. Through our research efforts we must continue to debunk, demystify,
and deconstruct the intellectually inferior Native mythology. Indigenist science has implications for how indigenous communities are perceived and esteemed. This, in turn, has implications for the well-being of indigenous communities as well as the larger society. More importantly, indigenist science recognizes the contributions that indigenous knowledge has on the world. For example, many foods come from indigenous agricultural knowledge. Potatoes, chocolate, corn, beans, squash, and tomatoes, among other foods, originated in the Americas under sophisticated agronomist methods of planting, sowing, and harvesting (Mt. Pleasant, 2001). Yet, colonization erased knowledge of indigenous origins of these foods (Churchill, 1996). Potatoes became “Irish potatoes”; chocolate became “Dutch chocolate”; and vanilla became “French vanilla.”

To paraphrase Aboriginal scholar Karen Martin, indigenist research must decolonize Western research practices via reclaiming the research endeavor (Martin, 2001). Specifically, she states,

To reclaim research is to take control of our lives and our lands to benefit us in issues of importance for our self-determination. It is to liberate and emancipate by decolonisation and privileging the voices, experiences and lives of Aboriginal people and Aboriginal lands so that research frameworks are reflective of this. (2001, p. 2)

Moreover, she notes that indigenist research emphasizes the social, historical, and political realities that contemporarily shape indigenous lives and futures. Indigenist research, Martin notes,

...is undeniably political, emancipatory and confirming in its aim to control research on Aboriginal lands and regarding Aboriginal people and to regulate relations with governments, resource agencies, research institutions and visitors. (2001)

Indigenist research processes also involve redistributing and checking power. The product must be recognized as being always in the process of how and what we do. To honor ourselves and our partners we must “walk the talk” and be held accountable. Engaging in dialogue between indigenous and nonindigenous researchers and communities is essential to healing.

Accountability mechanisms include integrating elders, youth, and wise leaders into research efforts, for example, by creating leadership
councils of community members (including all segments of the target population). Our efforts will not be measured by how many papers we have published, but by how much we have truly assisted in eradicating the suffering, injustices, and health disparities of our partnering communities.

Implementing Indigenist Community-Based Participatory Research—The Honor Project

In our every deliberation we must consider the impact of our decisions on the next seven generations.

—From The Great Law of the Iroquois Confederacy

Most of the authors of this chapter were involved in a 5-year National Institute of Mental Health (NIMH) funded study called the HONOR (Honor Our Nations, Our Relations) Project. Discussed here are examples from our work on this study that illustrate the advantages—and the challenges—of indigenizing the research process.

After identifying a new NIMH funding priority in “Behavioral, Social, Mental Health and Substance Abuse Research with Diverse Populations,” the first author contacted several indigenous health and HIV programs in major urban centers where HIV/AIDS surveillance data indicated disproportionately high HIV/AIDS rates, specifically among indigenous men who have sex with men. Although in most CBPR approaches the community identifies the research and researchers with whom to partner, the first author, who is American Indian and two-spirit, believed it was worth the effort to contact indigenous agencies about the announcement to determine interest in a collaboration.

Overwhelmingly, urban indigenous organizations were supportive and signed on. In fact, only budgetary restrictions limited our ability to partner with several rural, reservation, and Native Hawaiian partners who also expressed interest. Five agency directors were contacted and all five agreed to submission of the grant, eventually entitled “Health Survey of Two-Spirit Native Americans” in 2001. We were quite lucky and our first application was funded; thus began our journey in building more depth and breadth to our partnerships.

The HONOR Project had four major aims: to test an indigenist stress and coping model (Walters et al., 2002; Walters & Simoni, 2002); to
establish preliminary baseline prevalence rates of trauma, HIV/AIDS, and health outcomes; to develop and evaluate an innovative sampling method; and to develop research infrastructure and capacity at the Native agencies. Our survey examined several areas, including traumatic stressors (e.g., historical trauma, microaggressions, traumatic life event); physical health (e.g., HIV risk behaviors, diabetes, human papilloma virus, cancer); mental health (e.g., posttraumatic stress disorder, depression, anxiety, substance use); spiritual health (e.g., traditional health and healing practices); and cultural protective factors (e.g., identity, community involvement, spirituality, enculturation). We imagined the findings could be used to inform service providers of critical health and wellness data so that they could better serve two-spirit (i.e., lesbian, gay, bisexual, or transgender; see Fieland, Walters, & Simoni, 2007, for a thorough explanation of the term) men and women at their agencies and to assist the local two-spirit communities in planning, implementing, and developing health policy. It was important to us that we incorporated research training opportunities for Native community members, students, and research professionals throughout the study. We were quite successful in the latter regard, hiring and training more than 30 American Indian and Alaska Native staff, investigators, and students on this project. Moreover, 60% of the investigators and professional staff self-identified as two-spirit, thus providing strong representation of the population of interest in directing the study. In addition, four American Indian investigators were key personnel (including the Principal Investigator [PI]), making this one of the few NIH-funded studies led by American Indian researchers. We had considerable support from community partners and non-Native research co-investigators and allies as well.

Participants in the HONOR Project were recruited from seven metropolitan areas in the U.S.: Seattle-Tacoma (Northwest Two-Spirit Society); San Francisco-Oakland (National Native American AIDS Prevention Center with additional support from Bay Area Two-Spirits); Los Angeles (United American Indian Involvement); Denver (Two-Spirit Society of Denver); Oklahoma City-Tulsa (Oklahoma City Native American AIDS Coalition, Indian Health and Community Resources Center, and Tulsa Two-Spirit Society); Minneapolis-St. Paul (Indigenous Peoples Task Force); and New York City (American Indian Community House and Northeast Two-Spirit Society). Eligibility criteria were (1) self-identifying as American Indian, Alaska Native, or First Nation; (2) being enrolled in a tribal nation or having at least 25% American
Indian blood; (3) self-identifying as gay, lesbian, bisexual, transgender, or two-spirit or engagement in same-sex sexual behaviors in the past 12 months; (4) being age 18 years or older; (4) English speaking; and (5) residing, working, socializing in the main city of the particular study site. Participants were recruited by two methods: targeted sampling and a modified respondent-driven sampling technique. A total of 452 participants were recruited in the survey in less than 2 years. In addition, 65 community-identified two-spirit leaders completed an extensive qualitative interview identifying wellness and resiliency themes among two-spirit persons. All participants received monetary remuneration for their participation.

**Forming Team Partnerships across Differences**

Once the grant was awarded, we needed to nurture the relationships within our diverse interdisciplinary team of indigenous and nonindigenous scientists as well as our community partners and put into place systems of community accountability with the use of national and local community advisory boards. One of the first steps in decolonizing protocols previously noted is the focus on critical self-reflection on our own intentions, research capacities, and limitations—from internalized colonial processes to the positions of power and unearned privilege that indigenous and nonindigenous investigators, staff, and students held. We encountered and processed within our Seattle site our struggles with different worldviews, epistemologies, and methodological approaches. Not surprisingly, initial struggles emerged between indigenous and nonindigenous researchers in terms of comfort with different orientations to time, outcomes, and processes of engagement within the team itself. For example, for the nonindigenous researchers, the entrée into the field work phase was incredibly slow, involving high levels of staff time (i.e., money spent with little observable “outcome”) as well as indigenous investigator time in community events, activities, and ceremonies that to nonindigenous researchers appeared to be only remotely related to the study aims. The PI and other indigenous researchers dialogued with the nonindigenous research personnel about the importance of community commitment, visibility, and genuine interest in all the communities’ wellness as part of the development of trust in us. On the other hand, the indigenous researchers and staff struggled with nonindigenous researchers’ push to move too quickly into the field. They
also interpreted cultural differences in communication styles (e.g., being more verbally direct) as chafing and sometimes disrespectful of indigenous values and protocols. Through dialogue and sharing of differences in worldviews, expectations, and protocols, the research team began to work through their differences—good-natured teasing of nonindigenous researchers coupled with the researchers’ demonstrated cultural humility quite often diffused tensions. Most importantly, however, indigenous and nonindigenous investigators became united in their intentions for the best interests of the community. One team member remarked at one point, “People are dying out there.” His rallying call helped to refocus the team, who decided they needed to use all the available resources, on indigenous terms, to better the health of the Native communities. In addition, over time and through working together on the team, the focus on the research tools (epistemological, theoretical, and methodological) that each person brought to bear on the research partnership became less threatening once the relationship to those tools became was clear—that is, they were shown as being used only in the best interests of the community.

Tensions between the University and Community Emerge

Similar to other studies, many tensions existed between university and community expectations, especially regarding the necessity of bureaucratic process around payment mechanisms. For example, many community members who worked directly with the project as consultants, transcriptionists, and artists had limited incomes and had to wait inordinately long periods to receive payment. This was particularly challenging because the Native staff understood the financial vulnerability of community members who were accustomed to being paid at the time services were rendered instead of waiting weeks and, in many cases, months to be paid. Moreover, many of our community members lacked sufficient savings to tide them over, thus increasing their economic hardship. Not only did this reinforce cultural mistrust among community members regarding the exploitation of Native peoples within university systems, but it also created unnecessary financial hardships on some of our most vulnerable community members. Thus, timing of payment schedules and reimbursements, and invoices versus payment at time of service all lead to some very challenging moments. We have not resolved this tension as of yet because, in large part, this involves shifting university
financial systems, which takes tremendous resources and effort—but we are engaged and hope to shift policies to be more inclusive of community members who have much to offer in the ways of their services to research endeavors.

In addition, from the beginning of the study we had to attend to high levels of community cultural mistrust regarding research in Indian Country and university systems in general. Prior community experiences and perceptions of cultural appropriation; abuse of indigenous intellectual property rights; and general exploitation of indigenous staff, personnel, and professors also came to bear in the present project. To address these concerns, we simply realized that we had to “walk the talk” and conduct ourselves honorably and with transparency. Moreover, we relied upon our local and national leadership councils (i.e., community advisory boards) of key two-spirit community-based leaders to guide us and provide key insights into major thematic issues, topical areas, and cultural protocols. Importantly, we made sure that the leadership councils had representation from some of the most marginalized voices in our community (e.g., members who were homeless, transgender, or young people).

When the Community Calls, Come Running

One of the most challenging issues has been the fact that the team largely consists of indigenous researchers, many of whom are two-spirit—thus we were “insiders” to the communities we were partnering with. Of course, this provided advantages (e.g., greater trust and authority delegated to the team by community members). However, being on the inside created other challenges. First, issues arose pertaining to boundaries. Indigenous researchers already carry many burdens and blessings in researching their own communities, some of which include familial or community obligations that come first but might be seen to interfere with research objectivity. For example, sometimes our indigenous staff is called on for ceremonial purposes (e.g., leading sweats, songs) within communities, including two-spirit communities; yet, these are the same communities with whom we are engaged in research. From an indigenous perspective, if someone is asked to give a blessing, sing a song, or pour a sweat and has the authority to do so, then it would be an insult to refuse without some strong spiritual or cultural justification. Another challenge is that sometimes, because of internalized
colonization, our own community members devalued the indigenous researchers’ knowledge and tended to hold nonindigenous counterparts’ knowledge in higher esteem. Finally, to illustrate tensions in competing obligations (research and community), at one point during the study we received a call from an indigenous elder who had heard of our study and wanted to help the two-spirit community. He wanted to bring special gifts to the community but asked if our project could collect and deliver them. After discussion with the team, we decided that in the interest of helping the community, we would assist this elder with funds from our own pockets (ethically and fiscally, we could not use the study budget). A group of us traveled from Seattle to the Idaho border by car and transported the gifts back in the same day. The elder was pleased to have something to offer the community and we had an opportunity to hear about two-spirit people of that person’s nation as well as sing together and have a meal together. Some of our nonindigenous colleagues thought we were “crazy” to travel 18 hours in a day to bring these gifts back and to meet with the elder. But the indigenous staff and researchers knew that not only was this culturally expected, but it was required. Now, upon reflection, we recognize that in doing so we learned many things that long day about two-spirit history and perspectives from an elder who wanted to help.

Almost Defunded

In the second year of the study, just when we were about to hire a full-time project director and launch the survey part of our study, we received a disturbing phone call from our project officer. He called to tell the PI that within 2 hours a congressional amendment from Representative Patrick Toomey (H.AMDT.221 to H.R. 260; July 10, 2003, Congressional Inquiry) was about to be introduced that called for defunding several NIH-funded projects, including our study. In addressing his congressional colleagues, Toomey stated, “Who thinks this stuff up?…if they want to do this sort of research, we need to fund this privately and not with taxpayer dollars. I simply want to make the point that there are so many far more important, very real diseases that are affecting real people.” Representative Chris Chocola went on to argue, “…I do not know that we can identify people who benefit from this taxpayer money being spent on these grants…we should be eradicating these horrible diseases that ruin families, ruin individual lives rather than grants that
benefit no one that we can identify." Fortunately, the amendment failed, though narrowly, in a recorded vote of 210 to 212. Needless to say that we were relieved but very concerned as to how the community would respond to such public discussion and visibility of the study. In fact, the project was discussed on major media outlets The O’Reilly Factor, The Scarborough Report, and CNN Headline News during that week. We also quickly found out that once we were in the public eye, we were vulnerable to more attacks. Many of our investigators, including the PI, had community organizing experience and advocacy experience and, if this attack had been on a more individual level, would perhaps have taken the challenge more publicly. However, given that we were funding more than 30 indigenous people on this project, we had to think more broadly about the pros and cons of the response we would make. At that time, we decided to contact our community partners and all staff and colleagues associated with our project to let them know what had happened. One of our partners became so impassioned that he was able to give a speech and receive a declaration of support on the floor of the United Nations Indigenous Peoples Work Group meeting in Geneva in support of our study. Indigenous communities worldwide rallied in support of the study, noting that an attack on any segment of our community is an attack on all indigenous communities. Non-Native individuals and research organizations came out to support us as well. On the community partner level, we received a few phone calls from some community members who were concerned about the government accessing our records. We then applied for a Federal Certificate of Confidentiality to address this concern. Interestingly, our grant was requested through the Freedom of Information Act by a conservative journalist. We attempted to remove the names of our community partners to protect them but were not allowed to do so unless we wanted to invest our resources in a court battle that our attorneys assured us we would likely lose. Thus, once again, we notified our community partners listed on the application that this journalist would know who they were and we would support them however we could in addressing whatever might come of it given their fiscal vulnerabilities (most are small agencies operating on very tight budgets). Although this was a challenging experience, creating some community apprehension, for the most part our community partners and indigenous communities provided tremendous support. We may even have gained more community respect: reflecting the Native community’s historic distrust of the U.S. government, one community
member stated, “We must be doing something right if Congress wants to defund us.”

The Power of Naming

Researchers typically develop acronyms and pithy names for their studies, sometimes giving little attention to the process of naming. From an indigenous point of view, naming is sacred. In many communities, a name is seen as emanating from the spirit world. Along with a name come responsibilities as to how to conduct oneself and establish one’s place in relation to the community. Naming creates relational accountability. At the time we initially discussed the HONOR project, we did not follow indigenous protocols and instead went the more Western route of devising an acronym. The community members discussed the importance of having a positive name, one that honored our two-spirit ancestors of the past and also would refocus on community strengths. Thus, the HONOR project was born—first as an acronym to reflect Honoring Our Nations, Our Relations, and later to simply honor the communities we are working with. From this naming experience, we learned the importance of following indigenous protocols, or indigenizing the research enterprise, and paying attention to the everyday details of research development and events, such as naming, which might be seen as insignificant in the scheme of the grand research project but may be critical to establishing accountability. Moreover, the community may choose to have an actual naming ceremony to provide a spiritual foundation for the study through the name. Of course, this should be done according to protocol that the indigenous community involved sets forth.

Feeding the Community

Consistent with indigenous protocols, our team sought first the permission from the local indigenous tribe and their leader to conduct our study on their land. We offered the tribal leader gifts and tobacco and asked to make a speech at our opening feast to acknowledge the study and the leader’s support for our efforts. In this way, we honored the indigenous peoples of that land and territory first and foremost, and then we sought permission to move forward with the study from tribal leaders, the urban indigenous community at large, and the two-spirit community more specifically. To accomplish this, we prepared a feast. Feeding
the community is both metaphor and practice as we prepared to share the study with the community, solicit their feedback and guidance, and announce the development of the leadership council. Feeding the community also means feeding our community spirit. This event was well attended, and we were able to get critical support and guidance from the community during the presentation of the research study. In addition, the community partners had an opportunity to meet one another from across the country at this feast, allowing cross-fertilization of knowledge exchange among community members and partners.

Overall in the course of the HONOR Project, we learned several lessons. Specifically, we learned about the importance of self-care of indigenous staff, interviewers, and researchers as we delved into the interview phases of our study. At times, traumatic material invoked a secondary traumatic response among our own personnel; we needed to ground ourselves spiritually, in our own traditions, to deal with difficult stories. As elders have noted, stories have their own spirit, and in this way we as a team began to incorporate more ways to cleanse, center, or spiritually ground ourselves (e.g., smudging the room before team meetings; for those who wanted, team members going to sweat lodges to cleanse). In addition, we realized early on that a considerable investment of resources (financial, personnel, and personal) is required to develop research capacity among our community partners and among our own team members, including indigenous and nonindigenous researchers. Specifically, the learning curve for our own indigenous staff, many of whom had limited research experience, took time to nurture and strengthen. In many instances the work involved having our own team recognize their gifts and knowledge that they already possess as not only being valuable, but also being a necessary asset to the success of any research enterprise.

In general, indigenist CBPR takes many more resources and time to implement properly than would a more traditional research approach. Getting into the community took at least two to three times longer than even the indigenous researchers thought would be necessary. Seemingly little things such as creation of outreach materials and logo took tremendous time and energy but were well worth it in terms of nurturing and supporting indigenous artists and the community to be actively involved in co-creating the images and message for the community outreach materials. For example, the Native two-spirit artist who designed the posters for our outreach materials fortunately provided several designs. After several focus groups with different target populations (i.e., gay-identified...
Native men, Native youth, elders, and middle-aged two-spirit activists), it became clear that three different posters needed to be developed to attract specific two-spirit populations to the study. This led to a higher cost than expected for outreach materials but at the same time gave us an opportunity to encourage hard-to-reach populations to enroll or find out more about the study (e.g., closeted gay Native youth) and simultaneously embraced generational cohort differences in values, worldviews, and issues (e.g., the middle-aged group liked the more “historic” poster, whereas the more “out” gay men preferred the image with two men nose to nose and dressed in traditional regalia).

Conclusion

This overview of how to “indigenize” collaborative research efforts with Native American communities, along with the case example of the HONOR Project, highlight one key reality: research in Native communities demands years of personal and professional commitment. Maintaining consistent contact, fighting for indigenous rights and against injustices, and having an ongoing presence beyond the data and study are critical to nurturing mutually satisfying, liberating, and trusting partnerships with indigenous communities. The opportunity to work in indigenous communities is a great privilege, but it comes with great responsibility.

We are at a crossroads of Western and indigenous knowledge and science—a time for opportunity and growth and also a time to strengthen indigenous knowledge production and traditions through indigenous CBPR. With the recent passage of the United Nations Declaration on the Rights of Indigenous Peoples (2007), the time is right to honor indigenous knowledge and intellectual traditions. As the Declaration states

1. Indigenous Peoples have the right to maintain, control, protect, and develop their cultural heritage, traditional knowledge, and traditional cultural expressions, as well as the manifestations of their sciences, technologies and cultures, including human and genetic resources, seeds, medicines, knowledge of the properties of fauna and flora, oral traditions, literatures, designs, sports and traditional games, and visual and performing arts. They also have the right to maintain, control, protect, and develop their intellectual property over such cultural heritage, traditional knowledge, and traditional expressions.
2. In conjunction with indigenous peoples, states shall take effective measures to recognize and protect the exercise of these rights. (Article 31, pages 14–15).

Reciprocity must be the defining feature of collaborative research efforts with Native American communities. Although non-Native partners might initially anticipate a sense of loss at the prospect of a truly collaborative partnership (indeed, they will be required to relinquish some control), their efforts eventually will be rewarded. As Oscar Kawageley (2001, p. 55) explained: “There is a need to broadly reconceptualize and revitalize Native knowledge and to integrate it thoroughly with mainstream science. The latter is an absolute must for our own people and for others; we have much to share with them” (p. 55).

REFERENCES


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


### POINTS TO REMEMBER

I. Indigenist community-based participatory research (ICBPR) principles and decolonizing partnership strategies
   
   A. Research in Indian Country.
      1. Demystify, externalize, and deconstruct the “intellectually inferior Indian.”
      2. Privilege and center indigenous knowledge, worldviews, and science.
      3. Promote healthy revitalization of and creation of new indigenous epistemologies.
   
   B. CBPR principles.
      1. Recognize the community as a unit of identity and/or analysis.
      2. Build on the strengths, resiliency, and resources of the community.
3. Facilitate co-learning, co-partnering, and community-capacity building.
4. Attempt to strike a balance between research and action.
5. Emphasize local relevance and ecological and historical contexts.
6. Generate systems growth through cyclical and iterative processes.

C. CBPR is Action research that includes the following:
   1. Participatory action research.
   2. Feminist participatory research.
   3. Cooperative inquiry.

II. BPR includes the following:
   A. Active involvement of community members, organizational representatives, and researchers.
   B. Focuses on relationships between and among research partners with goals of societal and communal transformation.
   C. Recognizes community as a unit of identity.
   D. Builds on the strengths, resiliency, and resources of the community.
   E. Facilitates co-learning, co-partnering, and community-capacity building.
   F. Recognition of
      1. sovereignty of the tribe or indigenous community to be self-determining, power, and authority rests with the community or tribal entity;
      2. process of knowledge exchange is reciprocal and always responsible to the best interests of the indigenous community.

III. Seven guiding indigenist principles for CBPR
   A. Respect
      1. Value and prioritize indigenous epistemologies, knowledge, cultural protocols, and healing practices.
   B. Relevance
      1. Actively engage community from earliest phases and aims.
      2. Develop aims with needs of community at forefront.
   C. Resilience
      1. Acknowledge community’s strengths.
   D. Reciprocity
      1. Collaborative and mutually respectful.
   E. Responsibility
      1. Enhance community capacity for research.
      2. Disseminate results in culturally meaningful ways.
      3. Anticipate the implications of findings.
F. Retraditionalization
   1. Co-develop mechanisms for developing innovative indigenous methodologies or hybrid methodologies that combine Western and indigenous approaches.

G. Revolution
   1. Challenging colonial or racist research practices within institutions.
   2. Promoting indigenous science and knowledge within universities.
   3. Recognizes the contributions that indigenous knowledge has on the world.