

## Finding middle ground: negotiating university and tribal community interests in community-based participatory research

Selina A Mohammed,<sup>a</sup> Karina L Walters,<sup>b</sup> June LaMarr,<sup>c</sup> Teresa Evans-Campbell<sup>b</sup> and Sheryl Fryberg<sup>c</sup>

<sup>a</sup>University of Washington Bothell, Bothell, <sup>b</sup>University of Washington, Seattle, <sup>c</sup>Tulalip Tribes, Tulalip, WA, USA

Accepted for publication 30 December 2010

Doi: 10.1111/j.1440-1800.2011.00557.x

MOHAMMED SA, WALTERS KL, LAMARR J, EVANS-CAMPBELL T and FRYBERG S. *Nursing Inquiry* 2012; 19: 116–127 [Epub ahead of print]

### Finding middle ground: negotiating university and tribal community interests in community-based participatory research

Community-based participatory research (CBPR) has been hailed as an alternative approach to one-sided research endeavors that have traditionally been conducted on communities as opposed to with them. Although CBPR engenders numerous relationship strengths, through its emphasis on co-sharing, mutual benefit, and community capacity building, it is often challenging as well. In this article, we describe some of the challenges of implementing CBPR in a research project designed to prevent cardiovascular disease among an indigenous community in the Pacific Northwest of the United States and how we addressed them. Specifically, we highlight the process of collaboratively constructing a Research Protocol/Data Sharing Agreement and qualitative interview guide that addressed the concerns of both university and tribal community constituents. Establishing these two items was a process of negotiation that required: (i) balancing of individual, occupational, research, and community interests; (ii) definition of terminology (e.g., *ownership* of data); and (iii) extensive consideration of how to best protect research participants. Finding middle ground in CBPR requires research partners to examine and articulate their own assumptions and expectations, and nurture a relationship based on compromise to effectively meet the needs of each group.

**Key words:** American Indians, community-based participatory research (CBPR), indigenous, tribal community.

The ways in which scientific research is implicated in the worst excesses of colonialism remains a powerful remembered history for many of the world's colonized peoples. (Tuhiwai Smith 1999, 1)

In the past decade, community-based participatory research (CBPR) has increasingly been hailed as an alternative approach to conventional one-sided research endeavors that have been conducted *on* communities as opposed to *with* them. The commonly identified ideal of CBPR is the formation of equitable partnerships, for example, between academic institutions and communities throughout all phases of the research process

(Israel et al. 2003). This orientation to research neutralizes power imbalances that commonly plague academic–community research relationships by transforming the socially constructed roles of the researcher as ‘knowledgeable’ and community as ‘unknowledgeable’ to one where expertise is shared and the roles of educator and learner are fluidly exchanged. Utilizing this approach is especially important when collaborating with marginalized communities, such as indigenous communities,<sup>1</sup> who have historically been exploited and harmed by more traditional research paradigms.

Correspondence: Selina A. Mohammed, Assistant Professor, Nursing Program, University of Washington 18115 Campus Way NE, Box 358532, Bothell, Bothell, 98011 WA, USA.  
E-mail: <selinam@u.washington.edu>

<sup>1</sup> In the United States (US), the national context for this article, indigenous communities and their peoples are most commonly referred to by the specific tribes to which they belong, or through use of more general terms such as American Indian/Alaska Native, Native American, Indian, Indigenous, or Native. Throughout this article, several of these terms are used interchangeably.

Although research in indigenous communities has often been well-intentioned, a history of colonization and inter-generational trauma, the rise and mutual reinforcement of scientific inquiry with imperialism, and a legacy of research abuses by 'outside experts' have left many indigenous communities distrustful of, and reluctant to participate in, research endeavors. As part of the colonization process, indigenous people have traditionally been framed through hegemonic, binary discourses and fields of representation based on western imagery and knowledge (Slemon 1995). These colonial discourses of power served to undermine indigenous knowledge and intellect, silence indigenous voices in the research process, and legitimize one-sided research endeavors that have historically treated indigenous people as "scientific objects with scant regard to community needs or the potentially harmful implications of research processes and findings" (Walters et al. 2009, 148). The costs of this approach to research have proven to be enormous for indigenous communities and have ranged from deriving little or no benefit, stigmatization and negative stereotyping, and an undermining of economic viability to egregious medical improprieties and experimentation, such as the use of tribal blood samples for genetic testing, sterilization practices, and radiation exposure, without the informed consent and understanding of participants (Dillingham 1977; Foulks 1989; Lawrence 2000; Manson et al. 2004; Shaffer 2004; Burhansstipanov, Christopher, and Schumacher 2005; Christopher et al. 2008; Walters et al. 2009).

In recent years, the norm of one-sided, exploitative research has clearly begun to shift. Tired of being 'researched to death', having little or no control over research studies, and typical 'parachute', 'drive-by', or 'helicopter' models of research where researchers drop in, quickly take what they need and leave, many indigenous communities are reclaiming rights to their own knowledge production and insisting on research processes that are based on inclusive, participatory, and accountable practices (Roubideaux and Dixon 2001). The recognition of past research injustices, the rights of indigenous people to develop and control research processes to ensure that they are ethical and beneficial to their communities and the need for 'insider' research in indigenous communities that is conducted by indigenous people themselves have brought about research concepts, guidelines, and protocols that are changing the landscape of research with indigenous communities worldwide. For example, concepts such as cultural humility (Tervalon and Murray-Garcia 1998) and cultural safety (Papps and Ramsden 1996) that move beyond more traditional concepts of cultural sensitivity or competence and instead call for critical self-reflection with respect to unearned privilege, analysis

of power imbalances and institutional discrimination, and nurturing of respectful partnerships with communities have increasingly been operationalized in work with indigenous peoples. For instance, the Canadian Institutes of Health Research (CIHR) has established Guidelines for Health Research Involving Aboriginal People to assist researchers in developing partnerships with indigenous communities and promote ethical and mutually beneficial research with Aboriginals that is consistent with their traditions and values (CIHR 2007). In New Zealand, indigenous initiatives such as Kaupapa Maori research privilege indigenous philosophies and practices to promote use of appropriate methodologies of research for, with, and by Maori (Tuhiwai Smith 1999). And, in the US, research policies enacted by the National Congress of American Indians (Sahota 2007) and funding initiatives designed to build research capacity within indigenous communities (e.g., training mechanisms through the National Institutes of Health and Native American Research Centers Grants sponsored by the Indian Health Service) have been established to protect indigenous communities from harm and increase tribal control, involvement, and leadership in research conducted within their communities.

The initiative to build research infrastructures in indigenous communities and advance indigenous research agendas has resulted in a burgeoning interest in the use of CBPR with indigenous communities. Community-based participatory research is particularly relevant to nurse scientists and other health-related researchers who are committed to engaging in ethical and community-driven research to promote social change. Although the numerous strengths of this approach have been recognized (e.g., the unpacking of issues around power, privilege, and racial discrimination, centering of local knowledge, and the creation of reciprocal partnerships), there have also been an increasing number of articles that describe various challenges of CBPR (Holkup et al. 2004; Manson et al. 2004; Minkler 2004, 2005; Burhansstipanov, Christopher, and Schumacher 2005; Khanlou and Peter 2005; Freeman et al. 2006; Israel et al. 2006; Strickland 2006; Wallerstein and Duran 2006; Foster and Stanek 2007; Christopher et al. 2008; Baldwin, Johnson, and Benally 2009; Kennedy et al. 2009; Lindamer et al. 2009; McHugh and Kowalski 2009; Walters et al. 2009). The purpose of this article is to add to that body of literature by describing some of the lessons we<sup>2</sup> have learned while implementing CBPR in a university-tribal<sup>3</sup> community collaboration. After an overview of CBPR and a brief description of

<sup>2</sup> The authors of this article are Native and non-Native academic research partners and Native community-based partners.

<sup>3</sup> The community we reference self-identifies as a tribal community.

the cardiovascular disease (CVD) project we reference, the rest of this article highlights the process of how we constructed a Research Protocol/Data Sharing Agreement (DSA) and qualitative interview guide that attended to the concerns of both university and tribal community constituents. We do not, in any way, make the claim that there is one 'correct' way of addressing either of the situations that we present. Instead, we offer these two examples to illustrate some of the complexities of this type of research in hopes that they will be useful to other university-community collaborations.

### OVERVIEW OF CBPR

"More than a set of research methods, CBPR is an orientation to research that focuses on relationships between academic and community partners, with principles of colearning, mutual benefit, and long-term commitment and incorporates community theories, participation, and practices into the research efforts" (Wallerstein and Duran 2006, 312). Shared decision-making and power throughout the research process (from project inception to dissemination of findings) and mutual ownership of research products are foundational to efforts based on this contemporary approach (Faridi et al. 2007). The conceptual basis of CBPR evolved from two major traditions: (i) the Northern tradition of action research developed by Kurt Lewin in the 1940s, which promoted the active involvement of individuals affected by the research problem at hand and a cycle of study involving planning, action and reflection on results; and (ii) the Southern tradition that emerged from work in the 1970s with oppressed communities in South America, Africa, and Asia. This tradition is characterized by the work of Paulo Friere, Fals-Borda, and other scholar-activists who utilized revolutionary, analytically reflective, and dialogic methods to counter the colonizing realms of research (Wallerstein and Duran 2003; Minkler 2004). Over the years, various relational and process-oriented theoretical frameworks such as feminism, postmodernism, poststructuralism, and postcolonialism have added critical dimensions to the nature and practice of CBPR (Shalowitz et al. 2009).

The collaborative, action-oriented, emancipative, and social justice dimensions of CBPR make it well suited to research in nursing and other disciplines that aim to address health inequalities. According to the W.K. Kellogg Foundation, "CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities" (2001, 2). Understanding that there are multiple ways to articulate CBPR and that guiding

principles are context dependent, Israel et al. (2003) have outlined a set of nine key principles that members of research partnerships may draw upon, as they deem appropriate. These include: (i) recognizing the community as a unit of identity; (ii) building on strengths and resources within the community; (iii) facilitating a collaborative, equitable partnership in all phases of research and using an empowering and power-sharing process that attends to social inequalities; (iv) fostering co-learning and capacity building among all partners; (v) integrating and achieving a balance between knowledge generation and intervention for the mutual benefit of all partners; (vi) focusing on the local relevance of public health problems and on ecological perspectives that attend to the multiple determinants of health; (vii) involving systems development through a cyclical and iterative process; (viii) providing results to all partners and involving them in wider dissemination efforts; and (ix) involving a long-term process and commitment to sustainability (Israel et al. 2003).

"An underlying assumption of CBPR is that through active and meaningful community involvement, community benefits are maximized and a range of potential harms to individuals and their communities can be minimized" (Shore et al. 2008, 1). Given the historical context of research injustices that have occurred against indigenous communities, CBPR is considered to be an ethical, respectful, and meaningful approach to research because of its emphasis on greater community power, decision-making, and leadership responsibility (Shalowitz et al. 2009). Focusing on issues of importance to the community, building on local knowledge and culture, and utilizing the unique strengths and resources of each community enhances the quality of research, increases chances for success and sustainability, and generates outcomes that are relevant to the community (Cornwall and Jewkes 1995; Warne 2006; Horn et al. 2008).

### DESCRIPTION OF THE PROJECT

The university-tribal community collaboration we reference is a 5-year, predominantly native-run developmental CBPR project funded by the National Heart Lung and Blood Institute (NHLBI) to design and test a culturally appropriate, feasible CVD risk prevention program for a tribal community in the Pacific Northwest of the US. Contact between the two groups was initiated when a university research team member approached community representatives regarding the possibility of collaborating on a health-related project. During the process of developing relationships and discussing community needs, a Request for Applications for CVD

prevention programs in Native communities was announced. Recognizing the magnitude of CVD as a health problem within this specific indigenous community, a decision was jointly made to pursue this funding opportunity and work together to identify prevalent risk factors for CVD (e.g., diabetes, obesity, lack of physical activity, low socioeconomic status, low educational attainment, acute and chronic stressors, historical and intergenerational traumas, racial discrimination, mental health issues, substance abuse, lack of social support, negative environmental conditions, etc.) among community members, and in effort to protect present and future generations, create an intervention to reduce risk for CVD that is grounded in the historical, cultural, social, political, and economic contexts of the community.

The research team is composed of key community members and providers<sup>4</sup> and university-based Native and non-Native investigators across disciplines, including social work, nursing, psychology, and medicine. The team primarily employs Native staff, routinely seeks advisement from a group of community representatives and providers, and has project processes approved by appropriate tribal officials. Specific aims for the project were developed after identifying foremost issues and concerns of community representatives. These aims include: (i) conducting a qualitative study involving focus groups and key informant interviews with community members to determine illness meanings around CVD and diabetes (we explore diabetes as well because of its inter-related nature with CVD and significance to the community), participants' experiences with food (e.g., transitions from traditional to Western diets, times of food insecurity, and balancing of income and food choices) and exercise (e.g., the role that exercise plays in one's life and types of exercise), and common historical, communal, familial, and individual barriers (e.g., historical traumas, boarding school experiences, environmental changes, racial discrimination, low income, and lack of time) and likely facilitators (e.g., support systems, positive cultural identities, and spirituality) to health and adherence to a culturally tailored CVD prevention program; (ii) surveying a stratified random sample of 375 adult community members to establish preliminary prevalence of CVD risk factors and test a modified theoretical indigenist stress-coping model (Walters, Simoni, and Evans-Campbell 2002) of the relationships between trauma, coping, and CVD-related health outcomes; (iii) designing a theoretically, contextually driven and culturally sensitive CVD prevention program for at-risk American Indian caregivers

of children under 18 years of age and conducting a randomized controlled trial (RCT) of the intervention to evaluate its efficacy; and (iv) disseminating the findings to the tribe and broader research outlets, as well as preparing translational materials for community consumption and programmatic implementation should the intervention be efficacious.

Understanding the history of colonization that Native people have survived and respecting tribal sovereignty are crucial to working with tribal communities. According to Walters et al.,

[e]xplicit 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 (2009, 2).

Wanting as a team to practice these convictions, we understood the value of not only decolonizing the research process, but of re-centering indigenous knowledge in the process as well. Therefore, in addition to drawing upon the principles of CBPR outlined by Israel et al. (2003), we are utilizing eight 'indigenist' principles that two of the authors had previously developed through their years of work with indigenous communities, to further promote beneficial relationships in our academic-tribal community partnership. These principles incorporate the innovative indigenous research capacity building work of Tuhivai Smith (2005) and include: (i) reflection – examining the privileged statuses from which partners frequently operate and the emotionally difficult task of acknowledging and developing empathy for the pain of Native communities; (ii) respect – partners valuing and prioritizing indigenous epistemologies, knowledge, cultural protocols, and healing practices; (iii) relevance – the community should contribute to defining research problems and strategies in response to their own self-identified needs and concerns; (iv) resilience – all aspects of the research must acknowledge the community's strengths; (v) reciprocity – the partnership needs to be collaborative and mutually respectful with knowledge exchanged in both directions; (vi) responsibility – partners are obliged to enhance community capacity to conduct indigenous and Western research, disseminate findings in culturally meaningful ways, and anticipate their implications; (vii) retraditionalization – traditional knowledge and methods must be integrated actively into the formulation of research questions and the process of scientific inquiry; and (viii) revolution – partners must actively seek to decolonize and indigenize the research process to transform science, as

<sup>4</sup> A provider is someone who offers health or social services care in the community. These individuals may or may not be enrolled tribal members, but can be designated as community representatives.

well as themselves, their communities, and larger society for the betterment of all (Walters et al. 2009).

At the beginning of our fifth year of the project, we are analyzing data from our qualitative and survey phases and have launched the intervention component. We have had several accomplishments to date, including approval of the project by tribal council resolution; creation of a tribal community advisory board (CAB) for consultation on the project's design and implementation; naming of the project by community members using the traditional language and the design of a representative logo by a local Native artist; capacity-building in both university and community settings through training within and between the two groups; procurement of a Federal Wide Assurance (FWA) that designates an area Indian Health Board as the Institutional Review Board (IRB) for protection of tribal participants; and the garnering of community support, participation, and enthusiasm for the project through culturally appropriate outreach efforts (e.g., local advertisements and involvement in community events). However, our partnership has also had a variety of challenges to work through, including varying communication styles (e.g., being verbally direct versus indirect); differences between Native and non-Native worldviews (e.g., differing orientations to time and foci with respect to process versus product); tensions regarding academic and community expectations (e.g., clarifying intentions, roles, and responsibilities); balancing of needs and interests (e.g., assessing whether decisions we make are reflective of community priorities or our own individual interests); navigation through three different IRBs (the university's, area Indian Health Board's, and a national Protocol Review Committee); insider/outsider politics and protectiveness, mistrust, and ambivalence by community members because of past experiences with research; and delays in our timeline. In the following sections, we explicate two process-oriented examples – the first regarding differing academic–community expectations and the second with respect to balancing of needs with interests – to illustrate some of the questions we deliberated, the manner in which we addressed them, and various time-consuming aspects of CBPR.

### **DESIGN OF A RESEARCH PROTOCOL/DATA SHARING AGREEMENT**

Some of the challenges we have encountered in our working relationship as a university–community team have revolved around differing assumptions and expectations, and the need to clarify partner intentions, roles, and responsibilities.

One example in particular that required further exploration was around the assumptions each partner made with respect to 'ownership' of data. In conversations between academic and community partners, university investigators have consistently underscored that this research is being conducted for the benefit of the community and value has always been placed on community ownership of the project. However, each partner interpreted what the language of ownership meant slightly differently, in terms of control of and access to data.

The issue around interpretation surfaced during discussions between community and university partners regarding where data should be stored. University investigators presumed that the data would be kept at their institution for the purposes of co-analysis and subsequent joint dissemination with community members, as this had been the norm with other research projects and the university was already set up to securely house data (e.g., on password protected computers and in locked filing cabinets/offices). Community partners, on the other hand, naturally assumed that ownership of data meant that raw materials would be stored on the reservation and accessed by university team members only with tribal approval. The inconsistency in our understandings led us as a group to question the subtleties of the term 'ownership' and the meaning behind it: Did the condition of ownership subsume complete control over access to data (in which case, academic researchers would be required to seek tribal approval for purposes of data analysis)? Is this the definition that university investigators anticipated when they emphasized community ownership of data? What would the process of accessing data entail and would permission procedures differ depending on who (university or community research team members) was requesting it? And, what would it mean for protection of human subjects to store data in one location versus the other? We knew of other tribal communities (e.g., the Navajo Nation) that proactively assumed ownership and control of research conducted in their communities, but were unclear as to how they handled issues around data storage and access.

The process of working out answers to the numerous questions that arose was a site of negotiation that required each party to divulge their intentions, examine how to logistically meet the needs of each group, and consider the ethical dimensions of the decisions we made in the process. For example, while university investigators were truly involved in this project for the good of the community, they had to admit that bureaucracies and pressures of the academy (e.g., 'publish or perish') made them tense about giving up complete control, in terms of accessing and reporting of data. Together, university–community partners were able to



establish principles regarding the co-authorship of an acceptable minimum number of project articles and create a Research Review Committee (RRC) consisting of three tribal and two university partners, who would be responsible for approving dissemination products and ensuring that they were not harmful to the community.

In terms of housing data, university and community partners came to the agreement that data should be kept in both locations (at the university for ease of analysis and within the community to honor tribal ownership of the data), but had to logistically determine how data would be stored in a manner that protected participants. Community and university partners maintained that confidentiality of participants was crucial, especially for those participants who felt that the information they provided would make them easily identifiable and vulnerable within their own community. Thus, a decision was made to initially store data exclusively at the university, until academic researchers cleansed the data of potentially identifying information, and then store a copy of cleansed data at tribal administrative buildings, where it would be kept in secure locations (similar to locked and password protected conditions at the university). If any individual other than a research team member wants to access cleansed data at either site, permission must be granted by the RRC. Research participants are made aware at the time of informed consent of these measures and have the right to refuse participation or withdraw from the study at any time.

The conversations that ensued as a result of differing interpretations with respect to the meaning of project ownership importantly raised a myriad of other uncertainties regarding the overall research process and our assumptions and expectations of each other. Committed to the principles of transformative, decolonizing research and the establishment of a mutually beneficial relationship, university and community partners engaged in lengthy dialogue about past research injustices committed by other researchers and the need to create policies that clearly delineate accountability with respect to each phase of the research process. Over the next 9 months, team members worked with tribal leaders to create a set of operating guidelines that clearly define the roles and relationships between the university and the community, as well as how research is to be enacted. This developmental process in itself was an exercise in CBPR. The result is a Research Protocol and DSA that was officially approved and executed by each party. The Research Protocol section of the document (Box 1) sets forth the conditions under which team investigators and other may perform project research activities on living human subjects within the territorial jurisdiction of the tribe. The DSA section

### **BOX 1: ELEMENTS OF THE RESEARCH PROTOCOL**

- (1) Background statements that establish the context under which the protocol was formed, in terms of recognition of tribal rights, past injustices committed by other researchers, tribal ownership of cultural knowledge, and the intent to promote collaboration within the framework of mutual respect, equity, and empowerment in the conduct of research that is beneficial to the community.
- (2) Statements of purpose that specify reasons why the protocol was developed (e.g., the need to clarify our partnership and set forth conditions under which project investigators may conduct research on living human subjects within the jurisdiction of the tribal community).
- (3) A description of policies to protect tribal members and ensure that the project is beneficial, culturally relevant, and consistent with community priorities.
- (4) Guiding principles for project interactions that acknowledge our mutual vision of decolonizing research practices and centering indigenous values.
- (5) Criteria and duties for the Research Review Committee (RRC) comprised three tribal and two university partners who will review all scientific proposals, processes, and products regarding the project, and provide oversight of all research protocols and DSAs related to the study.
- (6) Delineation of the CAB's function (e.g., to provide insight regarding the cultural and community relevance of project materials and procedures, examine project materials, provide consultation, and ensure that the community needs are being met, etc.).
- (7) Definitions of research-related terminology (e.g., 'tribal member', 'research', 'biogenetic samples', 'products of research', 'traditional intellectual property', etc.).
- (8) Regulations regarding the appropriate handling and destruction of biological samples.
- (9) Requirements for new data collection activities, analyses, or research proposals.
- (10) Policies regarding submission and review of new proposals related to the overall project,
- (11) Rules related to modifications of a previously approved project.
- (12) Tribal and university rights around qualms and grounds for project termination.
- (13) Prohibited conduct (e.g., that no research will be conducted or resources removed from the community without approval from the RRC).
- (14) The effective date of the protocol, and signatures of university and tribal representatives.

(Box 2) provides the conditions under which team investigators and others may perform project data collection, sharing, and dissemination activities.

## BOX 2: ELEMENTS OF THE DATA SHARING AGREEMENT

- (1) Purposes of the DSA that set forth the conditions under which project researchers may perform data collection, sharing, and dissemination activities within the community's jurisdiction.
- (2) A description of the overall academic research agreement so that the study proceeds in a manner that is culturally appropriate, relevant to the tribal community, and complies with federal and tribal laws related to research with human subjects.
- (3) DSA stipulations and conditions, including who specifically from the tribal community and the university will co-ordinate data sharing efforts.
- (4) Details of all data collection activities, including which research team members will be responsible for specific activities and a statement acknowledging that final reports will be produced in a university–community partnership and disseminated only with tribal approval.
- (5) Data storage and sharing responsibilities, specifying exactly how data will be secured; that all data will be co-housed at the university and the tribal community for analytic purposes after personal identifiers have been removed and the data have been cleansed by the university (prior to these de-identifying activities, data will only be stored at the university to maximize participant confidentiality); timelines for when data need to be destroyed by the university; and stipulations that data not be shared with non-research team members without explicit approval from representatives on the RRC.
- (6) General research responsibilities that include a commitment to recognize the rights of tribal people, respect traditions and values, build research infrastructures within the community, and continue giving back to the community after project completion.
- (7) Dissemination responsibilities that designate the RRC as being responsible for reviewing all study products, guarantee that products of research be relayed and provided to the community, and make a commitment to co-authorship of specific publications (e.g., findings publications for each project phase).
- (8) Operating guidelines for protecting human subjects and their data (how confidentiality will be maintained).
- (9) Provisions for DSA termination, which note that both the university and the tribal community have the right to terminate the DSA by giving 30 days written notice.
- (10) Length of time of DSA effectiveness.

The Research Protocol/DSA encouraged university and community representatives to contemplate our different understandings of issues around project ownership and

expand the conversation more globally in terms of what each group expected of themselves and each other throughout the scope of the project. Designing these documents was a useful process to explore the meanings and implications of terms that both groups used and devise project guidelines that are beneficial to investigators, community members, and participants. Similar to reports by other academic–community collaborations, in which research protocols were established (e.g., Herbert 1996; Macaulay et al. 1998; Holkup et al. 2004), we found that delineating each group's roles and responsibilities was a functional way to ease tensions that resulted from ambiguities, build trust between partners, and promote cohesive interactions by providing provisions of accountability.

## CREATION OF A QUALITATIVE INTERVIEW GUIDE

For the qualitative aim of the project, we planned to conduct face-to-face interviews with individuals who had been diagnosed with CVD and/or diabetes, so that tribally specific illness constructions and experiences could inform our intervention efforts and be used by the community to tailor and improve healthcare services that tribal members with these illnesses receive. CVD and diabetes are, respectively, the first and fourth leading causes of death for American Indians (CDC 2003). Prevalence rates for CVD and diabetes are highest among American Indians in comparison with the general US population (Barnes, Adams, and Powell-Griner 2010). The diabetes mortality rate for American Indians in the Pacific Northwest (142 deaths per 100,000) aligns with the rate for American Indians nationwide; however, the CVD mortality rate among American Indians in the Pacific Northwest (186 deaths per 100,000) is the highest of all other area racial/ethnic groups and is higher than the rate for American Indians nationwide (Washington State Department of Health 2005, 2007). Despite the enormous impact that both illnesses have among American Indians, knowledge of cultural perspectives around CVD and diabetes is extremely limited. As a research team, our goal was to create an interview guide that reflected the multitude of interests, in terms of what university/community research team members and community representatives sought to learn from tribal members who have these illnesses.

Committed to the process of collaboration and the production of knowledge that is useful to the community, we decided to conduct focus groups to develop the interview guide. Often, a difficult challenge in CBPR is determining who represents the community (formally and informally)

and who should be part of conversations regarding various community interests (Kennedy et al. 2009). Prior to initiating focus groups, our research team spent over a year establishing relationships with tribal members and developing this awareness. We informally interviewed several of these key community members (e.g., respected elders) and providers on a one-to-one basis to ascertain their perceptions regarding factors related to the prevalence of CVD and diabetes within the community. Next, we had the task of determining who from the community would be involved in formulating specific interview guide questions. In addition to the key community members and providers that we had informally interviewed, we determined it was important to broaden participation by including other providers from the community health clinic, who were directly involved in CVD and diabetes care, so that we could ask questions that these providers needed to improve health services. To recruit focus group members, the research team directly invited prospective participants by phone, email, and in-person. Coordinating a schedule when these individuals were available to meet was a challenging process that took nearly 2 months.

Two research team members (one from the university and one from the community) were responsible for organizing the focus groups. The groups consisted of tribal members, Natives (from various tribal affiliations), and non-Natives who came from a variety of disciplines (e.g., medicine, nursing, nutrition, and health education). As the group coordinators, we clarified the purpose of our meetings and came to the focus groups with two sets of sample questions, to use solely as a starting point for group discussion. We believed that providing questions for focus group members to react to would be an easier way to initiate a group conversation about the types of questions they wanted to ask. We emphasized to participants that these questions did not have to be included in the interview guide we were constructing, but were merely a starting point for reflection and discussion.

The first set of questions came from a compilation that one research team member assembled after a literature review for a previous project, which examined how urban American Indians construct diabetes (Mohammed 2004). The types of questions, tailored in terms of their relevance for this project, reflected the team's interest in capturing illness meanings of CVD and/or diabetes, narratives about peoples' experiences living with CVD and/or diabetes, as well as personal barriers and facilitators to disease management. Example questions (which could be framed appropriately for either illness) included: 'Tell me about your experiences with CVD/diabetes', 'What did you think about when you first found out you have CVD/diabetes?', 'People

have different explanations for how they got CVD/diabetes, how do you think this illness occurs?', 'What effects do you think having CVD/diabetes has on a person and what has it been like for you?', 'What kinds of things are you doing to manage your CVD/diabetes and how are these things helpful to you?', and 'What gets in the way of being able to manage your CVD/diabetes?' The second set of questions was assembled by community and university team members and stemmed from the key informant community member/provider informal interviews that were conducted prior to the focus groups. Although several of these questions assessed traditional risk factors for CVD (e.g., patterns of diet and exercise), many of them also probed for information regarding social determinants of CVD (e.g., low income and historical trauma). Example questions included: 'Why do you think heart disease and diabetes are so significant in this community?', 'How physically active are you at this time in your life?', 'Could you describe a typical day in terms of what you eat?', 'Have there been times when there wasn't enough food in the house?', 'What are some historical events in your community that have challenged the ability of tribal members to maintain healthy lifestyles?', and 'What are the things in your community that help people to have healthy lifestyles?'

As focus group members reviewed the questions, they commented on the relevance of each for the community. Some questions immediately interested participants – they felt that the questions allowed for people to share narratives about CVD and/or diabetes in ways that were personally or socioculturally meaningful. Other questions were quickly excluded. As individuals became more involved, different group dynamics began to develop. Typical to the nature of group interactions, distinct hierarchies and shifting identities emerged among the participants in each group. At times, these hierarchies and identities were related to whether or not individuals were enrolled tribal members (e.g., tribal members often assumed a more dominant role than non-tribal members and non-Natives), and at other times they reflected socially constructed occupational ranking between the different providers who were present (e.g., relational differences in power between physicians and other health professionals). Although we envisioned our focus groups as a space where participants could freely and equally represent their ideas, these hierarchies initially dictated who led conversations, as group members routinely gave deference to those individuals who had more 'authority'. These types of relational norms became more difficult for group members to interpret when the ranks of identity were not so obvious (i.e., it was trickier for them to determine which identity – tribal or occupational – carried greater positioning) and during these times, deference turned to silence.



On other occasions, comments that were emphatically enounced quieted individuals who either held different opinions or had different conversational styles. Although these types of interactions often left us with feelings of discomfort (i.e., long gaps of silence admittedly made us feel uncomfortable), as organizers of the focus groups, we believed that working out these group dynamics was a valuable part of the process of conducting CBPR. Thus, we chose not to intervene when these relational situations arose.

Over time, the impact of group hierarchies began to diminish and members started to increasingly participate in the process and respond to comments. They were able to take contentious questions that their fellow participants suggested to include in the interview guide and reframe them in more positive, open-ended ways. For example, questions that intonated too much individual culpability in lack of illness management were reconstructed to focus on ways in which the broader community could support these individuals.<sup>5</sup> As participants became more involved, it was apparent that the types of questions they put forth reflected their specific occupations at the clinic (e.g., nutritionists focusing on questions about diet). It was also clear that the clinic representatives were vested in how they could collectively improve the care they provide for individuals with CVD and/or diabetes. We left the meetings with a list of questions that represented what participants suggested to include, but was far too lengthy. As researchers invested in embodying decolonizing practices, we did not want to usurp power over the process and solely make the final decisions on what questions to include, cognizant that we may tend to favor questions that represented our own concerns. Therefore, we consulted with three additional key tribal community members who reviewed the questions posed and helped us systematically pare them down. Through this process, we found that we were able to incorporate the majority of the questions that focus group participants had suggested by combining different questions and using interviewer probes that signified their intent. Although this process was much more time-consuming than non-collaborative methods, in the end, we were able to design an interview guide that reflected community, clinic, and researcher interests.

## LESSONS LEARNED

In this article, we contribute to the body of literature on the complexities of CBPR by providing two examples of issues that we have encountered in a project designed to prevent

CVD among an indigenous community and discussing how we addressed them. Specifically, we explicate the construction of a Research Protocol/DSA and qualitative interview guide that addressed the concerns of both university and tribal community constituents. In the process of designing these documents, we have learned several key lessons.

In the case of the Research Protocol and DSA, we realize the benefit of defining meanings around the language that we use with each other, the value of transparency, voicing our needs and intentions, contemplating how different options have the potential to affect the protection of participants, and importantly, the advantage of creating a written document that clarifies the roles and responsibilities of each partner. There are several articles that provide recommendations for researchers conducting CBPR with Native communities (e.g., Burhansstipanov, Christopher, and Schumacher 2005; Strickland 2006; Christopher et al. 2008; Baldwin, Johnson, and Benally 2009) but fewer that, in a similar vein to our efforts, summarize the development and overall description of a mutually agreed upon protocol between academic researchers and communities. We believe that establishing contracts of this nature earlier in a working relationship rather than later would be more helpful in terms of reducing partnership uncertainties, establishing trust, getting community buy-in, and co-creating meaning – which was a valuable lesson we learned.

As for the qualitative interview guide, the process of constructing the questions in itself actualized the required compromise to balance and address individual, occupational, research, and community-driven interests. We had to navigate issues around community representation, shifting identities, and relational hierarchies between enrolled tribal members and non-members and different occupational disciplines. The various interactions that occurred in our focus groups required members to be introspective and examine how they had been trained and institutionalized. It also required that members come together in terms of prioritizing community needs, versus their own interests. Although much more time-consuming than utilizing one-sided models of research, conducting focus groups was beneficial, because it encouraged participants to broaden their perspectives, navigate group dynamics, and join together to generate relevant interview questions. Employing principles of CBPR enabled the co-development of an interview guide that is community-specific, culturally appropriate, reflective of community needs, and more engaging for interview participants. For researchers, co-creating the qualitative interview guide with community partners also enabled us to broaden our horizons and understanding in terms of meanings of health, how social determinants of health intersect and

<sup>5</sup> Specific illustrations of this example are not provided to protect focus group members' confidentiality.

operationally function within the tribal community, and which aspects of health community members and providers want to understand.

Overall, we discovered that academic–community collaborations are ongoing sites of negotiation that require constant care and attention. Each interaction between partners is an opportunity for relationship growth. Although roles, responsibilities, and level of academic or community involvement may vary in each phase of research and differ from project to project, working out relationships and maintaining equity throughout the research process is fundamental to CBPR. There are multiple ways to conduct CBPR and each partnership has to find its own rhythm. We believe that the success of CBPR is dependent upon both partners recognizing and valuing their own and each other’s knowledge and contributions, and promoting open and honest lines of communication. While there will always be issues that emerge in partnerships, engaging these practices has enabled us to maintain a relationship that is based on an assumption of good intentions.

Although CBPR can be used as a decolonizing research strategy to develop relationships that prioritize tribal sovereignty, successful implementation requires university partners to broaden their notions of the research process and project ownership, deconstruct power and privilege, and honor indigenous epistemologies and local knowledge (Tuhiwai Smith 2005; Pyett, Waples-Crowe, and van der Sterren 2008). Finding middle ground in a university-community partnership is a process that requires the embodiment of cultural humility and cultural safety in combination with process-oriented, egalitarian methods (Israel et al. 2005). Every step of the way, university and community partners must examine and articulate their own assumptions and expectations and take the time to nurture a relationship based on compromise, to effectively meet the needs of each group, enhance the quality of research, and increase research success.

## ACKNOWLEDGEMENTS

Preparation of this article was supported by grant 5U01HL087322-05 from the National Heart Lung and Blood Institute. We thank our indigenous community partners, university partners, and project participants for their dedication and sincere contributions to this work.

## REFERENCES

- Baldwin JA, JL Johnson and CC Benally. 2009. Building partnerships between indigenous communities and universities: Lessons learned in HIV/AIDS and substance abuse prevention research. *American Journal of Public Health* 99 (Suppl. 1): S77–82.
- Barnes PM, PF Adams and E Powell-Griner. 2010. Health characteristics of the American Indian or Alaska Native adult population: United States, 2004–2008. *National Health Statistics Reports* 20: 1–24.
- Burhansstipanov L, S Christopher and SA Schumacher. 2005. Lessons learned from community-based participatory research in Indian country. *Cancer Control* 12(Suppl. 2): 70–6.
- Canadian Institutes of Health Research. 2007. CIHR guidelines for health research involving Aboriginal people. <http://www.cihr-irsc.gc.ca/e/29134.html> (accessed 25 June 2010).
- Center for Disease Control (CDC). 2003. Surveillance for health behaviors of American Indians and Alaska Natives. *MMWR* 52(SS07): 1–13.
- Christopher S, V Watts, AK McCormick and S Young. 2008. Building and maintaining trust in a community-based participatory research partnership. *American Journal of Public Health* 98: 1398–406.
- Cornwall A and R Jewkes. 1995. What is participatory research? *Social Science & Medicine* 41: 1667–76.
- Dillingham B. 1977. Indian women and IHS sterilization. *American Indian Journal* 3: 27–8.
- Faridi Z, JA Grunbaum, BS Gray, A Franks and E Simoes. 2007. Community-based participatory research: Necessary next steps. *Preventing Chronic Disease* 4: 1–5.
- Foster J and K Stanek. 2007. Cross-cultural considerations in the conduct of community-based participatory research. *Family Community Health* 30: 42–9.
- Foulks EF. 1989. Misalliances in the Barrow Alcohol Study. *American Indian and Alaska Native Mental Health Research* 2: 7–17.
- Freeman ER, D Brugge, WM Bennett-Bradley, JI Levy and ER Carrasco. 2006. Challenges of conducting community-based participatory research in Boston’s neighborhoods to reduce disparities in asthma. *Journal of Urban Health* 83: 1013–21.
- Herbert CP. 1996. Community-based research as a tool for empowerment: The Haida Gwaii Diabetes Project example. *Canadian Journal of Public Health* 87: 109–12.
- Holkup PA, T Tripp-Reimer, EM Salois and C Weinert. 2004. Community-based participatory research: An approach to intervention research with a Native American community. *Advances in Nursing Science* 27: 162–75.
- Horn K, L McCracken, G Dino and M Brayboy. 2008. Applying community-based participatory research principles to the development of a smoking-cessation program for American Indian teens: “Telling our story”. *Health Education and Behavior* 35: 44–69.

- Israel BA, AJ Schulz, EA Parker, AB Becker, AJ Allen III and JR Guzman. 2003. Critical issues in developing and following community based participatory research principles. In *Community-based participatory research for health*, eds M Minkler and N Wallerstein, 53–76. San Francisco: Jossey-Bass.
- Israel BA, E Eng, AJ Schulz and EA Parker, eds. 2005. *Methods in community-based participatory research for health*. San Francisco: Jossey-Bass.
- Israel BA, J Krieger, D Vlahov, S Ciske, M Foley, P Fortin, JR Guzman et al. 2006. Challenges and facilitating factors in sustaining community-based participatory research partnerships: Lessons learned from the Detroit, New York City and Seattle Urban Research Centers. *Journal Urban Health* 83: 1022–40.
- Kennedy C, A Vogel, C Goldberg-Freeman, N Kass and M Farfel. 2009. Faculty perspectives on community-based research: “I see this still as a journey”. *Journal of Empirical Research on Human Research Ethics* 4: 3–16.
- Khanlou N and E Peter. 2005. Participatory action research: Considerations for ethical review. *Social Science and Medicine* 60: 2333–40.
- Lawrence J. 2000. The Indian Health Service and the sterilization of Native American women. *American Indian Quarterly* 24: 400–19.
- Lindamer LA, B Lebowitz, RL Hough, P Garcia, A Aguirre, MC Halpain, C Depp and DV Jeste. 2009. Establishing an implementation network: Lessons learned from community-based participatory research. *Implementation Science* 4: 17.
- Macaulay AC, T Delormier, AM McComber, EJ Cross, LP Potvin, G Paradis, RL Kirby, C Saad-Haddad and S Desrosiers. 1998. Participatory research with native community of Kahnawake creates innovative Code of Research Ethics. *Canadian Journal of Public Health* 89: 105–8.
- Manson SM, E Garrouette, RT Goins and PN Henderson. 2004. Access, relevance, and control in the research process: Lessons from Indian country. *Journal of Aging and Health* 16 (Suppl. 5): 58S–77S.
- McHugh TF and KC Kowalski. 2009. Lessons learned: Participatory action research with young aboriginal women. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 7: 117–31.
- Minkler M. 2004. Ethical challenges for the “outside” researcher in community-based participatory research. *Health Education & Behavior* 31: 684–97.
- Minkler M. 2005. Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health* 82 (Suppl. 2): ii3–12.
- Mohammed SA. 2004. The intersectionality of diabetes and the cultural-political contexts of urban American Indians. PhD diss., University of Washington.
- Papps E and I Ramsden. 1996. Cultural safety in nursing: The New Zealand experience. *International Journal for Quality in Health Care* 8: 491–7.
- Pyett P, P Waples-Crowe and A van der Sterren. 2008. Challenging our own practices in Indigenous health promotion and research. *Health Promotion Journal of Australia* 19: 179–83.
- Roubideaux Y and M Dixon. 2001. Health surveillance, research, and information. In *Promises to keep: Public health policy for American Indians & Alaska Natives in the 21st century*, eds M Dixon and Y Roubideaux, 253–74. Washington, DC: American Public Health Association.
- Sahota PC. 2007. Research regulation in American Indian/Alaska Native communities: Policy and practice consideration. National Congress of American Indians Policy Research Center. [http://www.ncaiprc.org/pdf/1196282550Research\\_Regulation\\_final\\_paper\\_110607.pdf](http://www.ncaiprc.org/pdf/1196282550Research_Regulation_final_paper_110607.pdf) (accessed 20 June 2010).
- Shaffer M. 2004. Havasupai blood samples misused. *Indian Country Today*, 10 March.
- Shalowitz MU, A Isacco, N Barquin, E Clark-Kauffman, P Delger, D Nelson, A Quinn and KA Wagenaar. 2009. Community-based participatory research: A review of the literature with strategies for community engagement. *Journal of Developmental and Behavioral Pediatrics* 30: 350–61.
- Shore N, KA Wong, SD Seifer, J Grignon and VN Gamble. 2008. Introduction to special issue: Advancing the ethics of community-based participatory research. *Journal of Empirical Research on Human Research Ethics* 3: 1–4.
- Slemon S. 1995. The scramble for post-colonialism. In *The post-colonial studies reader*, eds B Ashcroft, G Griffiths and H Tiffin, 45–52. London: Routledge.
- Strickland CJ. 2006. Challenges in community-based participatory research implementation: Experiences in cancer prevention with Pacific Northwest American Indian tribes. *Cancer Control* 13: 230–6.
- Tervalon M and J Murray-Garcia. 1998. Cultural humility versus cultural competence: A critical distinction in defining physician training outcomes in multicultural education. *Journal of Health Care for the Poor and Underserved* 9: 117–25.
- Tuhiwai Smith L. 1999. *Decolonizing methodologies: Research and indigenous peoples*. London: Zed Books Ltd.
- Tuhiwai Smith L. 2005. On tricky ground: Researching the Native in the age of uncertainty. In *Handbook of qualitative research*, eds NK Denzin and YS Lincoln, 85–107. Thousand Oaks: Sage Publications.

- W.K. Kellogg Foundation. 2001. *Stories of impact*. Ann Arbor: School of Public Health, Community Scholars Program, National Program Office, University of Michigan.
- Wallerstein N and B Duran. 2003. The conceptual, historical and practice roots of community based participatory research and related participatory traditions. In *Community based participatory research in health*, eds M Minkler and N Wallerstein, 27–52. San Francisco: Jossey-Bass.
- Wallerstein NB and B Duran. 2006. Using community-based participatory research to address health disparities. *Health Promotion Practice* 7: 312–23.
- Walters KL, JM Simoni and T Evans-Campbell. 2002. Substance use among American Indians and Alaska Natives: Incorporating culture in an “indigenist” stress-coping paradigm. *Public Health Reports* 117 (Suppl. 1): S104–17.
- Walters KL, A Stately, T Evans-Campbell, JM Simoni, B Duran, K Schultz, EC Stanley, C Charles and D Guerrero. 2009. “Indigenist” collaborative research efforts in Native American communities. In *The field research survival guide*, ed. AR Stiffman, 146–73. New York: Oxford University Press, Inc.
- Warne D. 2006. Research and educational approaches to reducing health disparities among American Indians and Alaska Natives. *Journal of Transcultural Nursing* 17: 266–71.
- Washington State Department of Health. 2005. Diabetes. *The Health of Washington State* 5: 1–7.
- Washington State Department of Health. 2007. Coronary heart disease. *The Health of Washington State* 5: 1–6.