

# The Adaptation and Implementation of a Community-Based Participatory Research Curriculum to Build Tribal Research Capacity

| Valarie Blue Bird Jernigan, DrPH, MPH, Tvoli Jacob, MPH, the Tribal Community Research Team, and Dennis Styne, MD

We studied community-based participatory research in American Indian/Alaska Native communities. We have presented a case study describing a community–clinic–academic partnership with the goal of building tribal capacity and infrastructure to conduct health disparities research. The 2-year intensive training was guided by the framework of an evidence- and community-based participatory research curriculum, adapted and implemented with practice-based data collection activities and seminars to address issues specific to community-based participatory research with sovereign tribal nations. The initiative highlighted important challenges and opportunities in transdisciplinary partnerships; identified gaps in conducting health disparities research at the tribal, clinical, and university levels; and led to important policy change initiatives in all the partner settings. (*Am J Public Health*. 2015;105:S424–S432. doi:10.2105/AJPH.2015.302674)

Community-based participatory research (CBPR), defined as “systematic inquiry with the participation of those affected by an issue to education and action for social change,”<sup>1(p4)</sup> can be a powerful tool for addressing American Indian and Alaska Native (AI/AN) health disparities.<sup>2–5</sup> CBPR is congruent with the research protocols set forth by many tribal nations,<sup>6–8</sup> and tribes are increasingly applying Indigenous values, practices, and knowledge<sup>9</sup> as part of CBPR partnerships to address obesity and diabetes,<sup>2,4</sup> environmental health,<sup>10</sup> breast cancer screening,<sup>11</sup> suicide prevention,<sup>12–14</sup> and other health issues. However, significant disparities exist in the level of CBPR training and resources available between tribes and their academic partners.<sup>15</sup> Indeed, tribes report a lack of knowledge, skills, resources, and leadership within their communities to engage in, support, and sustain CBPR processes and products.<sup>6,16,17</sup> As a result, many CBPR efforts dissolve when external funding ends.

Several CBPR training curricula have been developed<sup>18,19</sup>; however, few or none address important aspects of conducting

research with sovereign tribal nations.<sup>20</sup> For example, although each of the more than 550 federally recognized tribal nations has its own governing structure and laws, many tribes maintain their own community research review boards<sup>21,22</sup> or federally certified institutional review boards (IRBs)<sup>23</sup> developed in response to abuses against tribes in the name of scientific research.<sup>24–26</sup> These boards weigh the risks and benefits of proposed research on tribal lands and with tribal community members in the context of tribal culture and community. These boards may require tribal ownership of all data collected and often mandate tribal review and approval of all publications, thus making research with tribal citizens different from research with any other racial or ethnic group.

The Community–Campus Partnerships for Health (CCPH) at the University of Washington offers an evidence-based<sup>27</sup> CBPR curriculum—the Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum (hereafter referred to as the CCPH curriculum)—that is designed for academic

and community partners alike and is available at no cost via the CCPH Web site. We adapted and implemented the CCPH curriculum as part of an intensive 2-year training partnership from 2010 to 2013, with the goal of developing capacity and infrastructure to conduct research in 3 tribal communities and 2 tribal clinics in Northern California.

## METHODS

Our partnership consists of 2 clinics, 3 communities, and an academic institution. The 2 clinic partners play a central role in interfacing with the academic and community partners and organizing the day-to-day partnership activities. The clinic partners are staff members from 2 Indian health clinics—a reservation-based clinic and a rural clinic. The reservation-based clinic is located on a federally recognized reservation in a remote valley approximately 2 hours away from the nearest hospital and emergency services. The clinic provides primary health care to approximately 3000 AIs living on and near the reservation. Similar to other reservation communities, this population experiences high rates of poverty and associated negative health outcomes.

The other clinic involved in this initiative, although also located in a rural environment, is not located on a reservation. This rural clinic provides basic medical, dental, behavioral, and community health services to a 4-county region in Northern California with an AI population of approximately 7300 (about 2.2% of the total population of the region). The majority of the AI population resides in small- to medium-sized towns scattered widely throughout this mostly rural environment. Rates of poverty and associated

negative health outcomes are as high in these AI communities as in those seen in the reservation community.

The academic partners include a pediatric endocrinologist (D.S.) at the University of California, Davis (UC Davis) School of Medicine, and an AI interventionist (V.B.J.) specializing in CBPR and implementation science (also affiliated with UC Davis at the time of this training initiative).

### Partnership Development

Although the efforts of the formal CBPR training program began in 2010, the origins of this partnership stem back to 2004, when clinic staff, faced with severe budget cuts as part of the economic recession, approached the academic researchers to obtain external funding to continue their health promotion efforts. The AI interventionist (V.B.J.) introduced CBPR to the clinic staff early in the partnership because of its focus on research for action and social change. Over the next 5 years (2004–2009) the clinic staff worked with the academic partners to conduct small pilot studies addressing community health priorities. The pilot studies provided an opportunity for academic partners to visit the tribal communities, learn about the cultures and health priorities of the communities, and build relational accountability and trust within the partnership.

In 2010, as part of the American Reinvestment and Recovery Act (Pub. L. No. 111-5, 123 Stat 115, HR 1, 111th Cong), the partnership received a training grant from the National Institute of Diabetes, Digestive, and Kidney Diseases to provide formal and structured training in CBPR to an expanded group of the clinic staff and members of the 3 partnering communities as well as academic partners from UC Davis interested in gaining skills to conduct CBPR. A subgroup of 6 individuals representing the community, clinic, and academic sectors, who were involved in the partnership from its earliest stages in 2004, took a leadership role in guiding the training and served as the “leadership group.” The academic sector representatives included the study principal investigator (D.S.) and the AI interventionist (V.B.J.). The clinic partners included a public health nurse and a grant writer, both of whom were the project directors at the

clinic sites. Two community members, a health worker and a community educator, represented the community sector.

### Training Recruitment and Compensation

The clinic project directors, working in consultation with clinic boards and staff, were responsible for recruiting community research trainees (CRTs) to participate in the training. Recruitment efforts were similar in both settings: the clinic project directors, with input from the clinic health boards, generated lists of individuals from different families and of varying ages, all of whom had an interest in fostering greater community well-being. AI community members from diverse sectors of each of the 3 tribal communities, including tribal council members, youths, elders, and community health workers, were identified and invited to participate.

Compensation was considered a critical sign of respect for the time commitment the CRTs were making. Thus, the CRTs were provided with a \$50 stipend for participating in a half-day training, \$100 for participating in a full-day training, and bonuses of \$75 to \$100 for completing project activities such as the online Collaborative Institutional Training Initiative examination,<sup>28</sup> a Web-based human participants research training curriculum that covers the historical development of human participant protections as well as current information on regulatory and ethical issues in biomedical and social, behavioral, and educational research. In total, 28 CRTs participated.

### Curriculum Adaptation and Implementation

Before making any changes to the existing CCPH curriculum, the leadership subgroup hosted a 2-day partnership summit, held at UC Davis, to kick off the project, solicit the CRTs’ ideas and priorities for using research to create change within their communities, and foster a spirit of colearning and participation. All 28 CRTs attended, as did the clinic staff and faculty members. With the exception of 6 members of the leadership group, the summit attendees had little or no exposure to CBPR. On the basis of the feedback received during the summit, the leadership group determined that the CCPH curriculum addressed many of the priorities identified by the CRTs and that

therefore its integrity should be retained with only the following slight adaptations.

First, the leadership group felt that the CCPH curriculum was too long and written from an academic perspective, thus the group abridged and reduced the reading level of the 7 CCPH curriculum units. Additionally, telemedicine equipment, used by the 2 tribal clinics to receive specialty medical care from UC Davis, was used to deliver the trainings to the CRTs who met in groups at both clinic sites. We elected to use the telemedicine equipment because hosting in-person meetings with all 28 CRTs was cost prohibitive and delivering the trainings via the Internet to CRTs at home was not feasible for CRTs with unreliable or no home Internet access. Using the telemedicine equipment allowed participants at all 3 of the sites (i.e., UC Davis and both clinics) to view each other and engage in high-quality participation.

The telemedicine trainings were held quarterly for 2 years with each of the 7 modules (Table 1) presented separately in 3-hour intervals, and every meeting included food and provided transportation to and from the clinic sites. Two in-person meetings were also held each year, with the location rotating between the partners. Both the telemedicine trainings and the in-person trainings were video recorded and posted on a project Web site, allowing CRTs who had to miss a training to view it at home, if possible, or at the clinic sites and still receive the stipend.

The CCPH curriculum exercises and examples were also adapted, as described in Table 2. Exercises are activities that typically require trainees to work in groups and discuss or role-play potential scenarios that emerge in CBPR. For instance, an exercise in unit 2 asks trainees to role-play the difficult process of choosing research priorities as members of a CBPR partnership with competing agendas and demands. Examples, conversely, are primarily real-world case studies illustrating the application of the curriculum topics. For instance, unit 3 of the curriculum discusses the development of partnership operating procedures and bylaws. “Harlem Community & Academic Partnership Operating Procedures and By-Laws” is presented as an example of how 1 CBPR partnership developed and implemented partnership bylaws.

**TABLE 1—Summary of Curriculum Units, Learning Objectives, Exercise Topics, and Examples**

Curriculum Unit	Learning Objectives	Exercise Topics	Selected Examples
1: CBPR—Getting Grounded	Identify principles of CBPR Describe differences between CBPR and traditional research Identify ethical considerations	Ethical issues in CBPR	Redwood-Jones Photovoice Project
2: Developing a CBPR Partnership—Getting Started	Identify and select partners Set priorities	Identifying and selecting new partners Choosing priorities	Detroit Community–Academic Urban Research Center
3: Developing a CBPR Partnership—Creating a Shared Vision	Create a shared vision Establish organizational structure Establish mission statement and bylaws Identify applicable policies and procedures	Creating a “shared vision” Applying CBPR principles Developing operating norms	Seattle Partners for Healthy Communities
4: Trust and Communication in a CBPR Partnership	Articulate the importance of trust Establish and maintain trust Make decisions and communicate Resolve conflicts Motivate, recognize, and celebrate partners	Understanding why people get involved Understanding assumptions Understanding what hinders trust in partnerships Overcoming obstacles Transparency and communication “The real world”	The Harlem Community and Academic Partnership
5: Show Me the Money—Securing and Distributing Funds	Identify funding sources for CBPR Respond to proposal requests Develop proposals Secure long-term funding	Assembling the research team A partnership’s “household” finances Assessing your current funding	
6: Disseminating the Results of CBPR	Disseminate results Create policies and procedures		The North Carolina Public Health Initiative Authorship Guidelines
7: Unpacking Sustainability in CBPR Partnerships	Identify strategies for sustainability Conduct participatory, formative evaluation Identify barriers to sustainability Identify efforts to continue Deal with change	Understanding what sustainability means Factors for sustaining partnerships Determining continuing efforts Reaction and prioritization scenario Temporary funding scenario Loss of funding scenario	Prevention Research Center Michigan

Note. CBPR = community-based participatory research.

In the CCPH curriculum none of the exercises or examples references AI/AN communities. Therefore, the leadership group retained exercises and examples that were broad and relevant to AI/AN communities and slightly adapted some of them, if necessary, to focus on research issues often experienced in AI/AN communities. For instance, a unit 1 example presents ethical issues that arise in CBPR and illustrates these issues in a case study of an urban African American CBPR partnership. We modified this to be an urban AI/AN community with similar but slightly different

cultural issues and challenges. A unit 3 exercise asks trainees to work in groups to identify what resources are needed to support their CBPR partnership. We did not make adaptations to this general and broadly relevant exercise.

As part of our efforts to abridge and reduce the reading level of the curriculum we eliminated approximately half of the original CCPH curriculum exercises and examples. We replaced the remaining half with real-world case studies and scenarios specific to AI/AN communities that were taken from our own

experiences or from the experiences of other AI/AN communities; researchers shared these with permission. Each adapted exercise and example was included as long as the leadership group felt it retained the key concepts and learning objectives of the 7 units. The revised exercises and examples focused on topics such as the challenges and opportunities in working with non-AI researchers, translating AI/AN language and cultural concepts into partnership processes, and engaging with tribal councils to support and promote research development (Table 2).

**TABLE 2—Augmented and Adapted CBPR Curriculum, Learning Objectives, Exercises, and Examples**

Curriculum Unit	Augmented Learning Objectives	Adapted Exercises and Examples	Specialized Training
1: CBPR—Getting Grounded	Identify American Indian perspectives of research Understand how tribal values relate to research Incorporate tribal values in decisions regarding research in tribal communities	Exercise: Indigenous ways of knowing, scientific ways of understanding Example: The role of culture in research Example: Tribal community values and scientific values	
2: Developing a CBPR Partnership—Getting Started	Facilitate tribal leadership in study management and design	Exercise: Developing a research plan Exercise: Identifying opportunities for tribal leadership and policymakers to become involved in research Example: Identifying and interviewing potential academic partners Example: Guiding a research design process	
3: Developing a CBPR Partnership—Creating the “Glue”	Incorporate tribal values as a guide for developing and managing research Identify ethical considerations related to conducting research with tribal nations	Exercise: Individual versus tribal rights Example: Aspects of genetics research could help tribal communities Example: Tribal conflict of interests Example: Engaging in culturally appropriate ways of recruiting	
4: Trust and Communication in a CBPR Partnership—Spreading the “Glue” and Having It Stick	Identify key characteristics of effective tribal research policy IRBs Identify tribal research agreements	Exercise: Discussion of individual versus tribal rights Exercise: Creating tribal research agreements Example: Northwest Portland Area Indian Health Service IRB Example: California Rural Indian Health Board IRB Example: Choctaw Nation IRB Example: Chickasaw Nation IRB Example: Navajo Nation IRB	National Congress of American Indians Training: “Research That Benefits Native People: A Guide for Tribal Leaders” CITI examination
5: Show Me the Money—Securing and Distributing Funds	Grant Writing 101—Telling your community story Understand the Indigenous evaluation model	Exercise: Indigenous evaluation model	Data collection activities Community based Participatory Research Institute San Francisco
6: Disseminating the Results of CBPR	Understand the participatory article development model Identify the value in sharing your story through publication Learn to speak to diverse stakeholders	Exercise: Translating practice-based knowledge and Indigenous knowledge into academic language for publication Exercise: Communicating research processes and findings to tribal citizens Example: San Jose Diabetes Action Committee	Data analysis activities Indigenous evaluation workshop Participatory article development workshop
7: Unpacking Sustainability in CBPR Partnerships	Learn community organizing and community building for sustainability	Example: Tribal youths initiative Example: Video voice participatory documentation	

Note. CBPR = community-based participatory research; CITI = Collaborative Institutional Training Initiative; IRB = institutional review board.

**Specialized Training**

After implementing the first 4 units of the modified curriculum in year 1 of the project, the CRTs wanted to discuss in more depth

a policy development process for tribal ownership of data as well as a publication review and approval process. The CCPH curriculum does not address either of these topics,

specifically with regard to research within tribal nations. Thus we partnered with the National Congress of American Indians Policy Research Center to plan and host a special 1-day

workshop held at 1 of the clinics. This workshop, which kicked off in year 2 of the project, was grounded on the National Congress of American Indians' newly developed 5-module curriculum: Research That Benefits Native People: A Guide for Tribal Leaders.<sup>20</sup>

The special workshop aimed to facilitate participation from tribal leadership and build tribal infrastructure capacity to conduct research. The workshop focused specifically on data sharing and ownership issues and ways to assess and evaluate the potential impact (positive or negative) of particular research projects. In addition to the CRTs, members of the tribal councils and health clinic boards were invited and several, although not all, attended.

Curriculum units 5 through 7 were implemented in project year 2 and augmented with hands-on quantitative survey data collection. All 28 CRTs and clinic staff took the Collaborative Institutional Training Initiative examination using laptops made available to them at the clinics (approximately 4–5 individuals at a time). The CRTs then participated in monthly working groups to plan and conduct a community pilot project of relevance to their communities, design surveys around healthy food access, and engage in data collection and cleaning, data entry, and data analysis.

Also during year 2 of the project the 28 CRTs were supported to attend the internationally recognized week-long Community-Based Participatory Research Institute held in San Francisco, California, and sponsored by San Francisco State University and the University of California, Berkeley. The institute features key leaders in the field of CBPR and covers important topics in CBPR, such as partnership development, collaborative study design, developing culturally embedded interventions, and the intersection of CBPR and policy change.

The participation of the CRTs was greatly valued by the institute organizers and attendees and led to the impromptu invitation, by request of the institute attendees, to hold a tribally specific CBPR workshop track so that specific issues in working with Indigenous communities could be presented and discussed. This provided attendees working with tribal communities the opportunity to hear directly from tribal community members trained in CBPR.

Finally, and also at the request of the CRTs, project year 2 concluded with a 1-day intensive workshop on participatory and Indigenous evaluation. The purpose of this culturally tailored training, guided by LaFrance's Indigenous evaluation model,<sup>29</sup> was not to conduct a formal evaluation but to train community members and clinic staff in approaches to conducting evaluations that are responsive to community needs and that incorporate AI community values. The evaluation training was implemented in person and included a focus on the dissemination of the findings to diverse key stakeholders, including tribal community members as well as academic partners. At this time the CRTs also discussed and determined how they would like to share the story of their training experience and with whom.

During the course of the evaluation training, the CRTs were inspired to conduct an evaluation of their own CBPR training experience. Thus, the CRTs generated a list of 16 questions they wanted to ask themselves to assess the value of the 2-year CBPR training and capture their experiences. The questions, informed by the Indigenous evaluation framework in their grounding in community values of connectedness and relational accountability, were framed in a "we" perspective and included What did we learn through this project? What challenges did we face? What lessons can academics learn from our communities? What was the most valuable part of the training? and What do we see as the future for CBPR? The questions formed the basis of a focus group guide that was administered and facilitated 1 month later by the clinic project directors and 1 CRT trained in qualitative data collection. The focus groups were conducted with 3 groups of 9 CRTs.

The focus groups were recorded and transcribed, and 2 academic partners and the project directors and CRT used a descriptive content analysis approach<sup>30</sup> to analyze the transcripts independently. After the independent review and identification of themes, the individuals met as a group to present, discuss, and triangulate<sup>31</sup> their findings.

## RESULTS

The focus group findings were presented back to the community participants to further

confirm the identified themes. Overall 4 key themes were identified.

### Focus Group Findings

*Community capacity.* The focus group participants reported that the trainings built the capacity of the community participants to engage in research.

The CRTs reported feeling more capable of asking questions, evaluating the pros and cons of research, and participating as true partners in the research process, as illustrated by this comment:

We have the skills to work with researchers now and conduct research. We have the skills, ability, empowerment, to do this—whatever it is we are concerned about in health, and this increases our accountability and our responsibility.

*Individual capacity, or "finding our voices."* An overlapping and related finding suggested that the training not only built the capacity of community participants to conduct research but also built individual capacity and self-efficacy in general, evidenced by 1 CRT's comment: "Before I started the project I was like a frightened turtle inside a shell. As the project came along it gave me the confidence to come back out of the shell."

Another CRT stated,

The time we went to San Francisco . . . we were in the room with a lot of people with big titles and you know we were just community people. By the time the training was over I realized how unique our group was because people were asking us questions at the end. . . . They came and asked us to facilitate a group . . . and I was, like, wow, that's pretty neat.

*Community–academic trust.* Participants reported how the training built trust between community and academic partners, as 1 CRT stated,

They [the academic researchers] were open to changes we needed and respected our beliefs. I thought they were going to come in with their own agenda, but they gave us full rein of what we wanted to do.

Another CRT commented,

I learned that the doctors and researchers are people too. They were really respectful, they didn't push us to do anything we didn't want to do, and in return we were more willing to share our information with them.

*Colearning for true partnership.* Although CRTs reported that the trainings facilitated

trust, focus group participants also emphasized the need for training among all partners, not just the community, to facilitate cultural humility and true partnership to improve health.

As 1 CRT remarked,

If this is truly a partnership why do we have to learn everything from [the academic] point of view? Like the Collaborative Institutional Training Initiative test—I liked the test, I learned a lot, but it is their way of thinking. What about our ways? The researchers aren't made to take a test in our ways.

Another CRT stated, “We can help them as much as they can help us.”

### Policy and Systems Outcomes

This project led to several policy- and systems-level outcomes. One of the tribal communities developed a research review board, distinct from the tribal council and the clinic health board but composed of members of both of these boards as well as several CRTs. The purpose of the research review board is to determine appropriate research partnerships and review all research to ensure that it benefits the community and is being carried out in a way that is culturally respectful. The board is currently before tribal council for approval and is a direct result of the cross-sector collaboration this training fostered within this community.

Another participating tribal community formalized a requirement at the tribal council level that all research done within that community receive prior approval by the tribal council. This community, along with the third tribal community, developed and passed, during the course of the training, a data-sharing agreement with the university through tribal health clinic board action items. As a result of this training, both of the clinics have incorporated CBPR into ongoing community-clinic efforts and developed community action councils that guide these efforts.

The partnership also led to unexpected and important change initiatives within the university. The National Institutes of Health as well as some universities where faculty work regularly with tribal nations have policies that recognize the right of sovereign tribes to own their own data.<sup>32,33</sup> When tribes do not have IRBs or community research review boards or the infrastructure in place to confer research

approvals, both the university researchers and the tribal communities are left vulnerable. In this project, none of the 3 AI communities had tribal IRBs or community research review boards in place, nor did the university partner have policies regarding data collection and ownership with sovereign tribal nations.

UC Davis recognized, in large part because of this initiative, these gaps within its own research infrastructure and sought technical assistance from researchers at other universities in developing these policies. These included the University of Oklahoma, the University of Washington, and the University of Colorado—all universities with larger numbers of faculty members working with local tribal nations. The need for these policies was recognized and acknowledged at the highest levels of the UC system. At the time of this writing the university was reviewing the policies of other large universities that regularly work with tribal nations to address the gaps in its own policies and procedures.

### DISCUSSION

Engaging in CBPR can build the capacity and infrastructure of tribal nations to conduct research by requiring tribes to formalize research partnerships and protocols and develop tribal research agendas.<sup>9,34</sup> Community members participating in CBPR can obtain marketable skills in study design and implementation that not only increase economic opportunities and build a more engaged tribal citizenry base but also fill gaps in translational and implementation science.<sup>5,35</sup> This project built individual-level and community capacity among tribal members to conduct research and resulted in system-level changes within the tribal community and clinic settings as well as the university setting. The process also highlighted important challenges and opportunities for expanding CBPR training and resources that are culturally appropriate and incorporating the needs and perspectives of tribal nations and AI/AN communities.

The participating tribal communities and clinics had baseline differences in their capacities and infrastructures to conduct research. There were also differences in the amounts of research they were conducting as well as their desire to expand research efforts. These factors

contributed to the diverse experiences within the project. The reservation community and clinic forged ahead with the development of a research review board and continued efforts to seek out further research initiatives. However, for the rural clinic and partnering communities, drafting research protocols and moving those protocols through the clinic policymaking process, as well as the tribal council policymaking processes, were beyond the resources available through this project.

The clinic project directors determined that additional technical assistance and staff time would be required to develop formal research review processes and IRBs. Additional funding, and the prioritization and commitment of the tribal councils and the health clinic board, would also be necessary. It is unknown whether these communities and clinics will continue to engage in enough research to warrant these efforts and whether research will be prioritized among competing demands.

The role that health clinics play in research with AI/AN communities remains a complex issue. On the one hand, for small tribes that do not regularly engage in research, or urban AI/AN communities in which no central tribal government exists, the development of tribal IRBs and research review boards may be unwarranted or inappropriate. In these circumstances, AI/AN health clinics, which are overseen by boards composed of AI/AN community members,<sup>36</sup> often function as default research review boards. From the perspective of an academic researcher, these clinics are valuable partners; they are easily identifiable institutions with access to AI/AN communities and can receive and administer research funding and subcontracts. The clinic staff can also do the “work on the ground” of recruiting community members and organizing meetings when academic researchers reside away from the tribal communities or are “outsiders” to the community.

On the other hand, the reality remains that tribal clinics are underfunded and understaffed and are hard pressed to serve in the capacity of developing, reviewing, and approving research projects.<sup>37</sup> Furthermore, clinic boards and staff members may not be appropriate for serving as gatekeepers to AI/AN communities and determining the cultural impact of research.<sup>38</sup> For many Indigenous communities, health clinics

are a symbol of colonization and loss of traditional healing practices.<sup>2,39,40</sup>

Nevertheless, training and resources in community-engaged research processes can build a community's capacity to use research for action and social change<sup>22</sup> and support Indigenous ways of knowing to improve health.<sup>9,41</sup> Training and resource opportunities to build research capacity may also prevent smaller AI/AN communities from being left behind in an increasingly competitive funding climate.<sup>42</sup> For example, the Institute of Medicine and the Centers for Disease Control and Prevention increasingly recommend and fund interventions that incorporate policy, systems, and environmental strategies to eliminate health disparities.<sup>43,44</sup>

Tribal communities must engage multisector leadership teams and implement intervention strategies that intervene at multiple levels. Tribal communities that have a strong research and practice infrastructure in place, including tribal IRBs and community research review boards, may be better positioned than are communities with less research capacity to receive and implement these funding opportunities and intervene broadly to address health disparities, potentially exacerbating intragroup disparities.<sup>45</sup>

### Lessons Learned and Recommendations for Future Practice

This project was not a research study but a practice-based, iterative training that aimed to respond to community-identified needs. Therefore the experience generated important lessons and recommendations for future practice. First, despite the project's participatory orientation, the university-based team solely administered the curriculum trainings. Having an AI university-based investigator is not the same as having a community leader or partner. Future efforts to implement this work must have community leaders or partners involved in the delivery of the trainings. Best practice examples of trainings delivered for and by AI/AN communities can be found in the Healthy Native Communities Partnership Fellowship trainings, which are AI/AN-led trainings that incorporate Indigenous knowledge and practices.<sup>46-48</sup>

The growing trend of offering community member discounts and scholarships to national

conferences must be continued and expanded. CRTs and clinic partners said that the opportunity to attend the Community-Based Participatory Research Institute in San Francisco was a critical experience, allowing them to network with others in the field and truly understand the full value and potential of their work. However, the cost for all the community and clinic partners to attend was more than \$30 000, which would make such an endeavor cost prohibitive for many partnerships wishing to replicate this type of training.

Because of the iterative and community-responsive nature of this training, as well as its informal and community-driven evaluation, it is impossible for us to separate the impact of the CCPH curriculum from the impact of the additional specialized training components, namely the National Congress of American Indians session, the Community-Based Participatory Research Institute, and the Indigenous evaluation session. There was certainly overlap in the Community-Based Participatory Research Institute with the adapted curriculum and with general Indigenous research principles,<sup>46</sup> including respect, relevance, and reciprocity, presented as part of the National Congress of American Indians and Indigenous evaluation sessions,<sup>20,29</sup> but how effective the adapted curriculum is and whether it would be enough on its own without the specialized trainings are unknown.

CBPR education (e.g., workshops, trainings, and publications) must incorporate more diverse voices to truly foster bidirectional learning. Despite CBPR being an orientation to research that values community and academic knowledge equally, most CBPR education to date continues to be from an academic voice and for academic audiences. This is illustrated by the extensive focus on ways to engage community partners as a topic in much of the education. Fostering bidirectional learning was a continuing challenge throughout this initiative, as illustrated in the focus group findings. Indeed, an example of the important contribution communities can make in fostering bidirectional learning is the influence of the CRTs in initiating revisions to the UC Davis research review process.

The expectations and the needs of each of the participating sectors must be clearly

communicated at the onset of the partnership and must continue to be discussed and revisited throughout the partnership as expectations and needs change, especially in long-term CBPR partnerships such as this. The early years of our 10-year partnership did not generate publications and were focused on building community capacity and trust in the participatory research process. For the academic partners, investing in such a long-term and time-intensive CBPR partnership without producing peer-reviewed articles, particularly for junior researchers, has been a challenge, and the receipt of National Institutes of Health funding to support the partnership work heightened this challenge. For the clinic partners, publication, even research, is less of a priority when faced with budget cuts and relentless AI/AN health disparities. The community partners' goals, however, have remained largely constant: to foster community-driven, culturally centered research efforts that lead to real change and wellness within their communities. These goals anchor our work, are shared by all partners, and remain unwavering.

This article would be not be complete without referencing the need for community and clinic partners to take an active role in the publication process, particularly because of the importance of publication in providing evidence to decision makers and funders about the value and impact of a project, ensuring sustainability, and translating findings to other communities. Well-written reports from a community perspective fill a critical gap in the Indigenous and decolonizing methodologies literature<sup>9</sup> and are critical to eliminating health disparities.

To this end, we concluded our 2-year initiative by hosting a large gathering to reflect on our experiences and prepare this article for publication. The participatory publication process we drew from, in part, is described in detail elsewhere,<sup>35</sup> and the communities also used traditional practices for "creating medicine," a community-identified term for our process of creating this article together. The community-generated goal for publishing is to honor the Native value of sharing knowledge, expressed as the "Indian way," and to document tribal history, articulated by 1 community participant, "We can publish because it will be

a record for our relatives, future generations, to show to them that we cared, that we worked hard to create a better life for them.”

## Conclusions

Despite varying outcomes, all the participants in this partnership agree that important steps were taken in building and strengthening capacity and research infrastructure within all the partner settings, even if only to further the conversation on what the value of research is in tribal communities and clinics and how it can contribute to improving AI/AN health. As 1 community participant poignantly remarked, “This is how academic researchers end things—they write about them. I’m glad we are writing about this, but it doesn’t end there.” Indeed, the communities and clinics continue to expand and apply many newfound skills with the goal of improving community health, and this article is our record that we are working hard to create a better life for future generations. ■

## About the Authors

At the time of the study, Valarie Blue Bird Jernigan and Dennis Styne were with the Department of Pediatrics, School of Medicine, University of California, Davis. Tuli Jacob was with the College of Public Health, University of Oklahoma, Tulsa. The Tribal Community Research Team is a consortium of Tribal Researchers of Northern California, Willows.

Correspondence should be sent to Valarie Blue Bird Jernigan, DrPH, MPH, Associate Professor of Health Promotion Sciences, College of Public Health, University of Oklahoma—Tulsa, 4502 E. 41st St., Tulsa, OK 74135 (e-mail: Valarie-Jernigan@ouhsc.edu). Reprints can be ordered at <http://www.ajph.org> by clicking the “Reprints” link.

This article was accepted March 13, 2015.

## Contributors

All authors participated in the development and implementation of this project, data collection and management, data analysis and interpretation, and writing and reviewing article drafts.

## Acknowledgments

This work was funded in part by the National Institute of Diabetes, Digestive, and Kidney Disease as part of the American Reinvestment and Recovery Act (grant DK089859) and the National Heart, Lung, and Blood Institute (grant R01HL117729).

The authors wish to thank the tribal clinic health staff, Joan LaFrance, PhD, and the National Congress of American Indians Policy Research Center.

## Human Participant Protection

This study was approved by the University of California, Davis institutional review board.

## References

- Minkler M, Wallerstein N. *Community Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass; 2003.
- Jernigan VB. Community-based participatory research with Native American communities: The Chronic Disease Self-Management Program. *Health Promot Pract*. 2010;11(6):888–899.
- Jernigan VBB, Lorig K. The Internet diabetes self-management workshop for American Indians and Alaska Natives. *Health Promot Pract*. 2011;12(2):261–270.
- Jernigan VB, Salvatore AL, Styne DM, Winkleby M. Addressing food insecurity in a Native American reservation using community-based participatory research. *Health Educ Res*. 2012;27(4):645–655.
- Wallerstein NB, Duran B. Using community-based participatory research to address health disparities. *Health Promot Pract*. 2006;7(3):312–323.
- Burhansstipanov L, Christopher S, Schumacher SA. Lessons learned from community-based participatory research in Indian country. *Cancer Control*. 2005;12 (suppl 2):70–76.
- Lomawaima KT. Tribal sovereigns: reframing research in American Indian education. *Harv Educ Rev*. 2000;70(1):1–23.
- Davis SM, Reid R. Practicing participatory research in American Indian communities. *Am J Clin Nutr*. 1999;69 (4 suppl):755S–759S.
- Simonds VW, Christopher S. Adapting Western research methods to indigenous ways of knowing. *Am J Public Health*. 2013;103(12):2185–2192.
- Severtson DJ, Baumann LC, Will JA. A participatory assessment of environmental health concerns in an Ojibwa community. *Public Health Nurs*. 2002;19(1):47–58.
- Lantz PM, Orians CE, Liebow E, et al. Implementing women’s cancer screening programs in American Indian and Alaska native populations. *Health Care Women Int*. 2003;24(8):674–696.
- Fisher PA, Ball T. The Indian Family Wellness Project: an application of the tribal participatory research model. *Prev Sci*. 2002;3(3):235–240.
- Fisher PA, Ball T. Tribal participatory research: mechanisms of a collaborative model. *Am J Community Psychol*. 2003;32(3–4):207–216.
- Jumper-Thurman P, Plested BA, Edwards RW, Foley R, Burnside M. Community readiness: the journey to community healing. In: Nebelkopf E, Phillips M, eds. *Healing and Mental Health for Native Americans: Speaking in Red*. New York, NY: Altamira Press; 2004.
- Andrews JO, Cox MJ, Newman SD, et al. Training partnership dyads for community-based participatory research: strategies and lessons learned from the Community Engaged Scholars Program. *Health Promot Pract*. 2013;14(4):524–533.
- Strickland CJ. Challenges in community-based participatory research implementation: experiences in cancer prevention with Pacific Northwest American Indian tribes. *Cancer Control*. 2006;13(3):230–236.
- Thomas LR, Rosa C, Forcehimes A, Donovan DM. Research partnerships between academic institutions and American Indian and Alaska Native tribes and organizations: effective strategies and lessons learned in a multi-site CTN study. *Am J Drug Alcohol Abuse*. 2011;37 (5):333–338.
- Allen ML, Culhane-Pera KA, Pergament SL, Call KT. Facilitating research faculty participation in CBPR: development of a model based on key informant interviews. *Clin Transl Sci*. 2010;3(5):233–238.
- Jones L, Wells K. Strategies for academic and clinician engagement in community-participatory partnered research. *JAMA*. 2007;297(4):407–410.
- Hicks S, Duran B, Wallerstein N, et al. Evaluating community-based participatory research to improve community-partnered science and community health. *Prog Community Health Partnersh*. 2012;6(3):289–299.
- Kelley A, Belcourt-Dittloff A, Belcourt C, Belcourt G. Research ethics and indigenous communities. *Am J Public Health*. 2013;103(12):2146–2152.
- Morton DJ, Proudfit J, Calac D, et al. Creating research capacity through a tribally based institutional review board. *Am J Public Health*. 2013;103(12):2160–2164.
- US Department of Health and Human Services. Human research participant protection in the Indian Health Service. 2014. Available at: [http://www.ihs.gov/research/index.cfm?module=hrpp\\_irb](http://www.ihs.gov/research/index.cfm?module=hrpp_irb). Accessed October 31, 2014.
- Foulks EF. Misalliances in the Barrow Alcohol Study. *Am Indian Alsk Native Ment Health Res*. 1989;2 (3):7–17.
- Atkins C, Reuff L, Roddy J, Platts M, Robinson H, Ward R. Rheumatic disease in the Nuu-Chah-Nulth Native Indians of the Pacific Northwest. *J Rheumatol*. 1988;15(4):684–690.
- Mello MM, Wolf LE. The Havasupai Indian tribe case—lessons for research involving stored biologic samples. *N Engl J Med*. 2010;363(3):204–207.
- Examining Community–Institutional Partnerships for Prevention Research Group. Building and sustaining community–institutional partnerships for prevention research: findings from a national collaborative. *J Urban Health*. 2006;83(6):989–1003 [Erratum in *J Urban Health*. 2007;84(3):461. Seifer, Sarena D removed].
- Collaborative Institutional Training Initiative. 2015. Available at: <https://www.citiprogram.org>. Accessed January 28, 2015.
- LaFrance J, Nichols R, Kirkhart KE. Culture writes the script: on the centrality of context in indigenous evaluation. *New Dir Eval*. 2012;2012(135):59–74.
- Neuendorf KA. *The Content Analysis Guidebook*. Thousand Oaks, CA: Sage; 2002.
- Thurmond VA. The point of triangulation. *J Nurs Scholarsh*. 2001;33(3):253–258.
- Department of Health and Human Services. *National Institutes of Health PAR 14-260: Interventions for Health Promotion and Disease Prevention in Native American Populations (R01)* [press release]. Bethesda, MD; June 16, 2014.
- University of Washington. Protected and vulnerable populations. 2015. Available at: <http://www.washington.edu/research/hsd/topics/Native+American>. Accessed March 14, 2015.
- Walters KL, Simoni JM. Decolonizing strategies for mentoring American Indians and Alaska Natives in HIV and mental health research. *Am J Public Health*. 2009;99 (suppl 1):S71–S76.



35. Blue Bird Jernigan V, Brokenleg I, Burkhart M, Magdalena C, Sibley C, Yepa K. The implementation of a participatory manuscript development process with Native American tribal awardees as part of the CDC Communities Putting Prevention to Work initiative: challenges and opportunities. *Prev Med*. 2014;67(suppl 1):S51–S57.
36. US Code Title 25, Chapter 18. Indian Health Care (2010).
37. Warne D, Frizzell LB. American Indian health policy: historical trends and contemporary issues. *Am J Public Health*. 2014;104(suppl 3):S263–S267.
38. Crowhurst I, Kennedy-Macfoy M. Troubling gatekeepers: methodological considerations for social research. *Int J Soc Res Methodol*. 2013;16(6):457–462.
39. Walters KL, Simoni JM. Reconceptualizing native women's health: an "indigenist" stress-coping model. *Am J Public Health*. 2002;92(4):520–524.
40. Browne AJ, Fiske JA. First Nations women's encounters with mainstream health care services. *West J Nurs Res*. 2001;23(2):126–147.
41. Brugge D, Missaghian M. Protecting the Navajo people through tribal regulation of research. *Sci Eng Ethics*. 2006;12(3):491–507.
42. National Institutes of Health Office of Budget. 2014. Available at: <http://officeofbudget.od.nih.gov/index.htm>. Accessed November 4, 2014.
43. Centers for Disease Control and Prevention. Recommended community strategies and measurements to prevent obesity in the United States. *MMWR Recomm Rep*. 2009;58(RR-7):1–26.
44. Koplan JP, Liverman CT, Kraak VI; Committee on Prevention of Obesity in Children and Youth. Preventing childhood obesity: health in the balance: executive summary. *J Am Diet Assoc*. 2005;105(1):131–138.
45. Jernigan VB, Duran B, Ahn D, Winkleby M. Changing patterns in health behaviors and risk factors related to cardiovascular disease among American Indians and Alaska Natives. *Am J Public Health*. 2010;100(4):677–683.
46. Walters KL, Stately A, Evans-Campbell T, et al. Indigenist collaborative research efforts in Native American communities. In: Stiffman AR, ed. *The Field Research Survival Guide*. Oxford, UK: Oxford University Press; 2009:146–173.
47. Cochran PA, Marshall CA, Garcia-Downing C, et al. Indigenous ways of knowing: implications for participatory research and community. *Am J Public Health*. 2008;98(1):22–27.
48. Healthy Native Communities Partnership. About HNCP. 2014. Available at: [http://www.hncpartners.org/HNCP/About\\_HNCP.html](http://www.hncpartners.org/HNCP/About_HNCP.html). Accessed November 4, 2014.