



Nina Mikhailenko. *Basket Umbrellas*.
Oil on canvas, 20" × 16".

A research approach that includes respect toward tribal culture and participation by tribal community leaders can result in more effective research projects.

Lessons Learned From Community-Based Participatory Research in Indian Country

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The purpose of this article is to share lessons learned from implementing community-based participatory research (CBPR) in Indian Country that may be generalizable to other medically underserved communities. CBPR is currently included in multiple grant announcements by the National Institute of Health and Centers for Disease Control and Prevention, but information about this methodology vs traditional research methodology is often misleading. This article addresses some common mistakes made by academic research institutes by sharing what we have learned about how CBPR can be implemented in a respectful manner. The majority of tribal Nations prefer, if not mandate, that CBPR be used in most proposed studies involving their communities today.

Introduction

The purpose of this article is to share lessons learned from using a community-based participatory research (CBPR) approach in Indian Country. These lessons may be generalizable to other medically underserved communities.

CBPR refers to a “partnership approach to research that equitably involves community members, organization representatives, and researchers in all aspects of the research process.”¹ Since 1995, staff from Native American Cancer Research (NACR), a community-based, nonprofit American Indian-operated corporation, have used a CBPR approach

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The lessons learned presented here are from multiple studies implemented since 1995. These were supported by the Robert Wood Johnson Foundation (1995), National Susan G. Komen Breast Cancer Founda-

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Abbreviations used in this paper: CBPR = community-based participatory research, NACR = Native American Cancer Research.

on multiple projects (supported by foundations such as the Susan G. Komen Breast Cancer Foundation and federal agencies such as the National Cancer Institute). Likewise, an American Cancer Society project has successfully used CBPR with the Apsáalooke community (commonly referred to as the Crow Nation).

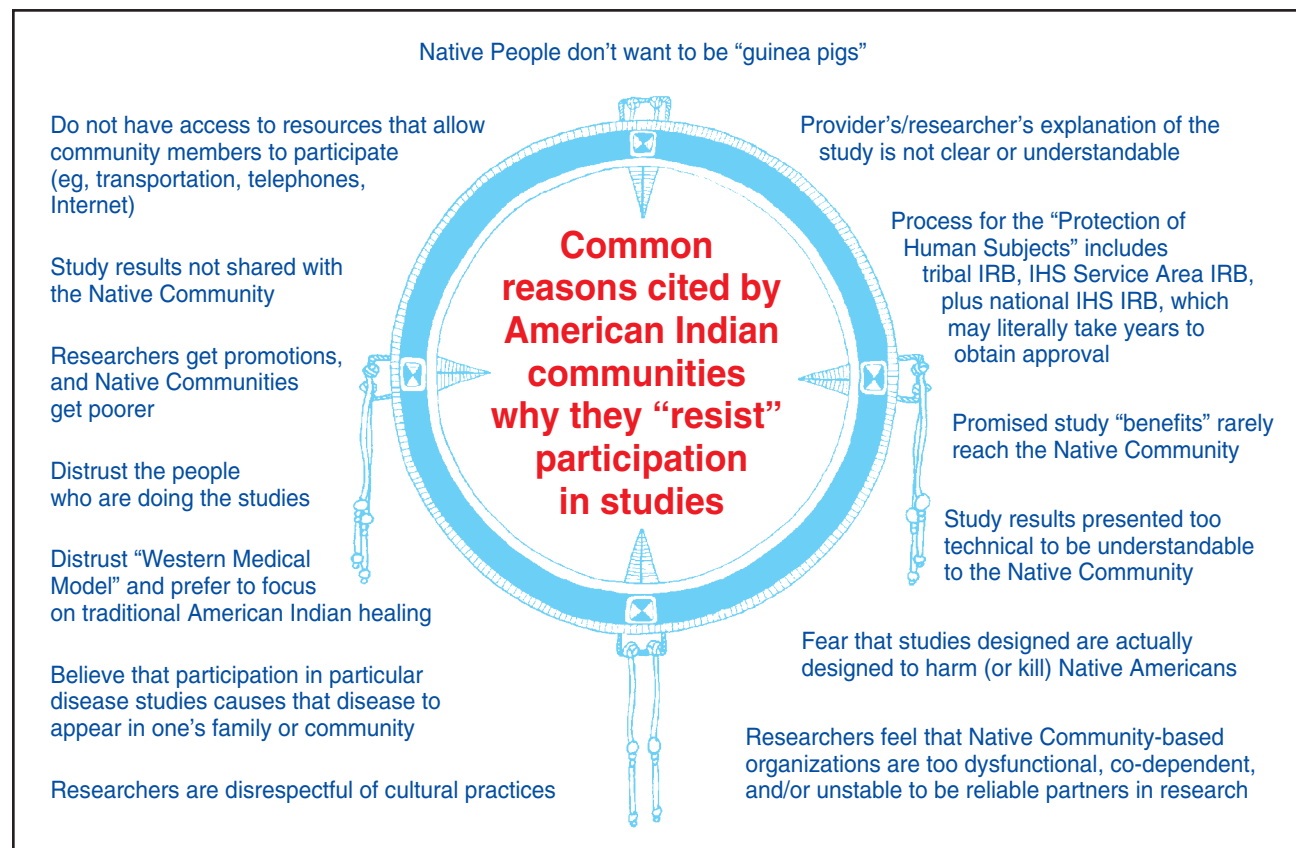
Native American communities are strongly supportive of CBPR and express less enthusiasm for research processes that are not based on participatory practices. This lack of enthusiasm is typically due to indiscretions by previous or ongoing researchers. Most Native communities feel that they “have been researched to death.”²⁵ Many researchers approach tribal nations with great enthusiasm and a desire to implement a research project, but the project has been developed without the input of the community.

Survey researchers often implement surveys but follow with insufficient or no interventions to address the issues noted on the surveys. In most cases, neither the community participants nor the tribal nations receive summaries of findings from surveys implemented in their communities. Of particular concern are studies that indicate the need for an immediate intervention (eg, epidemiologists who document negative behavioral patterns within the community). Although such findings are upsetting, both the researcher (epidemiologist) and community leaders can alleviate the discomfort by candidly

discussing the potential findings and how they can be used in subsequent proactive interventions. Communities would rather receive negative findings than no findings at all. In addition, researchers frequently promise that the survey will result in an improvement in tribal health services or health status, yet such changes have rarely been implemented. The Figure summarizes common reasons why Native communities are reluctant to participate in standard traditional research methodologies.⁵ In addition, researchers have made several errors, such as grouping all tribes together, excluding Native American individuals and communities in research taking place in their communities, reinforcing stereotypes, emphasizing negative behaviors, blaming individuals and communities as the causes of problems, placing their own interests ahead of those of the people they are working with, violating Institutional Review Board (IRB) standards or informed consent, and using tribal specimens for research not specified within the study protocol and IRB application.⁶

CBPR is an appropriate method for changing this negative history into a positive future because it engages individuals and communities in research ventures and can help to surmount past trust issues.^{7,8}

Recommendations for working with Native communities include working honestly and cooperatively with



Reasons why Natives are resistant to taking part in traditional research methodologies. From Burhansstipanov L. Developing culturally competent community-based interventions. In: Weiner D, ed. *Cancer Research Interventions among the Medically Underserved*. Westport, Conn: Greenwood Publishing; 1999:167-183. Reprinted with permission of Greenwood Publishing Group Inc, Westport, CT.

communities, working from a standpoint of respect, spending time with communities, working with tribal colleges, and ensuring that Native communities are involved in all stages of the research endeavor. “Native communities that participate in research must be involved in the planning process and in data gathering, must be informed of the findings, and must directly experience the outcomes of the research project.”⁹ Several other comparable recommendations have been cited elsewhere.¹⁰⁻²¹

Methods

Utilizing a CBPR approach requires that both the community and the research institution (or funding agency) have decision-making and leadership roles in every step of the research project. Many research institutions erroneously believe they have satisfied the requirements for CBPR if they have community members collecting surveys, if they receive a letter of support from a tribal organization, or if an underserved community is the target population of a research project. We do not regard such efforts as using a CBPR approach.

To form a true partnership, the focus of the research project must be a priority topic for the community as well as for the research institute. A CBPR approach involves partners working together to not only design, implement, and evaluate the intervention, but also decide how results will be disseminated to the local community and through peer-reviewed publications and presentations. It also defines how the data will be collected, cleaned (data quality management), and stored in the community and research institute. Every step of the research process (of which only a few are listed in the previous sentences) involves leadership and decision-making responsibilities by both the academic or research institution and the tribal organization.

In 1993 testimony to the President’s Cancer Panel, Gilbert H. Friedell, MD, Director Emeritus of the Markey Cancer Center at the University of Kentucky, addressed the need for communities to be in control of their projects by concisely noting that “if the problems are in the community, the solutions are in the community.”²² When we were having difficulty helping a research institute understand how to move from paternalistic relationships with tribal communities, Dr Friedell provided us with the clearest strategy. To make the transition from “paternalism” to “partnership,” research institutions and their employees must be willing to give up some control, power, and money.

Many CBPR projects have community-based organizations (CBOs) and universities as partners. One of the challenges that academic research institutions might face is that many tribal communities do not have established community-based organizations. Instead, groups of tribal leaders function as recognized community leaders. Also, information is traditionally gathered and spread by word of mouth (referred to as the “moccasin telegraph”). While a “formal

network” may be lacking, the closeness of the community and family enables information to be relayed from one person to another. This informal communication develops trust relationships with people in the community. Projects such as the American Cancer Society-supported Messengers for Health project in Apsáalooke have successfully relied on a “community” such as this.²³⁻²⁶

In some projects, working with an informal network rather than a community-based or tribal organization (eg, Tribal Health) can provide distinct advantages. Officials elected by the tribe may change during the course of a project, which can adversely affect the project if it is operated through tribal organizations. If a project is strongly identified as being supported by the previous tribal leadership, the incoming tribal leaders may refuse to allow the program to continue to evolve. Thus, it is essential that the project obtain a tribal resolution from the local tribal health board and, when feasible, the tribal or Indian Health Service area institutional review board approval to help identify the project as a tribal community project that is independent of local tribal political leadership. In the Messengers for Health project, several community members stated that it was good that the project ran independent of tribal politics because even if tribal administrations and policies change, the project would not be adversely affected. When working with the community of intertribal Native cancer survivors, the survivors were adamant that the subsequent Native American Cancer Survivors Support Network be totally independent of tribal organizations for fears of loss of confidentiality. For example, a family member might work at the clinic and inadvertently violate privacy rights by sharing with other family members that a relative has cancer and needs help. Thus, for selected projects, community members have said that this independence gives them a feeling of confidence and security and that they believe they have an added assurance of confidentiality.

Results

Below are eight lessons we learned from utilizing a CBPR approach in tribal communities.

Lesson 1: Invest Time to Create the Partnership Team and Subsequent CBPR Project

Most community-driven projects (which are initiated by the community and then an appropriate research organization to partner with is found) and CBPR projects (which involve organizations and individuals outside of the tribe) require multiple years to build relationships in order to develop sufficient trust to work together successfully. In addition, long approval times are needed to obtain (1) time on the agenda of the Indian Health Board, Indian Tribal Health Council, and/or Tribal Council for overall approval of the project, (2) tribal resolution of support

from the Tribal Health Board and/or Council, (3) letter(s) of support from the Tribal Health Director, Tribal Health Board, and/or Tribal Council Chair, (4) HIPAA-approval protocols and compliance documentation, (5) local tribal IRB approval, (6) Indian Health Service IRB approval, (7) National Indian Health Service IRB approval, and (8) academic IRB approval. This approval process can take longer than 12 months. Thus, at a minimum, most tribal CBPR projects should have 3 years of involvement prior to submitting a grant to a funding agency.

Recent releases of CBPR-based requests for applications (RFAs) have been encouraging. A true CBPR approach cannot occur with an RFA that does not allow time for partnership-building or flexibility for the community to choose the area of focus. In some cases, researchers do not discuss a project with the community until after the RFA has been released. Since most grants are due within 90 days of the RFA release, this leaves insufficient time to develop a CBPR relationship and obtain appropriate approvals. Minkler et al²⁷ discussed additional public health funding implications for conducting CBPR.

Lesson 2: Allocate the Budget "Comparably" Among the CBPR Partners

Lovell Jones, PhD, Experimental Gynecology-Endocrinology of The University of Texas M. D. Anderson Cancer Center, has also implemented CBPR nutrition studies (personal communication, 2002). To effectively create a strong partnership with the community, one of the first steps that Dr. Jones recommends is to divide the money equitably among the partners. NACR has implemented this suggestion and found it to be helpful in creating strong leadership among all of the partners. The NACR process is to give the partner who is the grant recipient approximately \$40,000 per year to fund additional staff (statistician, evaluators) and consultants and to carry out administrative tasks (progress reports, IRB applications, HIPAA applications) for the project. Once the \$40,000 is subtracted from the total amount of monies available, the dollars are divided equally. For example, NACR has a CBPR project in submission with Exempla/St Joseph Hospital for an NCI cancer education grant that has a maximum of \$300,000 per year. Both partners alternate the leadership role of a grant (eg, St Joseph's is the recipient of our ongoing NCI grant and NACR will be the recipient if the grant in submission is awarded). The NACR budget averages approximately \$160,000 per year, and the St Joseph's budget averages \$120,000 per year.

Lesson 3: Create Partnerships With Leaders Who Have Decision-Making Responsibilities From Each Organization

In creating the partnership, issues can arise regarding which individuals should be selected within the community and within the research institute. It is important that the selected "leaders" have a role in decision-making for

their community or academic institution. In many instances, researchers spent months developing a working relationship with a tribal member, even obtaining a letter of support for a project, only to learn later that the individual had no authority to provide such a letter or to establish a working relationship with the researcher. Vice versa, tribal members have believed that an academic researcher was authorized to comply with tribal research protocols, only to discover later that the academic institution had standard operating procedures that prohibit modifications required by tribal research protocols.

To help identify appropriate tribal community partners, it is helpful to ask permission of the tribal health board/director to meet with tribal members about a potential project. When requested, most tribal health board directors will suggest key people with whom the researcher should work. It is also advisable to determine who serves on the tribal research committee and/or IRB and to involve someone from those bodies in the development of the partnership relationship. Most tribal communities have elder organizations, such as an elder beading or craft class, an elder health committee, a cultural history or language class coordinated by a group of elders, and/or an elder meals program. It is essential to have at least one recognized, respected tribal elder as a member of the partnership team. In the Apsáalooke community, elders are well-respected individuals of the tribe. They are relied on for their wisdom, knowledge, experience, advice, and spiritual support. They provide guidance on handling matters or situations in a culturally appropriate manner. A person who behaves in a culturally disrespectful manner is considered foolish and described as someone who did not receive proper guidance.

A traditional Indian healer may also be a key member of the partnership team to provide spiritual guidance throughout the development and implementation processes. If health services are to be incorporated within the subsequent CBPR project, then administrative decision-making leadership from the health clinic is essential on the partnership-development team.

The process to help the tribal community identify appropriate academic research partners is slightly different. Due to the long history of broken promises from researchers, most communities are cautious about whom they feel they can and cannot trust. If a researcher has a successful history of working respectfully within a tribal community, the researcher is likely to be approached as a partner or asked to suggest partners. Successful history means that several conditions were met, eg, the tribal leadership was treated respectfully throughout the process, sufficient meetings were held to discuss the progress of the project, data were shared with the tribal community, and leadership from the tribal community was included on peer-reviewed publications. The researcher who insists that protocols can be carried out only in a selected way is less likely to be requested on the partnership team. Like-

wise, a researcher who worked once with a tribe that refuses to work with the researcher again is clearly perceived as disrespectful. The term respect has a powerful connotation in Indian Country compared with the general society. To refer to someone as disrespectful implies great shaming from the Native perspective.

Lesson 4: Provide Salaries to Tribal Partners and Project Staff

In much traditional research, academicians received salaries while the people doing the work in the communities were volunteers. This is inappropriate. Since the majority of our tribal communities live in poverty, the staff needs to be paid competitive salaries for their training efforts. If researchers provide staff inservice training for volunteers, they must accept that the volunteers may take their new skills to a paying job. Although someone may be devoted and want to volunteer, people still need to pay their rents and buy food and clothing for their families.⁴ A CBPR project in Indian Country rarely succeeds if the project relies on volunteerism from communities of poverty.

Lesson 5: Implement Active, Effective Communication Among All CBPR Partners

Many researchers are accustomed to working with cancer centers and academic organizations that have immediate access to state-of-the-art communication systems. Some of these researchers have expressed exasperation with Native staff because there are so many unanticipated communication breakdowns in these communities. When working with project staff in rural areas, on reservations, or in small villages, standard assumptions about communication need to be examined and appropriate alternatives developed, if feasible. This frustration may be as minor as access to quick and efficient mail service delivery. Ground mail delivery can be delayed for several weeks in some rural communities. If local project staff require last-minute intervention information, such materials may be undeliverable because they live in areas that do not have next-day delivery service. This barrier can affect timely implementation of cancer interventions because special resources are not accessible to the staff. Most communities can be reached within 2 days, but some, such as remote, isolated villages of Alaska or the Pacific islands, can require 3 or more days. This delay is due to mail delivery services having to rely on air or sea travel in climates that frequently prohibit such modes of transportation. For example, Bering Sea storms can ground air travel for a week at a time. When working with reservation communities, the investigator frequently mails to a post office box, which next-day mail service providers regard as an undeliverable address. Alternative strategies need to be developed to overcome these mailing problems. For example, when mailing to partners living on Pine Ridge Reservation in South Dakota, all mail sent via Federal Express is sent to the local gas station. When stopping for

gasoline, the community partner picks up the priority mail. These conditions occur whether the individual lives in poverty or simply in a rural environment. However, investigators need to be aware of such communication barrier issues and be prepared to address them by providing sufficient time for all project staff to receive intervention resources prior to implementation.⁵

Likewise, many areas, both rural and cities/towns, do not have cellular telephone service. Academic partners come to the community anticipating telephone services that do not exist. Even satellite telephone services may be interrupted daily because mountain ranges may block the satellite in early morning or evening hours.

E-mail may or may not be a feasible form of communication among CBPR partners. For many tribal settings, there are no landlines or wireless telephone services available to many regions on the reservation or in rural communities. The hours of access to libraries, tribal centers, or schools may be limited, which can eliminate the option of daily e-mail communication. In several tribal settings, all connections to the Internet require a toll fee, which is frequently unacknowledged by researchers who require that partners participate on selected Web sites for inservice training or comparable Web courses.

Although it is easier for academicians to coordinate and attend meetings held at their institution, it is essential that the meeting locations alternate between the partners. Thus, one meeting may be at the university and the next at the tribal headquarters. For the Messengers for Health project, it was not feasible for community partners to travel 200 miles to the university. University partners traveled to the reservation monthly or more often when needed. This effort had the benefit of quickening the relationship and trust-building process because community members saw that the researchers were invested in their community.

Direct visitation to a community provides academic researchers an opportunity to learn some things that they would not understand without making the time and effort to be present in the local setting. For example, researchers assume because they have seen photographs of areas, such as the Alaska Bush or Pine Ridge, that they understand the distances, but it is not until they travel to the area that they begin to comprehend the issues. Another example is researchers' attempt to use their wireless Internet and find it is not available. They hook into a telephone line and find that the fastest landline Internet access is much slower than 28000 kb and also that it is a toll call rather than free. Also, they may want to buy food from a local store and have difficulty finding good-looking, healthy fruits or vegetables. Direct contact and visibility in the community are powerful ways of building trust.⁴

Lesson 6: Share Raw and Summary Data Related to the CBPR Project

Tribal programs maintain confidential, private databases for their tribal and health care records and want access to

collected for any CBPR project. Many academic institutions are uncomfortable with this, fearing that the tribe does not have the capacity to maintain an accurate database. For some small tribes with limited resources, inservice training on how to provide a secure, confidential database may be necessary, but today many tribes have such procedures and policies in place. Data collected from the CBPR project may provide guidance for other tribal health priorities that are unimportant or irrelevant to the CBPR project. Tribal health councils regularly review study data to help determine emerging health priorities for the local community, as well as other uses extraneous to the CBPR.

During the planning phase and prior to the implementation of a CBPR project, both the tribal organization and researcher need to candidly discuss how data can be shared and stored by both organizations while still maintaining confidentiality and privacy regarding the study participants. Both parties need to recognize their respective areas of expertise. Thus, tribal members are the most qualified to interpret how and why a finding may occur, and the researcher is most qualified to help the tribal leaders learn how to correctly phrase statistical findings to others to avoid misrepresenting the findings. For example, inexperienced researchers frequently compare mortality rates that were based on different formulas or standard populations. They might compare age-adjusted diabetes mortality rates that are *per 1,000* with age-adjusted cancer mortality rates that are *per 100,000*, or they might compare an age-adjusted cancer rate that was based on “1970 US Standard Population” with an age-adjusted cancer rate that was based on “2000 US Census Population.” Likewise, inexperienced researchers might confuse “mortality” and “survival,” as well as the significance of P values and which are or are not statistically significant.

Lesson 7: Modify Standardized Evaluation Procedures to Be Culturally Acceptable and Respectful of the Local Community

The types of data collection used in traditional research designs may or may not be acceptable for CBPR. Some data collection methods or questionnaire items are regarded as invasive, disrespectful, and intrusive. Methods are needed that allow for culturally acceptable forms of data collection and monitoring for both process and outcome evaluation. The tribal leadership can eloquently clarify how and why certain types of data collection or surveys are inappropriate and how they need to be changed to be respectful. For example, the CBPR project personnel located in one tribal community cannot collect survey data from another tribal community that is used as a control group. The use of the control group community is another instance of tribal members providing survey information and not receiving benefit. The solutions to this lesson are tribal-specific.

Lesson 8: Follow Both Tribal and Researchers' Protocols for Disseminating and Publishing the Findings

Most tribal communities or Indian Health Service IRBs have publication committees that must approve conference abstracts prior to any member of the CBPR team submitting an abstract for presentation.²⁸ Likewise, the outline of what is to be presented at any meeting must be approved by these committees. These practices evolved after researchers shared study findings with others uninvolved with the study before sharing with the community, and in some cases the researcher misinterpreted data and subsequently presented erroneous or stereotypic information about the community. These committees are in existence to avoid such problems from occurring in the future. Likewise, tribal publication committees and/or Indian Health Service IRB committees must approve draft manuscripts prior to their submission to a peer-reviewed journal for publication.

Tribal newsletters, local tribal radio shows, and comparable media should be used to inform the community of the presentations of findings. Ascertaining which media sources are trusted and used within the community is important. When feasible, key representatives from all partners of the CBPR team should present the information. These presentations may be made by the tribal partners with or without the presence of research partners. For short presentations (10 minutes) at professional conferences and symposia, the professional may need to present alone. However, the presence of community members brings a heightened level of accuracy to the presentation and is strongly encouraged.

Conclusions

CBPR provides the opportunity for a “win-win” relationship between an academic research institution and tribal organizations or communities. To secure funding, some projects assert that they are using a CBPR approach but in fact they do not follow the components necessary for true CBPR. The community must have at least an equal role in every step of the research process, from conceptualization of the research question through dissemination of the findings. CBPR works well in Indian communities, and it promotes unique, real outcomes: the program continues after outside funding ceases, the training received by local tribal people leads to their implementing similar skills for other projects, and local tribal services are more likely to change or improve.

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