



# *‘Walk Softly and Listen Carefully’*

Building Research Relationships with Tribal Communities

The **Center for Native Health Partnerships (CNHP)** was developed in response to Native American community members interested in starting community-based participatory research (CBPR) projects in their communities and university researchers interested in learning how to partner successfully with Native communities. The mission is to create an environment to improve Native American health through community-based participatory research. The Center is based at Montana State University and was established through a five year grant from the National Institute on Minority Health and Health Disparities (NIMHD) at the National Institutes of Health.

The **National Congress of American Indians (NCAI) Policy Research Center** was established in 2003 as a national tribal policy research center to serve the goal of “supporting Indian Country in shaping its own future.” The mission of the NCAI Policy Research Center is to provide tribal leaders with the best available knowledge to make strategically proactive policy decisions in a framework of Native wisdom that positively impact the future of Native peoples. The NCAI Policy Research Center is based at the Embassy of Tribal Nations in Washington, DC.



National  
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Indians





## ABOUT THIS PUBLICATION

This publication was produced with insights from those involved with tribal research in Montana and elsewhere. It was developed collaboratively by the National Congress of American Indians (NCAI) Policy Research Center and Montana State University's (MSU) Center for Native Health Partnerships by Suzanne Christopher (Professor, Montana State University), Malia Villegas (Director, NCAI Policy Research Center; *Alutiiq/Sugpiaq*), and Christina Daulton (Program Manager, NCAI Policy Research Center).

The vignette, "For Researchers Working with Native Communities: Reflections from a Native Researcher," was drafted by Desi Small-Rodriguez (*Northern Cheyenne*) and the vignette, "For Researchers Working with Native Communities: Reflections from a Tribal Community Organizer" was written by Ada Bends (*Apsáalooke/Crow*). The vignette, "Traditional Relationships to Teach Contemporary Health: Messengers for Health," was written by Alma Knows His Gun McCormick (*Apsáalooke/Crow*) and Suzanne Christopher. Beth Bahe (NCAI Wilma Mankiller Fellow; *Tohono O'odham*) assisted in the writing of the vignette "Fostering Effective Partnerships: RezRIDERS." We also would like to thank Greg Tafoya (*Santa Clara Pueblo*) and the Pueblo of Jemez leadership for allowing us to include a vignette on their RezRIDERS program.

The content for the section of the paper on ***Developing Research Relationships with All AN Communities in Montana*** was drafted from the reflections and insights offered during two open conference calls held in May and June 2012. The strength of this section is the participants' powerful words and personal recommendations for researchers working with tribal nations.

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# ‘Walk Softly and Listen Carefully’

## Building Research Relationships with Tribal Communities

“ Trust takes time. You need to prove—as a researcher or as an outsider—that you can actually function as a positive member of that community; and there’s no way to do that without becoming a part of that community. That takes time. ”

(Teleconference Participant, May 2012)

“ You have to be able to humble yourself before another person, to understand that each person has something valuable to contribute. So you have to be able to quiet down your own agenda and your own thought processes and open up your entire spirit. ”

(Teleconference Participant, June 2012)



Increasingly, tribal leaders acknowledge that research is a key tool of tribal sovereignty<sup>1</sup> in providing data and information to guide community planning, cross-community coordination, and program and policy development. Efforts to address longstanding issues, such as health disparities for American Indians and Alaska Natives (AI/AN), have increasingly used partnership research approaches. This document seeks to strengthen these partnerships by providing insight about how culture, sovereignty, and experience matter in research with Native communities. In doing so, we acknowledge that ‘researchers’ are not just those who are outsiders coming into Native communities for short periods of time to collect data<sup>2</sup> that is then held and owned by colleges and other research institutions and organizations. The term ‘researcher’ in this document applies to all those who conduct research including tribal leaders, Elders,<sup>3</sup> tribal and other college and university employees, Native scholars and students, community-based investigators, and staff of research organizations or government agencies.

This is especially important, as there has been an increase in the number of AI/AN people pursuing research careers, many who are intent on developing research that has benefit for Native communities.<sup>4</sup> These emerging scholars stand with the generations of Native scholars and culture bearers who have been committed to using the best knowledge and information to shape positive futures for Native peoples. Engagement with research and partnerships with researchers may be seen as one expression of self-determination.

Tribes have used research as a tool of sovereignty to address issues like water quality, early childhood education, cancer, diabetes, and elder care. Yet tribal leaders also continue to express concern about the need to protect cultural information and their communities from dangerous and unethical research practices. There have been historic and present-day ethical violations in the use of data and knowledge collected from AI/AN peoples (e.g., taking and misusing of blood specimens, religious items, traditional practices) and a lack of benefit returned to AI/AN communities who have participated in research.

<sup>1</sup> Sovereignty is a legal word for the authority to self-govern. Tribal sovereignty means that each tribe has the inherent legal and political authority to govern itself. Currently, 566 sovereign tribal nations (variously called tribes, nations, bands, pueblos, communities, and Native villages) have a formal nation-to-nation relationship with the US government. Tribal governments exercise jurisdiction over lands that would make Indian Country the fourth largest state in the nation, and are an important and unique member of the American family of governments, which includes tribal governments, the US federal government, and the US states. The US Constitution recognizes that tribal nations are sovereign governments. As members of tribes, American Indian and Alaska Native people have both an ethnic and political status. Tribes are governments that have distinct legal and political authority to represent their citizens and to regulate all activities occurring on their lands, including research. Similar to federal and state governments, tribes have sovereign power over their lands, citizens, and related affairs. Researchers are required to follow the laws of each tribe, including the tribe’s research regulation policies and any tribal laws pertaining to research being conducted with tribal citizens and on tribal lands.

For other resources on tribal sovereignty, see: Coffey, W., & Tsosie, R. (2001). Rethinking the tribal sovereignty doctrine: Cultural sovereignty and the collective future of Indian nations. *Stanford Law and Policy Review*, 19(12):191-221; Gould, Scott L. (1996). The consent paradigm: Tribal sovereignty at the millennium. *Columbia Law Review*, 96(4): 809-902; and d'Errico, P. (2000). Sovereignty. *The Encyclopedia of Minorities in American Politics*. American Political Landscape Series. Phoenix, AZ: Oryx Press: 691-693.

<sup>2</sup> Examples of data can include knowledge, stories, opinions, surveys, participant observation, biological specimens and tissue.

<sup>3</sup> When capitalized “Elders” refers to culture bearers.

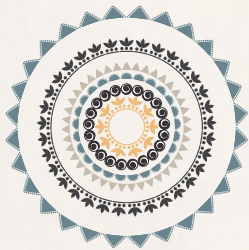
<sup>4</sup> Within this paper, the terms American Indian and Alaska Native (AI/AN), tribes, tribal nations, Native communities, Native, and Indigenous peoples are used interchangeably. All terms are inclusive of the 566 federally recognized tribal nations and the more than five million people in the United States who identify as being American Indian and/or Alaska Native.

Additionally, more often than not, researchers in universities and in communities operate in isolation from each other, which can limit the impact and benefits of research.

There are many examples of longstanding and meaningful research partnerships that have provided benefits to Native communities and contributed innovative solutions to complex challenges (see vignettes on pages 6 and 7). These partnerships offer insights to tribal leaders, researchers, and other communities interested in using research to address community issues. Developing ethical and meaningful research partnerships with AI/AN communities requires researchers to understand and commit to an ongoing process of authentic and deliberate relationship-building, cross-cultural learning, open communication, trust, and reciprocity. This is especially important for tribal leaders and communities in protecting knowledge, culture, and beliefs in the research process while also providing benefit to their tribal citizens.

***Working with tribes in a research capacity and forming trusting relationships cannot be accomplished by following a simple checklist or navigating a 'how to' roadmap.***

Tribal nations are diverse. Each tribal nation and each research project and team is unique. Additionally, developing effective relationships cannot be accomplished from behind a desk or without active, in-person participation in the community. Partnerships between tribes and researchers require an orientation to research that is both culturally-based and community-centered. It is our hope that this document initiates a *learning process* regarding research partnerships. It is offered in the spirit and hope of cultural humility, which requires a process of self-reflection and commitment to life-long learning.<sup>5</sup>



*We imagine this paper to be a living document that can be adapted and changed. We welcome feedback and thoughts. Please email these to: Christina Daulton - [cdaulton@ncai.org](mailto:cdaulton@ncai.org) and/or Suzanne Christopher - [suzanne@montana.edu](mailto:suzanne@montana.edu).*

## AUDIENCE

The primary audience for this document is Native and non-Native researchers working with tribal communities, academic institutions, and research organizations and agencies. It is also intended for tribal leaders who have the responsibility to make decisions regarding research in their communities and to set policy regarding tribal oversight of research. Another important audience is tribal community liaisons who facilitate relationships with researchers on behalf of their communities and help researchers navigate the research process within their community. These liaisons have a vested interest in ensuring that research is conducted in a good way.

<sup>5</sup> Tervalon M, Murray-García, J. (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(2):117-125.

## TRADITIONAL RELATIONSHIPS TO TEACH CONTEMPORARY HEALTH: MESSENGERS FOR HEALTH

Messengers for Health (MFH), a highly effective community-based participatory research (CBPR) project partnering the Crow Indian Nation in Southeastern Montana and Montana State University-Bozeman, provides advocacy and outreach to share the most contemporary of information and encouragement in the same way Crow (Apsáalooke) women have learned about health and life for centuries - through tribeswomen they know and respect. This long-standing partnership began in 1996 between Ms. Alma Knows His Gun McCormick, Crow Tribal member and current Executive Director of MFH, and Dr. Suzanne Christopher, Professor from Montana State University (MSU)-Bozeman. MFH advocates for health and wellness amongst Crow Indians across the expansive (2.2 million acres) and geographically isolated seven district communities of the Crow reservation. Approximately 72 percent of Crow's 11,757 enrolled members reside on the reservation.

Tribal members interested in cancer education and awareness successfully wrote for a planning grant from the Montana state health department to coordinate a breast and cervical cancer prevention project for Crow Indian women. The partnership between Alma and Suzanne began when Suzanne was assisting the state health department with the planning grants and worked with Alma and other tribal members to conduct a survey in the community with Crow women to assess their health screening behaviors and needs. During the one-on-one sessions, Crow women expressed that they needed someone to personally talk with them about cancer screening. By providing outreach throughout the state, Alma gained valuable experience and insight to the critical need of providing special emphasis in the area of cancer outreach education to Indian women.

The partnership continued, and in 1998 Alma and Suzanne began to meet with Crow women to brainstorm and discuss developing an intervention that would work respectfully with the Crow culture. In 2001, partners received a research grant, and MFH was implemented by Crow community members and MSU-Bozeman students and staff. MFH has had numerous student researchers from the Crow Nation and from other tribal nations. Partners work together on every step of the project, and decision-making is led by a Community Advisory Board made up of individuals who helped with planning the grant, cancer survivors, tribal elders and leaders, and women who work with or are interested in women's health.

With the community, MFH created educational materials that Crow women could relate to. Often, educational materials are culturally irrelevant and people in communities do not utilize them.

Community members wanted positive messages on the front of the educational materials, as well as to see some words in the Apsáalooke language, photos of women from the community in traditional dress, and traditional Apsáalooke design and colors.

Alma leads a network of more than 20 female volunteers, trusted and respected Crow women—the Messengers—who provide advocacy and outreach and relay health information in a manner that is most comfortable for them. This strengths-based approach involves community members who intimately understand the psychosocial and psychocultural factors that enable fellow tribal members to address their personal health issues. MFH embraces an approach of holistic healing for women of the Crow reservation.

Cancer awareness has begun on the Crow reservation and has impacted everyone in the community. Now, Crow women approach Messengers in public and request Pap tests and mammogram appointments. Crow men are asking the question, “What about us?”, and men's health programs have begun. Most importantly, MFH has an established trust relationship with the Crow community and has shown that a research partnership with a university can result in positive benefits for the community. MFH's keys to success include the individual passion of project partners, the ability to weather the bumps along the road, the integrity of following through our words with actions, and a commitment to project sustainability.

MFH has received national attention as a role model for evidenced-based practices in cancer research and prevention that can be replicated with other tribal nations. What began in 2001 as a research grant from the American Cancer Society to MSU-Bozeman and the Crow Nation has evolved into a fully-fledged, fully-networked, community-based effort that works closely with community, state, and regional partners for cancer awareness and prevention. In 2010, the MFH partnership transitioned from a research grant into a 501(c)(3) nonprofit organization to accomplish our mission of “Strengthening the capacity of our tribal communities by empowering individuals to assess and address their own unique health-related knowledge, attitudes and behaviors.” As a non-profit organization, the community and university partners commit to their working relationship into the future.

For more information, contact: Alma Knows His Gun McCormick ([alma.mccormick@montana.edu](mailto:alma.mccormick@montana.edu)) and Suzanne Christopher ([suzanne@montana.edu](mailto:suzanne@montana.edu)).



## FOSTERING EFFECTIVE PARTNERSHIPS: REZRIDERS

This vignette provides information about RezRIDERS, a program initiated through a partnership between the Pueblo of Jemez, one of 19 pueblos in New Mexico, and the University of New Mexico Center for Participatory Research (UNM-CPR). RezRIDERS (Reducing Risk through Interpersonal Development, Empowerment, Resiliency, & Self Determination) seeks to deter substance abuse among Native youth at high risk by establishing an intergenerational mentoring approach that incorporates extreme sport into a culturally-based positive youth development curriculum. The year-round curriculum engages risky Native youth in extreme-sport activities (snowboarding, white-water rafting, rock climbing) directly linked to the sacred cycle of water (mountain snows to rivers, rain, and clouds). RezRIDERS has four major components: 1) extreme sports paired in activity clusters with; 2) Indigenized behavioral-cognitive lessons; 3) Native adult cultural mentorship; and 4) youth-driven community empowerment/action projects. These activities provide the context for experiential curriculum lessons in core values, optimism, self-determination, and empowerment. The Jemez-UNM-CPR RezRIDERS partnership is funded by the National Institutes of Health.

The Pueblo of Jemez is located approximately 50 miles north of Albuquerque, New Mexico, and is the only tribe in the world known to speak the Towa language. The tribal government is secular and includes the Governor, two Lieutenant Governors, two fiscales, sheriff, and the Tribal Council of ex-governors. The spiritual/traditional leadership appoints all political leaders each year. According to the Jemez 2002 Tribal Census, there are 3,475 enrolled tribal members where adolescents made up 38 percent of the population, while individuals ages 19-44 constituted 40 percent of the community; in 2006, the Pueblo of Jemez Department of Education found approximately 80 percent of Jemez tribal members speak Towa, across all ages and to varying degrees.

Like most United States tribal communities, leaders and program staff often have access to public health prevention programs that have been developed for non-Native populations, which are not culturally-specific or reflective of the needs of tribal youth. As such, the Pueblo of Jemez and the UNM-CPR partnered to fill a void in public health prevention that could meet the specific needs of Jemez youth. The Jemez people and UNM-CPR team have been working toward shaping healthy, positive behaviors while fostering a prevention continuum. The 13 years of partnership began as the Jemez Health Human Service and Jemez Education Department sought to team up with the UNM-CPR to begin implementation of the Centers of Disease Control and Prevention grant in 1999 led by Dr. Nina Wallerstein (UNM-CPR) and Director Kevin Shendo (Pueblo of Jemez Department of Education). Together, these tribal-academic partners have developed and implemented a family-based program for elementary school-aged children, and continue collaboration with ongoing tribal health and education programming that center on Jemez children, youth, and families utilizing protective factors around community cultural strengths and traditional knowledge. RezRIDERS incorporates past partnering accomplishments and results to inform subsequent prevention and intervention research, all of which work towards tribal needs through core public health functions of assessment, policy development, and assurance. Community action projects developed by program participant teams returns beneficial outcomes immediately to the community and matter to overall community well being, an example of research findings that RezRIDERS incorporates and builds upon.

This partnership offers several insights for those working on cultivating effective research relationships with American Indian/Alaska Native communities or tribal nations.



First, it suggests that personal, sustained relationships between community-based and academic researchers are essential. The RezRIDERS research team is an assembly of tribal members and academic staff revealing that UNM-CPR is working with the Pueblo of Jemez on preventing substance abuse among their youth.

Second, this research relationship is made up of dedicated and committed people. In this case, Mr. Greg Tafoya - Pueblo scholar, community advocate, extreme sport professional and UNM-CPR researcher - played a key role in initiating and sustaining this project. Tafoya is the creator of RezRIDERS and has been working with the Jemez Pueblo for the past six years where he credits both academic opportunities and supportive community partners, especially Ms. Janice Tosa, who encouraged the evolution of an idea into action. The efforts of both Mr. Tafoya and Ms. Tosa in working between tribal-academic partners has been critical. Both partners' ongoing commitment to relationship-building has helped to ensure this program will persevere with the potential of extending to other tribal communities, as well as, non-Tribal and inner city settings. Tafoya believes RezRIDERS has the potential to impact all of Indian Country by tapping into challenging extreme sport environments that challenge all involved. It is believed this challenge connects historical tradition in contemporary times. Pueblo of Jemez partners have shown that Community-Based Participatory Research (CBPR) is deeply rooted in community responsibility and requires efficient, respectful, and trustworthy collaboration among all parties involved with research agendas.

Third, this partnership established a Tribal Research Team (TRT) that advances the role of a community advisory board/committee commonly found within CBPR.

By having the TRT pilot an abbreviated version of the RezRIDERS program before youth participated, the TRT was able to direct changes to the program based on actual experience. The TRT is an action body, which also conducts asset assessments and identifies communal resources and cultural knowledge where needed, ensuring tribal members and culture are involved in research designs in addition to decision-making. In this case, the TRT is made up of adults who maintain strong traditional ties, who represent health and education tribal programs, and also traditional leadership, and who work together towards long-term project objectives and program consistency. Ms. Janice Tosa, the Jemez TRT leader, purposefully selected a team, responding to the challenge that they themselves would test RezRIDERS extreme sport and research activities. Ms. Tosa and the Jemez TRT, along with UNM-CPR, are developing a dialogue-to-action model with research intended to benefit the nation, tribes, and the Jemez community alike.

Fourth, Jemez initiated this partnership on a topic that has lasting significance for their community – and the health of Jemez youth and with action addressing it. In this way, tribal values drive the project through direct TRT participation to inform and guide the research, in addition to providing youth mentors experiencing extreme sport together. Additionally, this partnership evolved from a long-standing relationship with proven, positive impacts and connects previous research endeavors with a new one targeting a known need. Place-based, long-term experiences and participation are important for sustaining meaningful partnerships and offer potential for partners to evolve together and to provide research benefit for program participants to funders in an equitable manner.

For more information, contact Nina Wallerstein ([nwallerstein@salud.unm.edu](mailto:nwallerstein@salud.unm.edu)) and Kevin B. Shendo ([shendo@jemez.pueblo.org](mailto:shendo@jemez.pueblo.org)).

## BACKGROUND

This document was developed collaboratively by the National Congress of American Indians (NCAI) Policy Research Center and Montana State University's (MSU) Center for Native Health Partnerships to share insights that emerged out of tribal research regulation and research partnership work to foster responsible research with AI/AN communities. The independent and collaborative work of both organizations is reflected in this paper and includes:

- ✧ Proposed core values related to research, program evaluation, and partnerships with tribal communities from the NCAI research regulation curriculum and training.
- ✧ Resources collected on Indigenous knowledge and research, key tribal research protocol and ethics guidelines, and guidance on effective research relationships with Native communities.
- ✧ Information from American Indian community members and academic researchers offered during a 2009 Montana-based *Intersecting Interests* gathering held at Chico Hot Springs, Montana.
- ✧ Insights provided by Native and non-Native researchers working in Native communities.
- ✧ Information provided from two open conference calls held in 2012 with Montana tribal citizens, researchers, and other interested participants who shared their reflections and insights on research with tribal communities.

In September 2009, the NCAI Policy Research Center launched a research curriculum and in-person training after several years of development and pilot testing with Native communities. Several Montana tribes were among the first to inquire about receiving the training in order to establish greater oversight of research taking place on their lands and with their citizens. While the demand from tribal communities seeking the training was substantial, NCAI was also overwhelmed by the response from federal and state agencies, universities, and researchers who were interested in receiving the training in order to work respectfully with tribes. Though the curriculum was specifically designed for tribal leaders, it was clear that there was a need for another set of tools for other audiences.

An opportunity to address the needs of Montana tribal leaders and researchers working in partnership arose in 2011 when the NCAI Policy Research Center and the MSU Center for Native Health Partnerships were awarded a grant from the National Institutes of Health to deliver curriculum trainings to three Montana tribes and to develop insights about how to strengthen research partnerships. This paper is our collective attempt to provide a set of resources for researchers with a commitment to developing research that benefits Native peoples. While it draws on perspectives from those in Montana, it offers broad insights for researchers working with Native communities in many places.



Within the NCAI Policy Research Center curriculum, *Research that Benefits Native People: A Guide for Tribal Leaders*,<sup>6</sup> NCAI proposes five core values to consider in conducting research with tribes. These values were developed through a collaborative process with tribes, national Native organizations, and Native researchers. We propose that these core values provide a useful place to start and frame the discussion that follows. These core values acknowledge unique aspects of the research process in Native communities that should be considered in forming effective partnerships. These values include:

1. Indigenous knowledge is valid and valued.
2. Culture is always a part of research and thus research cannot be culturally neutral.
3. Responsible stewardship includes the task of learning how to interpret and understand data and research.
4. Tribes must exercise sovereignty when conducting research and managing data.
5. Research must benefit Native people.

Within this paper, we refer to Indigenous knowledge<sup>7</sup> as culturally-based processes, relationships, understandings, practices, protocols, and insights that have implications for how data is collected and used. Sometimes, Indigenous knowledge can be confused with a person's worldview. However, they are not the same. A worldview includes a more comprehensive sense of the origins of the world and humans' purpose in the world; Indigenous knowledge, or a cultural view on knowledge, is a part of worldview. When research is developed in a way that excludes, ignores, or otherwise disregards a tribe's knowledge, there is a significant danger that Native culture has been left out. Consequently what is being developed may not be applicable or useful for the community and may even be harmful. This exclusion has been justified with the suggestion that research must remain objective, without bias, or culturally neutral. As part of its research curriculum training, the NCAI Policy Research Center asserts that all research emerges from a particular cultural paradigm with a distinct cultural view on knowledge, relationships, and change; therefore, research cannot be culturally neutral.

In this paper, we first discuss how "culture," "sovereignty," and "experience" matter for researchers when working in partnership with tribes and AI/AN people and second provide a thematic summary of reflections provided by Montana-based community members and researchers. While the first section is presented as overarching insights for researchers working with AI/AN communities, we acknowledge that each community is distinct and that "place" also matters. It is essential for researchers to come to understand the particularities of place, including local histories and experiences with research, as part of building meaningful and effective research relationships. As such, we have made an attempt to emphasize the voices of Montana community members working in tribal research contexts in the first section as well as focus on Montana voices in the second section. We hope that this framework helps to anchor researchers navigating the growing information available on developing meaningful and ethical relationships with AI/AN communities.

<sup>6</sup> For more information on the curriculum, see: <http://www.ncaiprc.org/research-curriculum-guide>.

<sup>7</sup> For resources on Indigenous knowledge, see the Appendix at the end of this document.

## CULTURE, SOVEREIGNTY, AND EXPERIENCE MATTER

It is crucial for researchers entering into sustainable partnerships with AI/AN communities to develop an understanding and respect for: 1) Indigenous cultures and knowledge; 2) tribal sovereignty—and how it is exercised in the context of research regulation; and 3) the historic and present-day context of research with AI/AN communities broadly and in the specific community/communities with whom the researcher plans to work. In this way, researchers commit to a process of learning how the **cultures, sovereignty, and experiences** of AI/AN peoples shape the context of research.

### Culture Matters: Understanding the Value of Indigenous Knowledge in Research

Tribal nations are guided by sets of values rooted in rich cultural histories and traditions that form the foundation of their laws and policies. These values guide a community's position on research; its decision-making process regarding particular research projects and approaches; and its research policies, protocols, and research regulation structures. Cultural values are a foundational framework that guide tribal communities as tribes navigate today's complex research world. It is necessary for researchers to engage in a learning process to begin to understand a community's values, and how those values relate to traditions, histories, and a community's relationship to research.

Researchers must work to respect, appreciate, and understand Indigenous knowledge and ways of knowing—and how they apply in research. Indigenous knowledge is based on the collective wisdom of ancestors and built through careful observation and experiences of natural patterns of life. It is often learned, transmitted, and retained in the telling of stories. Indigenous knowledge provides a different approach than Western knowledge can offer, and in some instances, both can be used to solve complex issues.

An agreed on definition of Indigenous knowledge does not exist. It is not a solitary concept, but rather is characterized by intergenerational and collective relationships and processes. Indigenous knowledge is often unfamiliar to non-Native researchers because they may not have been exposed to it in school or everyday life. One description is from Yup'ik (Alaska Native) scholar, Angayuqaq Oscar Kawagley, and University of Alaska Fairbanks researcher, Ray Barnhardt, in their discussion of connecting Native and Western science.<sup>8</sup> They use an example from teaching science students about 'observation' and 'experimentation.' These researchers offer that many Native knowledge traditions and sciences *and* Western knowledge traditions and sciences have values and ways of thinking about observation and experimentation that are important in the teaching of science. In Native science, observation and experimentation are taught from a very young age as they are crucial for survival in the Arctic, for example. In Western science, observation and experimentation are central foundations of empirical research that are more likely taught in a university classroom and the US public school system.

By embracing Indigenous values about observation, researchers in Alaska were able to identify innovative approaches for developing science education. Developing a familiarity with how the people you are working with understand the nature and purpose of knowledge is important in research partnerships.

<sup>8</sup> Kawagley, A. O. & Barnhardt, R. (1999). Education Indigenous to place: Western science meets Native reality. In *Ecological Education in Action*. Gregory Smith and Dilafruz Williams, eds. Pp. 117-140. New York: SUNY Press. <http://ankn.uaf.edu/Curriculum/Articles/BarnhardtKawagley/EIP.html>



It is important to note that having an understanding of Indigenous knowledge is not necessarily the same as holding the knowledge yourself. In many communities, some knowledge is not intended for everyone.

There is strength in approaching research with multiple lenses, cultural worldviews, and methodologies rather than asserting that research is culturally neutral. When studies acknowledge the historical and contemporary, emotional, spiritual, social, and economic relationships of a tribal nation, they gain critical points of understanding that can lead to viable solutions. Having respect for the tribe's culture and Indigenous knowledge reinforces that the research outcome will be beneficial to all parties. It also makes it more likely that the research will focus on community strengths and assets versus deficits.

In addition to building a viable research partnership, strong consideration must be given to the potential benefits of the research project to the community. Potential benefits to the tribal community include: gaining desired knowledge about a certain issue, hiring and training local research staff, and building local research capacity through the inclusion of Native students.

The following list of practical tips for including culture in research is drawn from the NCAI Policy Research Center curriculum—*Research that Benefits Native People: A Guide for Tribal Leaders*:

- ✧ Be open to using a variety of types of research questions.
- ✧ Realize that the answers or outcomes of research may mean different things to different people.
- ✧ Involve community members in a meaningful way; research is strongest when community and university partners join together in every step of the research process.
- ✧ Use accessible language that is easy to understand and Native focused (when appropriate).
- ✧ Accept that outside researchers must learn and attempt to understand the tribal culture to be most effective.
- ✧ Use a broad, representative group of stakeholders to ensure that cultural considerations are well-represented in the research.

There are a variety of ways to engage community members, and it is important to ensure that community involvement is genuine and representative. The sovereign authority of tribal leaders and community members needs to be acknowledged and reflected in all aspects of the research process, including decision-making about research design, data collection and analysis/interpretation, and publication and dissemination. A good test is whether community members have 'veto authority' in decision-making, recognizing that working toward consensus may also be a key objective in fostering effective relationships.

## » APPLICATION

*Researchers who want additional information on Indigenous scholars writing about the nature of Indigenous knowledge and the power dynamics and historical relationships between academic researchers and tribal communities can use resources listed in the Appendix entitled, "Developing a Community-Based Research Orientation: Resources for Investigators Desiring to Work with American Indian & Alaska Native Communities."*

## Sovereignty Matters: Understanding the Political Status & Authority of Tribes in Research

For any researcher wanting to work with tribal nations, having an understanding and respect for tribal sovereignty and the unique political status of tribes and their citizens is paramount. For researchers, understanding tribal sovereignty means understanding both of these dimensions and then acting in accordance with the principles of respecting tribal sovereignty—both at the political/governmental level and the partnership or 'values' level. As such, it is important that researchers develop an understanding of how tribes and other Indigenous communities exercise their sovereignty in research by studying tribal governance and oversight models, research policies, ethical guidelines, and research protocols—both overarching and those that are unique to a particular community. Examples from tribes in the United States, as well as from Indigenous peoples from Australia, Canada, Japan, and Aotearoa/New Zealand are provided in the Appendix.

Tribal regulation of research can help communities maximize the benefits of research while protecting communities from potential harm, and ultimately improving the research. Federally-funded studies set out provisions as part of Federal Policy for the Protection of Human Subjects or 'the Common Rule' (45 CFR part 46) that require researchers to abide by ethical protocols designed to protect human subjects including respect for persons, beneficence, and justice. However, AI/AN governments also can—and do—formulate their own policies or laws regarding research that must be adhered to as with any other federal or state law.

Tribes are diverse in their views on research and the structure of their research regulation processes. While many tribes have Institutional Review Boards (IRBs), Ethics Committees, or other research oversight bodies to help regulate the alignment of research and tribal priorities, many do not. Some communities choose to work with the Indian Health Service, a tribal college, or other university in their geographic area to regulate research. Other tribal communities have created their own research codes as part of tribal law or have formed their own research review committees—either using the federal model of an IRB or another structure such as Community Advisory Boards or those bodies already existing in a community that are charged with this oversight.<sup>9</sup>

Researchers who seek to work with Native communities, therefore, must engage with key tribal stakeholders and decision-makers at all phases of the research process. Building these relationships requires patience, humility, and sincerity, regardless of whether or not the researcher is a tribal member. This is especially important when there is not a formal research regulation structure or review process in place, both for the protection of tribal citizens and the researcher. Changes in tribal leadership or fluctuations in tribal program priorities may affect decisions about research partnerships or alter the ability and interest of tribes to sustain research partnerships. Thus, it is essential that researchers draw on tribal and local protocols where they exist and invest in forming partnerships that take into account changes in tribal leadership.

<sup>9</sup> For more information on research regulation in American Indian and Alaska Native communities, see the NCAI Policy Research Center paper, "Research Regulation in American Indian/Alaska Native Communities: Policy and Practice Considerations" available at <http://www.ncaiprc.org/research-regulation>.



## » APPLICATION

*Regardless of the research review structure/process that is in place, it is crucial that researchers learn and adhere to the research protocols and procedures set by tribes with whom they seek to work. A first step is to ask who has the formal authority to make decisions about research in a community, inquire about the informal groups and leaders involved in community decision-making about research, and then meet with these groups and leaders.*

### Experience Matters: Understanding the Lived Context of Research for AI/AN Peoples

One reason that tribal sovereignty is so important is the long history of research in AI/AN communities. AI/AN people are one of the most studied groups in the United States. However, AI/AN people continue to be underrepresented in many major data collection efforts and statistical reports, making it difficult for tribes, states, and the federal government to develop policy solutions and social programs that effectively include and benefit Native communities. Access to quality data and reliable research equips tribal leaders to:

- ✧ make informed decisions,
- ✧ be proactive about shaping the future of their communities,
- ✧ secure funding for programs to benefit communities,
- ✧ invest in relevant research, and
- ✧ refine existing programs.

However, many Native people are wary of research and do not trust researchers, the academic institutions they represent, and/or the funding agencies. This is largely due to the fact that the term ‘research’ can remind Native people of the legacy left by researchers who did not prioritize the benefits for Native peoples and who, in some cases, caused harm by exploring inappropriate questions, misusing data and biological specimens, and using data gathered from community members to address issues that have little to no relevance to the community. Unfortunately, examples of harmful research with tribal communities still occur. One of the most recent and infamous examples initiated in 1991 – and settled in 2010 – by researchers at Arizona State University who conducted secondary analysis related to inbreeding and schizophrenia on biological samples originally collected for diabetes research in an AI/AN community – without the informed consent of study participants.

Consider the perspective offered by one teleconference participant:

*Researchers should come in very softly, understanding that our people are trying to recover from a long, long period of trauma and that we’re picking ourselves up and doing very well considering that. The researchers should come in with the idea of to do no more harm. Walk softly and listen carefully.*

Even when researchers have not personally conducted harmful or unethical research, their work can be suspect and they can be seen as being part of, and responsible for, the actions of others simply by claiming the role of ‘researcher.’ As such, tribal communities’ long history with research and the trauma it can cause needs to be understood in the context of all research projects with AI/AN peoples.

Researchers working with AI/AN communities should pay particular attention to political and cultural considerations (e.g., changes or shifts in formal and informal tribal leadership, handling/return of biological specimens) in: 1) securing individual and tribal consent for data collection; 2) planning for storing, sharing, and returning data to individuals and tribes; and 3) making decisions about who is involved in data collection, analysis, interpretation, and dissemination or publication of research findings.

It is also important to consider making appropriate translations between the local Native language and English for words or terms that may not be easily understood. This is critical in tribes that maintain strong Indigenous language use.

Conversations about timelines and funding requirements also need to occur, as seeding effective relationships often requires more time and funding than usual researcher-driven initiatives. Guidelines for negotiating working relationships with AI/AN communities are provided in the Appendix to this paper and include information on considerations in establishing formal processes of research decision-making and conflict management.

One key aspect of considering how “experience” matters relates to the particularities of place. Each Native community has a unique local history and present-day priorities that are important in developing relationships and planning research. It is important to seek out how “place” matters as part of fostering research that is meaningful and ethical, and to remember that what is true in one place may not be so in another. Toward that end, we next feature the perspectives of Montana community members working in tribal research contexts.

## » APPLICATION

*Learn about the research that has occurred in the community/communities with whom you are partnering, both good and bad. Learn about research in which your institution has taken part. Consider and be ready to share information about why you are doing this work and why you want to work with this specific community. Acknowledge past mistakes and lessons learned and specify how this research will be different and better. And then walk your talk.*



## DEVELOPING RESEARCH RELATIONSHIPS WITH AI/AN COMMUNITIES IN MONTANA

In May and June 2012, the NCAI Policy Research Center and the MSU Center for Native Health Partnerships (CNHP) hosted two conference calls open to any individuals who wanted to share their reflections and insights with researchers who currently work or want to work with tribal communities. More than 40 individuals participated in the calls, including those who identified as Montana tribal citizens, researchers working in partnership with Montana tribes, and a range of others with an investment in strengthening research relationships. No participant information was asked for or collected during either webinar. All responses offered by the participants were anonymous and no participant names or their tribal or organizational affiliations were documented. As part of these calls, participants were asked to comment on the values and characteristics they look for in a research partner and to offer any suggestions or recommendations for researchers working with tribal nations. Many of the insights framed above were shared during these conversations. More than thirty-five (35) people reviewed a draft of the document and provided comments and feedback to strengthen the final paper.

The following summary describes seven general themes from the May and June 2012 calls, as well as additional insights specific to Native researchers working in AI/AN communities in Montana and to community liaisons working across tribal and academic contexts. The general themes are:

1. *Listen and pay attention*
2. *Respect cultural and local knowledge*
3. *Leave pre-conceived research assumptions behind: Have an open heart and mind*
4. *Have personal integrity: Establish trust, be authentic, and act with humility*
5. *Have shared goals: Embracing community-driven research in a tribal context*
6. *Tribes are diverse: Learn about the tribes you are working with*
7. *Plan for sustainability and provide community benefit*



## 1. Listen and pay attention

Teleconference participants explained that “a good partner is someone who listens,” and that you can tell if you have been heard by that partner’s actions following the conversation. Listening often signals a person’s interest in learning and not centering their own perspective. As noted above, in developing meaningful research relationships, it is important to be a learner. A number of participants offered that it is important that both parties talk and that one person should not dominate the conversations. If a researcher does not listen, harm can ensue and the benefits of research for communities may never emerge. One participant offered:

*I think one of the most important things is that even though we keep telling researchers, “This is the way that it needs to be done,” they don’t listen. That’s really, really frustrating. And, they get impatient because they are on deadline. They get impatient because they have to do this or that, or get some article out, and they ignore the respectfulness of the tribal protocol, and that is extremely frustrating.*

The pressures on researchers to meet project and career goals may challenge their ability to listen and demonstrate respect for tribal research protocols in the way that some community leaders and members expect. It is important that researchers and community partners have early and frequent conversations where both listen and learn about each other’s experiences, responsibilities, and expectations. It is also important that partners consider that the answers to the questions they raise may not be readily available or straightforward.

For example, researchers may unknowingly ask questions about cultural concepts or knowledge that may be inappropriate or dangerous to answer. In some Native communities, knowledge about specific matters may not be shared with all people or may require particular training to ensure responsible stewardship of knowledge (e.g., plant medicines) and to prevent harm. As such, it is best for researchers and community partners to engage in regular conversations based on active listening and reflection.

## 2. Respect cultural and local knowledge

Valuing and appreciating the wealth of knowledge that tribal citizens have is integral in a research relationship. This includes respect for knowledge and expertise, not just for academic degrees. Respect is the cornerstone of developing an effective partnership. At times, researchers may be unaware of the dominance of their perspective or worldview and the need to embrace community values. One participant noted:

*At times there is subtle racism in researchers who come into tribal communities, and [they] think they are helping us, but there is that latent attitude of the ‘ignorant Indians’ on the reservations.*

Another teleconference participant suggested that Community-Based Participatory Research<sup>10</sup> methods and tribal research protocols could serve as useful guideposts for researchers intent on learning about respectful research processes. Therefore, it is important that researchers plan to regularly reflect on their own assumptions in their community interactions and research process—ideally with community partners who can guide them and raise questions that might not occur to the researcher working in isolation.

<sup>10</sup> Community-Based Participatory Research (CBPR) represents a spectrum of approaches to research. However, one common thread in all CBPR approaches is that communities, such as tribes, are full or lead partners in all aspects of the research process, from conception/design to publication/dissemination. For more information on CBPR, see the CBPR website resources in the appendix of this document; the Native American Research Centers for Health (NARCH) website on Research for Improved Health: A National Study of Community-Academic Partnerships at <http://narch.ncaiprc.org>; and the NCAI CBPR case studies paper at: <http://www.ncaiprc.org>.



### 3. Leave pre-conceived research assumptions behind: Have an open heart and mind

Participants noted that many researchers arrive with pre-conceived theories, research hypotheses, stereotypes, and assumptions that they seek to validate about what will work and what will not work, and that approaching communities in this way rarely serves community interests. They explained how important an “open heart and mind” is in understanding tribal needs and developing research that will benefit the community. Also, participants expressed that researchers need to be clear and upfront about their motivations and ensure that their research approach and methods will not harm a community. This is not to say that researchers should affect a ‘perfect,’ ‘neutral,’ or ‘unbiased’ demeanor, but they should be prepared to explain why they are asking the questions they are in their research, to share what drives them to explore these questions, and why they want to work in partnership with this community. Past work and summaries of research in other communities can be useful to guide research in a particular place, but it should not overwhelm the importance of tribal perspectives and priorities.

### 4. Have personal integrity: Establish trust, be authentic, and act with humility

The way researchers act and present themselves can make or break a relationship with a tribe. It takes time for a community to trust an individual. As one participant offered:

*Trust takes time. You need to prove, as a researcher or as an outsider, that you can actually function as a positive member of that community; and there’s no way to do that without becoming a part of that community. That takes time.*

In addition to time, trust also depends on developing real, authentic relationships at an individual level. Within research partnerships, sometimes personalities clash, and it may be best to find another partner. Partnerships can be strengthened from the beginning by ensuring regular communication and ground rules for talking openly and honestly – making it safe to be authentic, or to ‘be yourself.’ Authenticity and encouraging researchers to ‘be yourself’ was discussed in detail on the calls. Participants commented that they could “smell inauthenticity a mile away.” One participant explained:

*I suggest the researcher be gently advised to be authentic—that is the way that they are. Don’t apologize for it and never pretend to be something, to be something you’re not. Never try and be Native. That kind of pretending to be something one is not is the worst killer of trust.*

Another quality that tribal citizens look for in a researcher is humility—or the ability to humble oneself when working with other people, to value the knowledge and perspective of others. There is no place in a partnership for big egos, and a sense of humor is helpful. As one participant offered:

*You have to humble yourself before another person to understand that each person has something valuable to contribute. So you have to be able to quiet down your own agenda and your own processes and open up your entire spirit.*

Humility is also important in recognizing that our actions impact others and can have serious consequences – so consideration of others is essential. In some ways, the message here is to ‘be yourself’ but to realize you are not ‘by yourself,’ and that the perspective of others is central to developing work that has community benefit.

## 5. Have shared goals: Embracing community-driven research in a tribal context

When the community is at the center of the research—or driving the research—outcomes can benefit both the community and the researcher. Research topic areas should be relevant and important to the tribal community and research budgets should be fairly shared and controlled. By ensuring the community is an equal partner in all stages of the research (rather than merely a participant) different worldviews and perspectives shape the research, enriching the project outcomes and experiences of both the researcher and the tribal community. The community and the researcher—in equal partnership—can conduct an assessment of the issue(s), decide what they want to measure and evaluate, and determine how the research will benefit and protect all involved. Both the community and researcher are mutual learners, and through this process, both can develop mutual understandings of the issue. Shared goals can ensure broad community participation in research, and this is best accomplished if the partnership precedes any submission of a grant proposal. Throughout the community-driven process, it is also equally important to remember that research within a tribal context must take into account jurisdictional issues, history, place, culture, protocols, and tribal laws.

A list of resources to guide a process of developing shared goals within a tribal context is presented as part of the Appendix to this document. While the resources may seem overwhelming, we encourage partners to explore a few of these together and adapt them as necessary for their own purposes. This process ultimately helps develop a more trusting relationship between the academic community and the tribal community, where all perspectives and knowledge are valued and included in appropriate ways.

## 6. Tribes are diverse: Learn about the tribe(s) you are working with

Participants noted that researchers should work to develop an understanding of the history and current context of the tribe and the values of the community from the beginning of the relationship. Participants suggested that researchers ask community leaders for information, rather than relying on published tribal histories that may not have been written by community members and that may therefore contain inaccuracies. This means that the researcher must be committed to spending time in and with the partnered community. This is a large part of doing research with a tribe—taking responsibility for understanding who you are working with by talking with tribal members and asking questions. As participants offered, community members will most likely have the answers and feel that within the research partnership it is also their responsibility to provide that contextual background. Tribes are diverse, even within communities on a reservation, and there may be multiple community histories and perspectives that may at first appear inconsistent. Research with AI/AN communities often has to take these complexities into account and seek to recognize tribal diversity.

## 7. Plan for sustainability and provide community benefit

Many research projects have come and gone in tribal communities—some benefitted communities and some did not. The ethics of research strongly direct researchers to define the benefit to tribes from research conducted. Research partners should discuss sustainability from the beginning of the project and focus on providing benefit to the community, as defined by the community. Sustainability does not mean that research projects have to continue indefinitely, but that they should provide a lasting, positive impact. What sustainability means for a particular tribe and research project will vary as different types of research results in different kinds of sustainability. Each partnership can define how sustainability can be achieved or defined within a project. For example, a partnership may be established to collect baseline data on an issue of community interest, where sustainability could mean tribal ownership of the data for future use.



Another partnership may be formed to develop a health intervention research grant on an issue of community interest, where sustainability could mean integrating the project into an existing tribal department or forming a non-profit to continue the project work at the end of the research grant.

Other examples of how to build sustainability include establishing a permanent community advisory board to work on an issue, developing a permanent infrastructure for data collection/program evaluation that is integrated into a tribal department, working to create a permanent reference/resource/database that tribal citizens and staff can use (for example, through access at a tribal college library), or developing a permanent new program/educational initiative that is taken on by the tribe.

## **Additional Insights for Native people working in Native communities** (see vignette on page 21)

The politics of working within one's own community can sometimes be more difficult than being an outsider. Participants were explicit in noting that researchers can sometimes be Native people who want to develop partnerships in the community they are from or with those with whom they have relationships. Participants noted that researchers—both Native and non-Native—all have the same responsibilities as noted earlier, and also provided some additional guidance for Native researchers working in Native communities. One participant noted that:

*I'm a Native person but I never presume, even when I am back home that I really know. And, the other thing, I guess, kind of a rule, is to listen...I listen and look and learn. Because if you presume that you know what is going on, you have made your first mistake.*

Native researchers who are working with members of a different tribe were advised to remember that you are not a member of that tribe. Even if you are a member of the community with whom you are working, participants reminded researchers that they do not know all the issues. Therefore, it is important to remember to work with community members in discovering and learning about issues and realizing that you do not have all the answers.

Other Native researchers echo this sentiment related to feeling a deep commitment to serve their people and facing complexities in their work. These complexities emerge as a result of the role many Native researchers take on as 'border crossers' working across community and institutional contexts. It is important for Native researchers to identify support mechanisms as they work across contexts and actively engage tribal and community leadership.

## FOR RESEARCHERS WORKING WITH NATIVE COMMUNITIES: REFLECTIONS FROM A NATIVE RESEARCHER

Desi Small-Rodriguez, a Native scholar who presented at the NCAI Policy Research Center's Tribal Leader/Scholar Forum shares reflections on being a Native researcher, provides insight for other researchers, and offers thoughts on tribally-driven research and data collection as an exercise of sovereignty.

Now is an exciting and critical time for research in Indian Country. This was the pervasive sentiment I gathered from participants at the NCAI Policy Research Center's 2012 Tribal Leader/Scholar Forum in Lincoln, Nebraska. The wide scope of research topics, from language preservation efforts and tribal data development to cancer detection and diabetes prevention, illustrates the growing expertise of our Native researchers. It further demonstrates the need for us to not only address issues of non-Native researchers seeking to conduct research with Native communities, but also the precarious position that we Native researchers have in working with our own peoples. One might expect Native researchers to be held to a higher standard of ethical, methodological, and cultural responsibility than non-Native researchers. As a social researcher and an enrolled member of the Northern Cheyenne Tribe, I have felt this disproportionate burden and am thankful for it. This dual responsibility keeps me true to my training and profession, but more importantly, to my own identity and the people for whom I do this work. Perhaps some of the best advice I have received as a researcher in Native communities is "to tread lightly," particularly in one's home community.

Overall, researchers must take it upon themselves to ensure that their work aligns with tribal agendas to hope for any measure of sustained relevance and impact in Indian Country. Some tribes have the equivalent of university Institutional Review Boards and Ethics Committees to help regulate the aforementioned alignment of research and tribal priorities, but many do not. More often than not, researchers in the academy and in communities operate in silos; this is especially evident of research involving marginalized communities. Academic and community collaboration is increasing, but work to bridge research and the policy arena at all levels (tribal, federal, and state) remains.

Opportunities such as the NCAI Policy Research Center's Tribal Leader/Scholar Forum provide an avenue to reach one of the most important audiences, tribal leaders. Researchers who seek to work with Native communities, therefore, must engage with key tribal stakeholders and gatekeepers at all phases of the research process starting from inception. Building these types of relationships is a feat that requires finesse regardless if one is a tribal member or not.

Many conversations at the NCAI Policy Research Center Tribal Leader/Scholar Forum spoke to the issues that are unique to tribal contexts, including the history of research as a tool of colonization, tribal politics, leadership turnover, fluctuating budgets largely dependent on federal and state funds, and incredibly powerful cultural protocols and taboos.

**Tribal Data Collection and Ownership.** At the Tribal Leader/Scholar Forum, I focused my presentation and discussion on developing tribal data as an exercise of self-determination. Oftentimes, data development is rarely viewed as a political act and an exercise of tribal self-determination. Utilizing a case study of one of the international Indigenous communities I work with as an example, I explained how this Indigenous community is increasingly gaining the economic and political leverage to commence significant economic, social, and cultural development on behalf of their tribal members. However, they do not have the data to guide them in their efforts. Understanding the limitations of national censuses and surveys, this Indigenous community is beginning to develop their own tribal censuses and surveys to capture the specific circumstances and needs of their populations. Some tribes in the United States also are beginning to develop their own tribal surveys.

Over the course of the Forum, several tribal leaders discussed their tribe's data requirements, such as: demographics, education, socioeconomic needs, language fluency, and cultural priorities. A model for tribal data development was also suggested as useful and could be based on other models being conducted with other Indigenous peoples. The ownership and sharing of tribal data and its application are also two important issues for future thought. Conducting tribal censuses will result in the creation of large tribal databases that will only be useful if there are skilled technicians within tribes to analyze the data and apply it in meaningful ways to support the functions of tribal governments. Additionally, this kind of tribal data is very unique and could potentially be a very valuable resource that will have to be managed properly and securely.

For more information, contact Desi Small-Rodriguez at ([desisr@gmail.com](mailto:desisr@gmail.com)).



## Insights for those serving as community liaisons to researchers (see vignette on page 23)

Community members who serve as community organizers or liaisons to researchers are vital to navigating and nurturing partnership relationships. For example, MSU's Center for Native Health Partnerships included community organizers who successfully served as a researcher's first point of contact with the tribe, aided in setting ground rules for partnerships, assisted in navigating tribal research protocols and review structures, partnered in the research design and process, provided cultural knowledge about tribes, and served as a bridge between the academic world and their own communities. These community liaisons often assume great risk in their roles of bridging between researchers and tribal communities. For many tribes, the term 'research' can often invoke negative memories and associations. By presenting a potential research project to the tribal community, the community organizer's relationship to their own community—and their reputation—is on the line and at risk. Oftentimes, community liaisons are working with researchers who may not have had much personal or professional experience with Native cultures and communities; so they often bear responsibility for any inappropriate (though often unintentional) missteps on the part of researchers.

Researchers should recognize the great risk that community members take to bring them into a tribal community. It is equally important to always be cognizant of the leap of faith that tribal communities take to partner with researchers, particularly with the very real reminder of the history of trauma caused by research in the past. They see potential benefit in research—for data and information that can assist their tribe. However, if the research is not performed appropriately, there is the potential for harm. Community liaisons play a very significant role in preventing this, but also assume great risk if the researcher's actions and research are irresponsible.

## CONCLUSION

Our goal is for this resource to be a part of a learning process for researchers committed to working with AI/AN communities as they develop understandings about the cultural, political, and lived realities of Native peoples that must be considered in research. It is a living document that has been created in dialogue across cultures and contexts, and we hope that it will be used in this way—as part of a reflective and shared dialogue in research training contexts, and in the process of forming, reflecting on, and sustaining research partnerships that benefit Native peoples and communities.

While building meaningful relationships with communities often takes more time and resources than non-partnered research, there are deep insights and rich innovation that can come from these efforts. We are hopeful that these resources will encourage researchers in their work and strengthen the pathway to effective partnerships with AI/AN peoples and communities.

## FOR RESEARCHERS WORKING WITH NATIVE COMMUNITIES: REFLECTIONS FROM A TRIBAL COMMUNITY ORGANIZER

The Center for Native Health Partnerships at Montana State University employed Tribally-based community organizers to serve as a liaison between their Tribal community and the university. Below are the reflections from Ada Bends, one of the Tribal community organizers who worked in partnership between her Tribe and the university for five years.

As a past Crow Community Organizer, I took my job very seriously. I represented my Crow Tribal communities and people, and this was my responsibility to protect, speak up for, ask, inquire, learn, develop trust, interpret, and stand up for my Tribal community. There were a lot of lessons learned. As community organizers, we struggled very hard for the first two years through many interpretive challenges of our way of life versus the university's timelines and view of us as Tribal nations. The next year, I began reaching out to my Tribal community because I took that responsibility to learn, listen, interpret, present, and go back and provide the process again until it was accepted and trusted.

I am grateful for the opportunity to have been a part of this Community-Based Participatory Research (CBPR) process, and to be Montana State University Bozeman's Center for Native Health Partnerships liaison for the Crow Nation and the University. A key to this process was being an active member of the Crow Environmental Health Steering Committee, which is made up of all Crow Tribal members from various professional and non-professional/Tribal community members. All members are actively involved in all of our Crow cultural activities.

**Advice for Researchers.** Researchers have a responsibility to learn—be a student always of this research process. This document is a really good start, and I truly encourage all researchers to look at the NCAI Policy Research Center's *Research that Benefits Native People* curriculum training. This curriculum is an asset to Native people/leaders/community members and non-Tribal community members. In the appendix, there is a good list of resources for researchers to educate themselves. I also would encourage non-Native researchers to take a course in cultural diversity, and actively be involved with university or ethnic based clubs at Tribal colleges, societies, social activities, etc.

Researchers need to make the time to visit a prospective Tribal community. The potential researcher's commitment to provide research that benefits a tribe/tribes must also include the researchers total commitment to visit the Tribal community and never assume that one or two visits suffice. It is helpful for each researcher to partner with a local Tribal community member(s) and actually spend time with them to get to know the community, the people, and the subtle innuendos of the everyday life in that community. However, they must never act like they know a particular Tribal community just because they have spent a few years in a Tribal community.



Too many times, non-Native researchers come into our Tribal communities and assume that they know, can talk for, write about, and give their perspective on a particular Tribal community or Tribal members that they met or worked with for a few years. This is insulting and unethical on the part of an outsider coming to work within our Tribal communities. I see this happen over and over again, and it is so detrimental to our people, Tribal governments, and way of life. The researcher gets all the glory/acknowledgements.

The key is to always ask and seek out more than once, twice, three times as you begin to learn about a particular Tribal community. Even me, as a Tribal member, I am always asking what is the proper Tribal protocol. I never assume nor do I take the responsibility of speaking for my Tribal community or people. Respecting the vastness, uniqueness, and sacredness of each Tribal nation/community is so vital in developing and building long lasting partnerships. Researchers are coming into our sacred homeland. Just as I would give an outside non-Tribal member the due respect and non-assuming attention and grace were I to visit their community/homeland.

We are not just linear-minded; we are also holistically-minded in our Tribally-based approaches. We live in a multi-dimensional perspective of our daily living each and every new day as we are connected to everything in this sacred universe and see each day as a brand new day.

Interpretation is also another very important and respectful consistency that a potential researcher must adhere to in introducing and working within a Tribal community. "Words are Sacred" and each word in our Tribal Indigenous languages have one or more definitions. It is good to have a translator and researcher partner up so that it can be a benefit to the tribes (communities, the everyday people) for the sustainability and successfulness of a research project to be developed.

Learn to go with the flow of Tribal communities. Time is linear within the Tribal communities, but the holistic timeframe is a way of life too. Being flexible and patient is a great attribute for any researcher. You will make friendships (family ties) that will last forever if you truly invest your time, effort, trust, respect, and openness to learning from being, living, and spending time with Tribal community people.

For more information, contact Ada Bends ([adab@crownsations.net](mailto:adab@crownsations.net)).

## APPENDIX

We have provided a range of resources in this Appendix, including:

- ✦ “Developing a Community-Based Research Orientation: Resources for Investigators Desiring to Work with American Indian and Alaska Native Communities”
- ✦ Community-Based Participatory Research (CBPR) Related Websites

We also encourage researchers to explore the NCAI Policy Research Center and Montana State University’s Center for Native Health Partnerships websites that provide additional tools and resources, including the:

- ✦ NCAI Policy Research Center’s website ([www.ncaiprc.org](http://www.ncaiprc.org)), which offers a research regulation toolkit, information on a Tribal Leader/Scholar Forum that annually takes place in June, and Module I of the *Research that Benefits Native People: A Guide for Tribal Leaders* curriculum.
- ✦ NCAI Native American Research Centers for Health (NARCH) website ([narch.ncaiprc.org](http://narch.ncaiprc.org)), which provides a set of research protocols developed as part of a community-academic partnership project.
- ✦ NCAI Genetics Resource Guide website ([genetics.ncai.org](http://genetics.ncai.org)), with information for researchers and tribal leaders related to genetics research partnerships.
- ✦ Montana State University’s Center for Native Health Partnerships website ([cnhp.montana.edu](http://cnhp.montana.edu)), which features resources for researchers interested in working with tribes, including seminars on community-based participatory research and information on the *Intersecting Interests: Tribal Knowledge and Research Communities* gathering.

### Developing a Community-Based Research Orientation: Resources for Investigators Desiring to Work with American Indian & Alaska Native Communities

Developing meaningful and ethical research with American Indian and Alaska Native communities requires that investigators commit to a sustained process of relationship building, cross-cultural learning and respect, and reciprocity. This is especially important given both the historical context of research in Native communities and the role of research and information in geopolitical and economic decision-making. Tribal governments are sovereign nations and therefore have the legal authority to regulate all activities conducted on their lands and with their citizens, including research. Tribes are also diverse in their views on research and the structure of their research regulation processes. As such, guidance for investigators intent on designing and implementing meaningful research with American Indian and Alaska Native communities should not take the form of a simple checklist or how-to approach; rather it must reflect the process of developing a research orientation that is community-based, culturally relevant, and supports a tribal agenda. Toward that end, we have amassed a set of resources that may be useful for investigators to begin the process of understanding the nature and role of research in Native contexts and of developing a research stance that is meaningful and appropriate. We encourage investigators to use these resources to identify aspects of the research process that may be unique to Native communities; concepts of power, knowledge, and culture that may be important for research inquiry in these contexts; and elements of research objectives, methodology, analysis, outcome, and data ownership that may differ in Native communities. Resources for Indigenous researchers working with their own Native communities are limited, reflecting a critical gap in the literature; however, we have included some sources throughout that explore this perspective.



## Indigenous Knowledge, Ethics, and Research Methods

These resources feature the work of scholars on the nature of Indigenous knowledge and how it matters in the context of research and the design of research methods. They can inform key foundational elements of the paradigm and ethic of conducting research in Native contexts.

- ✧ Battiste, M., & Henderson, J. Y. (2000). *Protecting Indigenous knowledge and heritage: A global challenge*. Saskatoon, SK: Purich Publishing.  
This book discusses the impact on Indigenous peoples by colonizing powers, including the assault of modern society on Indigenous society, the commercialization of Indigenous language, culture, art, knowledge, and the lack of consent, acknowledgment or benefit of knowledge and enterprises taken. This book illustrates why current legal protections are inadequate to protect Indigenous knowledge and puts forward ideas for reform. It also examines issues from an international perspective and explores developments in various countries including Canada, the United States, Australia, and New Zealand.
- ✧ Bishop, R. (1999). Kaupapa Māori Research: An Indigenous Approach to Creating Knowledge. In Robertson, N. (Ed.), *Māori and psychology: research and practice - The proceedings of a symposium sponsored by the Māori and Psychology Research Unit*. Hamilton, NZ: Māori & Psychology Research Unit.  
This paper explores an Aotearoa/New Zealand model for Indigenous self-determination research. The Kaupapa Māori research approach draws authority from Māori cultural practices regarding what is acceptable and what is not acceptable research in reference to the people and the cultural context within which it operates. Central to this approach is that cultural aspirations, understandings, and practices of Maori people anchor the research process. The article also explores issues of power, legitimacy, and accountability by politicizing the research process and asserting that it is based in a different world-view from that of the dominant discourse. It acknowledges the need to recognize and address the ongoing effects of racism and colonialism in the wider society.
- ✧ Burkhart, B. Y. (2004). What Coyote and Thales Can Teach Us: An Outline of American Indian Epistemology. In A. Waters (Ed.), *American Indian Thought: Philosophical Essays* (pp. 15-26). Malden, MA: Blackwell Publishing.  
This essay speaks about basic principles upon which to discuss and understand Native knowledge. This understanding, according to the author, should be based fundamentally on observed and first-hand knowledge and not on a Western standard that prioritizes factual or causal knowledge.
- ✧ Cajete, G. (1999). *Native Science: Natural Laws of Interdependence*. Santa Fe: NM: Clear Light Publishers.  
The book discusses multiple levels of meaning and relationships that inform Native astronomy, cosmology, psychology, agriculture, and the healing arts.
- ✧ Carjuzaa, J. & Fenimore-Smith, K. (2010). The give away spirit: Reaching a shared vision of ethical Indigenous research relationships. *Journal of Educational Controversy*, 5(2), Summer 2010, ISSN 1935-7699.  
This paper discusses the dilemma that emerges when protocols taken from Western research paradigms are applied to research in Indigenous communities. The authors raise a number of ethical issues related to voice and privilege that should be resolved in order to be inclusive of multiple perspectives.
- ✧ Castellano, M. B. (2004). Ethics of Aboriginal research. *Journal of Aboriginal Health*, 1(1), 98-114.  
This article discusses ethical codes of conduct in research with Aboriginal peoples or with external partners. It speaks to the rights of Aboriginal peoples to participate as principals and partners in research that affects their identity and culture.

- ✧ Deer, F. (2006). Research Perspectives in Indigenous Education: The legitimacy of Indigenous knowledge. *World Indigenous Nations Higher Education Consortium Journal*.  
The article examines how Indigenous knowledge can be used to understand student behavior and school climate in Indigenous school settings, particularly within the Canadian Indigenous context.
  
- ✧ Fisher, P. A., & Ball, T. J. (2003). Tribal Participatory Research: Mechanisms of a collaborative model. *American Journal of Community Psychology*, 32(3/4), 207-216.  
This article describes a unique research approach that places American Indian and Alaska Native communities at the center of every phase of the research process; from the research design to collecting, analyzing, and interpreting the data and reporting findings. It asserts that in order to produce lasting change, researchers must work within a historical framework that considers the impact of oppression, discrimination, and disempowerment on American Indian and Alaska Native communities. It also addresses the need for tribal oversight, building community research capability, and utilizing culturally specific methods. The Tribal Participatory Research approach advocates a strong, collaborative relationship between tribes and researchers and offers mechanisms for building these types of partnerships.
  
- ✧ Grenier, L. (1998). *Working with Indigenous Knowledge: A Guide for Researchers*. Ottawa, Canada: International Development Research Centre.  
This book illustrates how historically Western researchers have failed to consult properly with or include Indigenous populations in research studies, but that this trend is slowly changing. Through a comprehensive review of examples, the book highlights how Indigenous knowledge can contribute to improved research design and delivery and has tremendous impact on Indigenous peoples as well as the researcher.
  
- ✧ Harding, A., Harper, B., Stone, D., O'Neill, C., Berger, P., Harris, S., & Donatuto, J. (2011). Conducting research with tribal communities: Sovereignty, ethics and data-sharing issues. *Environmental Health Perspectives*.  
This article discusses how only tribal nations themselves can identify potential adverse outcomes to proposed research projects in their communities and how it is the responsibility of researchers to ensure all parties understand the assumptions and methods of the research. The authors assert that sovereignty, ethics and data sharing are critical areas for investigators to address when conducting Community-Based Participatory Research, particularly in a health or natural resource related field. Further, the article presents a model material and data-sharing agreement for use.
  
- ✧ Kirkness, V. J. & Barnhardt, R. (1991). First Nations and higher education: The four Rs—respect, relevance, reciprocity, responsibility. *Journal of American Indian Education*, 30(3), 1-10.  
Native people historically have been under-represented as college graduates in Canada and the United States. The reasons for under-representation differ between the university perspective and the Native student perspective. This paper looks at the implications of these differences in perspective and identifies ways in which initiatives within and outside of existing institutions are transforming higher education for Native people in both Canada and the United States.
  
- ✧ LaVeaux, D. & Christopher, S. (2009). Contextualizing CBPR: Key principles of CBPR meet the Indigenous research context. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health*, 7(1), 1-25.  
This article examines traditional Community-Based Participatory Research (CBPR) approaches and identifies what works and what does not when applied to Native American communities. Further, not only does it contextualize existing CBPR principles with tribal populations, it also suggests nine new principles specific to American Indians and Alaska Native peoples. These include: acknowledge historical experience with research, recognize tribal sovereignty, prepare for leadership turnover, interpret data within the cultural context, and utilize indigenous ways of knowing, to name a few. The article confirms the importance of using CBPR approaches in American Indian and Alaska Native communities.



- ✧ Lomawaima, K. T. (2000). Tribal sovereigns: Reframing research in American Indian education. *Harvard Educational Review*, 70(1), 1-23.  
This article discusses the power dynamics and historical relationship between academic researchers and American Indians and the shift in power that has occurred in these relationships over the past four decades. The author discusses how access to subjects, data ownership, analysis and interpretation, and control over dissemination of findings all reflect struggles for power and tribal sovereignty. The article asserts that an understanding of new tribal research protocols and policies are necessary for responsible and respectful scholarship.
- ✧ Piquemal, N. 2001. Free and informed consent in research involving Native American communities, *American Indian Culture and Research Journal*, 25(1), 65-79.  
This article looks at how conducting research among other cultures must use what is learned without betraying the confidence of those with whom they interact. The author offers recommendations including negotiating responsibilities before seeking consent, obtaining consent from relevant authorities, reconfirming consent as work proceeds, and providing the community with data.
- ✧ Richmond, L. S., Peterson, D. J., & Betts, S. C. (2008). The evolution of an evaluation: A case study using the tribal participatory research model. *Health Promotion Practice*, 9(4), 368-377.  
This article presents an evaluation case study of tribal youth development guided by the tribal participatory research model. It focuses on best practices in developing partnerships with tribal communities and organizations engaged in this type of work. Key learnings include the need for flexibility in the evaluation approach and for investigators to remain attuned to feedback from community stakeholders and experiences that are unique to American Indian communities.
- ✧ Smith, L. T. (1999). *Decolonizing methodologies: research and Indigenous peoples*. London: Zed Books.  
Research has historically been utilized as a tool of Indigenous colonization and it remains a powerful reminder of the continued marginalization of Indigenous peoples. This book looks at the historical and philosophical history of Western research and the different ways colonialism and imperialism are imbedded in research methodology and knowledge seeking. It also examines how Indigenous researchers are starting to reclaim control of Indigenous ways of knowing; yet, many still grapple with frustrations with Western research paradigms and the persistent “othering” of Indigenous populations.
- ✧ Taylor, J., Doran, B., Parriman, M., & Yu, E. (2012). Statistics for community governance: The Yawuru Indigenous population survey of Broome (pp. 1-30, Working paper No. 82/2012). Canberra: Centre for Aboriginal Economic Policy Research.  
This paper presents a case study of self-determination research amongst the Yawuru Indigenous population of Australia. In response to a need for information on its people, the Yawuru Native Title Holders Aboriginal Corporation sought to build internal capacity for governance and community planning by conducting a census-like survey of its population. The Yawuru people of Broome are one of the first in Australia to conduct this type of information gathering on their own terms as an exercise of self-determination. The article describes the research process from beginning to end, which was undertaken as a joint venture between the Centre for Aboriginal Economic Policy Research at Australian National University and the Yawuru people.

- ✧ Thomas, L. R., Donovan, D. M., & Sigo, R. W. (2010). Identifying community needs and resources in a Native community: A research partnership in the Pacific Northwest. *International Journal of Mental Health and Addiction*, 8(2), 362-373.

This article presents a model for using Community Based Participatory Research and Tribal Participatory Research methods to conduct a community needs assessment in a Native context. The approach embraces both traditional research methods and community-driven assets to identify community strengths and concerns in Native communities with the ultimate goal of designing relevant health interventions. Using a case study in the Pacific Northwest it shows how meaningful research partnerships can yield success in identifying community needs and resources.

- ✧ Walling, J., Small-Rodriguez, D., & Kukutai, T. (2009). Tallying tribes: Waikato-Tainui in the census and Iwi register. *Social Policy Journal of New Zealand*, (36), 2-15.

Utilizing a case study of the Waikato-Tainui iwi (tribe) in Aotearoa/New Zealand, this article highlights a critical gap in Indigenous research, the development of tribal data collected by tribes for tribes to drive development and policy. The case study examines inconsistencies between the New Zealand Census and the tribe's enrollment register and signals the need for tribes to depart from solely relying on existing official sources (i.e. Census, national surveys, etc.) for information on their own people.

- ✧ Weijer, J. & Emanuel, E.J. (2000.) Protecting Communities in Biomedical Research. *Science*, 289(5482), 1142-1144.

This paper discusses the ethical issues in biomedical research among indigenous, geographic, religious, disease, ethnic and virtual communities.

- ✧ Wilson, S. (2008). *Research is ceremony: Indigenous research methods*. Black Point, Nova Scotia, Canada: Fernwood Publishing.

This book describes how Indigenous researchers in Canada and Australia work within a research context of Indigenous ways of being and knowing. Through their partnerships, these researchers seek to make careful choices in the selection of topics, methods of data collection, analysis, and presentation of information in order to be accountable to indigenous communities.

### **Key Research Policies, Protocols, and Ethics Guidelines**

These resources include research policies, protocols, and ethics guidelines that have been developed by Indigenous peoples around the world. These resources may help researchers to develop their own frameworks and approaches to building effective research partnerships with American Indian and Alaska Native communities.

- ✧ Alaska Native Knowledge Network Resources – The Alaska Native Knowledge Network (ANKN) at the University of Alaska Fairbanks provides a number of resources related to Alaska Native knowledge and ways of knowing.

- » Principles for the Conduct of Research in the Arctic
- » Principles & Guidelines for the Protection of the Heritage of Indigenous People
- » Alaska Federation of Natives Guidelines for Research

- ✧ American Indian Law Center, Model Tribal Research Code explores the general role of research and Institutional Review Boards in the federal regulatory process for American Indian Tribes. It presents a model code to assist Tribes in developing law regarding their research regulations and needs.



- ✦ Australian Institute of Aboriginal and Torres Strait Islander Studies, *Guidelines for Ethical Research in Australian Indigenous Studies* include principles of ethical research in Indigenous studies and practical applications of these points. Main categories are: consultation, negotiation, and mutual understanding; respect, recognition, and involvement; and benefits, outcomes, and agreement.
- ✦ Canadian Institutes of Health Research, *Guidelines for Health Research Involving Aboriginal People* lays out a comprehensive ethical framework for conducting research with Indigenous peoples in Canada, including the need for community informed consent, research agreements, and protection of communities' cultural and sacred knowledge. The guidelines also discuss intellectual property and secondary use of biological specimens and data.
- ✦ Convention on Biological Diversity provides information on the protection of biological diversity and ecological life through policy. Article 12 of the declaration specifically speaks to principles around research and training.
- ✦ First Nations Centre, *Considerations and Templates for Ethical Research Practices* provides three participatory research templates grounded in the principles of ownership, control, access, and possession. The three templates are: a model Code of Research Ethics; a model for a Collaborative Research Agreement; and a model for a Data Sharing Protocol.
- ✦ Mataatua Declaration on Cultural & Intellectual Property Rights resulted from a 1993 convening of the Nine Tribes of Mataatua in the Bay of Plenty Region of Aotearoa New Zealand.
- ✦ Nibutani Declaration of the 2008 Indigenous Peoples Summit resulted from a gathering of Indigenous people from Japan and around the world in advance of the G8 Summit in 2008.
- ✦ United Nations Declaration on the Rights of Indigenous Peoples is a declaration of the rights of all Indigenous peoples.
- ✦ University of Arizona, Native Peoples Technical Assistance Office, *Research Protocols* provides a database of U.S. Tribes' research ordinances, codes, and protocols. Other resources include template research codes, model research agreements, and a bibliography on academic research in Indian Country.
- ✦ University of Washington Native American Law Center, *Model Tribal Health Research Code* is a user-friendly, fill-in-the-blank template for tribes that seek to develop their own Tribal Health Research Code.

### **Negotiating Research Relationships with Native Communities**

Negotiating research partnerships with American Indian and Alaska Native communities is often a long-term process of trust and relationship building. The resources below provide guidance on that process, including: navigating tribal research regulations; content outlines and templates for research agreements and policies; and examples of mutually benefiting partnerships between Native communities and researchers.

- ✦ Canadian Aboriginal AIDS Network, *Principles of Research Collaboration* provides template research agreements covering ethical considerations; ownership, control, access, and possession of data; and authorship of publications.

- ✧ Christopher, S., Saha, R., Lachapelle, P., Jennings, D., Cooper, C., Cummings, C., Webster, L. (2011). Applying indigenous community-based participatory research principles to partnership development in health disparities research. *Family and Community Health*, 34(3), 246-255.

This article explores how Native American communities in Montana and university researchers navigate the intricacies of building trust and sharing power while conducting community based participatory research. Sponsored by the National Institute of Health, the study embraces a mix of stakeholders in the partnership process including tribal members, health care professionals, and Native and non-Native researchers. It presents detailed application of Indigenous research principles (LaVeaux & Christopher, 2009), such as acknowledging historical experience, recognizing tribal sovereignty, and understanding tribal diversity, to name a few, in an effort to reduce health disparities.

- ✧ Hughes, P., & Grace, B. (2004). *Gracious Space: Working Better Together*. Seattle, WA: The Center for Ethical Leadership.

This book provides approaches for diverse communities to work better together—in partnership and through collaborative public learning. The term “gracious space” creates an environment where diverse opinions are welcome, where people can listen and learn together, and come to deeper understandings to solve complex problems.

- ✧ Mariella, P., Brown, E., Carter, M., Verri, V. (2009). Tribally-driven participatory research: State of the practice and potential 41 strategies for the future. *Journal of Health Disparities Research and Practice*, 3(2), 41-58.

This paper discusses the current practice of research with and by American Indian tribal governments in the United States. It begins with a brief overview of Community-Based Participatory Research and compares and contrasts its principles and methods with what this paper terms Tribally-Driven Participatory Research.

- ✧ Indigenous Wellness Research Institute, University of Washington, Research Policy Templates offers a template research protocol for tribes and template data sharing and ownership agreements developed in partnership by the University of Washington and Pacific Northwest tribes.

- ✧ Sample Genetic Policy Language for Research Conducted with Native Communities presents specific cultural issues related to genetics research in American Indian and Alaska Native communities, along with template language for policies or research contracts to address these issues.

- ✧ National Congress of American Indians Policy Research Center, Tribal Research Regulation Toolkit includes a series of papers on research regulation in American Indian and Alaska Native communities, including white papers on review of research studies, data control options, and genetics research.

- ✧ National Congress of American Indians Policy Research Center, Community-Based Participatory Research in American Indian and Alaska Native Communities offers exemplary cases of community-based participatory research conducted with American Indian and Alaska Native communities, with resulting lessons learned.

- ✧ *Negotiating Research Relationships with Inuit Communities: A Guide for Researchers* provides background on community perceptions of research and the spectrum of levels for community involvement in research. It also covers key elements of a negotiated research relationship and strategies for communication of research results.

- ✧ Northwest Portland Area Indian Health Board, Guidelines and Information for Researchers delineates researcher responsibilities and includes guidance documents on possible harms and benefits in genetics research, sample research protocols, and informed consent forms.

- ✦ World Health Organization, Indigenous Peoples and Participatory Health Research provides information on how research projects can be set up between Indigenous peoples and research institutions in a collaborative and ethically appropriate manner on the basis of good management practices. It outlines key principles for participatory research management, and steps in the communications process between Indigenous peoples and research institutions from the development of a research idea to negotiation of a mutually acceptable research agreement.

## Community-Based Participatory Research (CBPR) Related Websites

- ✦ Action research and evaluation on-line course: <http://www.scu.edu.au/schools/gcm/ar/areoll/areolind.html>
- ✦ Canadian Institutes of Health Research - Ethics of Health Research Involving First Nations, Inuit and Métis People: <http://www.cihr-irsc.gc.ca/e/29339.html>
- ✦ Canadian Institutes of Health Research - A Guide to Researcher and Knowledge-User Collaboration in Health Research: <http://www.learning.cihr-irsc.gc.ca/course/view.php?id=3>
- ✦ Centre for Community-based research: <http://www.communitybasedresearch.ca/>
- ✦ Community-based research Canada: <http://communityresearchcanada.ca/>
- ✦ Community-Campus Partnerships for Health: <http://depts.washington.edu/ccph/commbas.html>  
CCPH is a nonprofit organization that promotes health (broadly defined) through partnerships between communities and higher educational institutions.
- ✦ Community-engaged scholarship for health: [www.ces4health.info/](http://www.ces4health.info/)  
CES4Health is a free online mechanism for peer-reviewing, publishing, and disseminating products of health-related community-engaged scholarship that are in forms other than journal articles.
- ✦ Community-engaged scholarship – this is a toolkit to help community-engaged faculty make their best case for promotion and tenure - <http://www.communityengagedscholarship.info/>
- ✦ Community tool box: <http://ctb.ku.edu/en/>
- ✦ Comm-org: the online conference on community organizing: <http://comm-org.wisc.edu/node/22>
- ✦ CBPR skill-building curriculum: <http://depts.washington.edu/ccph/cbpr/index.php>
- ✦ CBPR resources: [www.mycbpr.org](http://www.mycbpr.org)
- ✦ CBPR wiki: <http://cbrnet.pbworks.com/>  
The National CBR Networking Initiative was funded by a grant from the Corporation for National & Community Service to support the development of high-quality community-based research programs and to create a national networking structure to assist and connect practitioners.
- ✦ Community campus partnerships for health: <http://depts.washington.edu/ccph/>
- ✦ Developing and sustaining CBPR partnerships: A skill-building curriculum - <http://www.cbprcurriculum.info/>



- ✦ Institute for Community Engaged Scholarship: <http://www.theresearchshop.ca/>  
Fosters collaborative and mutually beneficial community-university research partnership within the College of Social and Applied Human Sciences (CSAHS) at the University of Guelph.
- ✦ Interactive CBPR model from the University of New Mexico: <http://hsc.unm.edu/som/fcm/cpr/cbprmodel.shtml>
- ✦ Involving people in research: <http://www.involvingpeopleinresearch.org.au/index.php/resources/fact-sheets>  
The Fact Sheet series has been developed in response to requests from researchers for short simple ‘tools’ to support the implementation of consumer and community participation in health research. \*
- ✦ Métis Center: <http://www.naho.ca/metis/>  
The Métis Centre is one of three population-specific centres within the National Aboriginal Health Organization (NAHO). Incorporated in 2000, NAHO is an Aboriginal founded and guided institution whose aim is to advance and promote the health and well-being of First Nations, Inuit, and Métis.
- ✦ Mott Foundation: From the grassroots: Community organizing: <http://www.mott.org/news/news/2010/CommOrgVideosLandingENG.aspx>  
In this series of seven videos, community organizers from the U.S. and abroad share their personal experiences and perspectives on how the field is helping people to actively engage, inform and shape the processes of public decision making.
- ✦ National Association of County & City Health Officials - Roots of Health Inequity web-based course: <http://www.naccho.org/topics/justice/roots.cfm>  
Roots considers the root causes of inequity in the distribution of illness, disease, and death. The course, based on a social justice framework, is a conceptual introduction to ground public health practitioners in concepts and strategies for taking action in everyday practice.\*
- ✦ NIH grant workshop: <http://www.seiservices.com/nida/1014081/Presentations.aspx>  
Great presentations on CBPR approaches with tribal communities (focus is on substance abuse, but broad application)
- ✦ NIH Office of Behavioral and Social Science Research – e-source on behavioral and social science research: <http://www.esourceresearch.org/>  
Inside you will find 20 interactive chapters with authoritative answers to methodological questions on behavioral and social science research. With contributions from a team of international experts, this anthology provides the latest information on addressing emerging challenges in public health.
- ✦ Office of University Partnerships (HUD): <http://www.oup.org/aboutoup.asp>
- ✦ Ontario Women’s Health Network - link to their “Inclusion Research Handbook” <http://www.own.on.ca/inclusionhandbook.htm>
- ✦ Partner tool: <http://www.partnertool.net/>  
PARTNER is a Free Tool to Collect, Analyze, & Interpret Data to Improve Collaboration within Community Networks

- ✦ Peer research publications: Peer research has emerged as a popular form of community-based research (CBR) where research projects include members of the target population who are trained to participate as co-researchers. <http://www.wellesleyinstitute.com/uncategorized/peer-research-in-action/>
- ✦ Power study (Project for an Ontario Women's Health Evidence-Based Report): <http://powerstudy.ca>
- ✦ PRC Partnership Trust Tool: <http://www.cdc.gov/prc/program-material/partnership-trust-tools.htm>
- ✦ The Prevention Institute: health equity and prevention primer: <http://www.preventioninstitute.org/tools/focus-area-tools/health-equity-toolkit.html>
- ✦ Processes, Relationships and Evaluation in Participatory Research and Indigenous Health Research: – workshop video/information <http://pram.mcgill.ca/napcrg2009.php>
- ✦ Research for organizing: <http://www.researchfororganizing.org/>  
This toolkit is designed for organizations and individuals that want to use participatory action research (PAR) to support their work towards social justice.
- ✦ Science Shops: <http://www.scienceshops.org/>
- ✦ Sustainability toolkit – University of Montreal: [http://www.cacis.umontreal.ca/perennite/index\\_en.htm](http://www.cacis.umontreal.ca/perennite/index_en.htm) A tool-kit for the evaluation of sustainability processes and sustainability levels of public health programs and projects.
- ✦ University of Minnesota - Community and Faculty Training for CBPR Collaborations: <http://www.med.umn.edu/ccr/hdresearch/news/training/home.html>  
These training materials consist of two separate but parallel comprehensive curricula designed to prepare community members from immigrant and refugee communities and academic faculty to collaborate on community-based participatory research (CBPR) projects. The training is oriented towards research and CBPR naïve community members and CBPR naïve researchers who are developing new partnerships.
- ✦ University of Victoria Office of Community-based research: <http://web.uvic.ca/ocbr/>
- ✦ Wellesley Institute in Toronto community-based research (CBR) and capacity-building workshop materials: For CBR workshop materials, go to <http://bit.ly/aQb0ot>
- ✦ For capacity-building workshop materials, go to <http://bit.ly/br0M0Z>



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