

Protecting the Navajo People through tribal regulation of research

By Doug Brugge and Mariam Missaghian

Corresponding author:

Doug Brugge, PhD, MS; Assistant Professor
Department of Family Medicine and Community Health
Tufts University School of Medicine
136 Harrison Ave.; Boston, MA 02111
Voice: (617) 636-0326
Fax: (617) 636-4017
dbrugge@aol.com

Scope

This essay explores the process and issues related to conducting research that involves the Navajo People. We begin by painting with a rather broad brush the more general context of research ethics and Native Americans, move to the particular case of the Navajos, explore in some detail the process established by the tribe to regulate research and end by considering how this applies to a couple of case examples, including this paper itself.

Background

Due to past inhumane actions involving research participants, the Federal government has adopted regulations on ethical standards for research. As part of these regulations, Institutional Review Boards (IRBs) were created to review research and to ensure that the rights and welfare of research participants are protected (13). Institutions that conduct research and receive federal funding, such as universities and medical facilities, are required to establish IRBs, which are sometimes given other names, but serve similar functions (13).

These federal regulations reflect a society that values individual autonomy and rights. Yet this society is composed of many diverse ethnic groups that may place a higher or equal value on their family, clan or other identity group than on individuals. If individual rights are protected in research, then should cultures or communities also be protected in research? Are communities living entities with rights? Many believe that communities may be affected by research in different ways than individuals (1,2,4,5,6,7,8,9). For example, many Native American communities have complained about researchers who: 1) do not understand the problems in their communities, 2) are condescending, 3) stereotype the community in their publications, 4) do not give back to the community and/or 5) conduct research in their communities without adequately respecting cultural norms. Once the researchers leave, the communities are left to themselves to resolve the problems created by the research (4).

Participatory Action Research

Some researchers have proposed guidelines for community-based research, where value is placed not only on individuals, but also on the community. Although developed separately from the research review process, these methods in many ways mirror the approach of the Navajo Nation to regulating research. The essence of such research lies in a partnership between the researchers and the community. Researchers collaborate with the community rather than impose their research protocol on them. The research then becomes a project of the community as well. Community members are no longer passive subjects of research, but active participants involved in all of its stages. Because such research requires community participation, it is sometimes called *participatory action research (PAR)* (2).

Community participation may be achieved in various ways, but should always begin by assessing the concerns and interest of the community. Ideally the research topic emerges from the combined input of the community and the researchers. Once a topic is chosen, employing and training community members in research skills may become a mechanism of community capacity-building and empowerment (2). A research project has the potential to increase the community's ability to mobilize its resources in a way that may benefit all and make the community more self-sufficient.

Just as research involving human participants is governed by ethical principles, it could be said that PAR is governed by ethical principles too. Among these are *respect, equity* and *informed consent*:

Respect: PAR conducted in an ethnic community requires an understanding and respect for cultural differences. This means that both researcher and community must respect each other's social, political and cultural structures (5,8). What one culture might consider as respectful might not be so for another culture. Researchers need to also be aware of the historical treatment of the community in order to respond appropriately. Beyond cultural issues, respect also includes understanding each other's research protocol (8). While methods can be adjusted somewhat, communities must at some level respect that researchers use scientific methods and must decide whether they want to engage in research.

Equity: A partnership implies that networks, personnel, and power are shared between the scientist and the community (8). This requires an honest evaluation of how the researcher benefits from the study through publication, promotion and degrees. Furthermore, equity means reciprocal learning without paternalistic attitudes. Any resource that a team player contributes to the project must be considered of value. Equity also means that the disruption in the lives of communities be compensated. A researcher may give back to the community by reporting findings to the community through newspaper articles and at community gatherings or, particular perhaps to Navajo Country, over the radio (7). It is also advisable to deposit copies of data, recordings and photographs in community museums. In many cases it is possible to assist community partners with future grant writing. There should also be opportunities for shared authorship, or at least proper acknowledgement in publications (5).

Informed consent: The entire process of the project, any harms and benefits that may occur to individuals and the community, as well as any plans to publish must be conveyed to individuals and community representatives (5). It has been suggested that researchers should seek consent from leaders that represent the community at large and not those who represent a subgroup (5). In the case of the Navajo Tribe, this entails, as will be discussed more later, approval from the Tribal Government, approval from the chapter house (the local government), and from the individual.

Looking Through the Eyes of Native Americans

One Native American views researchers in the following way:

The researcher has the luxury of studying the community as an object of science, whereas the young Indian, who knows the nuances of tribal life, receives nothing in the way of compensation or recognition for his knowledge, and instead must continue to do jobs, often manual labor, that have considerably less prestige. If knowledge of the Indian community is so valuable, how can non-Indians receive so much compensation for their small knowledge and Indians receive so little for their extensive knowledge? (6)

It is certainly true that Native American communities have been studied extensively and in more detail than any other ethnic group in the US. There is nowhere near the intellectual interest in, for example, Blacks or Chicanos. Romanticizing combined with scientific interest in societies that were not industrialized has driven this interest. While portraying Native Americans as exotic and worthy of study, researchers, and even more so the media, have at times reduced them to stereotypes and undermined their humanity. One problem that results is that there are broad generalizations about Native Americans that are believed by substantial sectors of society. Native Americans are held as unattainable ideals by liberals and condemned by racists as unfit. We attempt next to suggest some ways that researchers might look at Native Americans in order to overcome their prejudices and preconceptions and gain a more realistic understanding.

One suggestion has been that any researcher who plans to study an indigenous community is urged to try to “think like an Indian” (6). Another point of view is that Western interpretations of Native Americans are inherently harmful and that these communities need to be allowed to interpret for themselves what they believe and stand for. We hold that there is still a role for non-Native American researchers to play, but also think that their function is limited by the need for Native Americans to produce their own research. Collaborations between Native American and non-Native researchers are one solution. Another key is for researchers to spend time with the Native community that they plan to work with, to approach them with an open mind and to be ready to learn.

Among the stereotypes of Native peoples is their use of oral tradition. While oral traditions certainly exist and have long been an integral part of many Native American communities, they may be more strongly held today by elders than by youth. Oral histories have tremendous value since they not only teach principles by which to live, but also provide a sense of identity and belonging and are a transmission of culture. Thus awareness of and consideration of how oral tradition can be integrated into the process and outcomes of research may be warranted. Yet, it is important not to assume that all Native Americans will relate to such an approach. A prospective researcher could as easily misstep in either direction, assuming oral history is a monolithic value of the tribe or missing the opportunity to include it.

When it comes to the spirit of nature and the environment, Native Americans have been seen as the population in the US that is most intimately tied to the land and even as environmental icons. The traditional views of Native Americans tend to support an environmental agenda, since they usually view nature not as a resource to be exploited by humans but rather to be lived with in balance. But even a quick look at Native lifestyle today shows that there are differences also with the US environmental movement. Many raise livestock and most eat meat. They hunt and fish, sometimes for endangered species. And the governments of many tribes have endorsed mining and drilling for minerals, oil and gas. There may be a critical distinction between the official view of the government and the views of individuals or groups within the population. Again the naive researcher could err in either direction. A more complex and three-dimensional understanding is needed.

The sense of community among Native Americans might also be a critical point to keep in mind for outside researchers who are used to dealing with less cohesive collections of individuals such as those found in most US cities. For example, when asked to define “helping,” Eskimos replied, perhaps differently than most Americans, that helping was “struggling together” (12). Still there is much diversity among Native Americans. While many indigenous people live in small and tight communities, others, such as many Navajos, like to live spread out, far from their neighbors. And there are vast differences between Native Americans who are urban or rural, young or old, or by education level or religious affiliation. Thus in the consideration of community, one must also be careful. Indeed more mainstream social forms may be growing as various tribes become integrated into the broader US political and economic system.

One of the dangers of generalizing about Native American communities is that most indigenous people believe in individual autonomy as well as communal responsibilities. For example, in the Navajo community, very young children are allowed to roam around in order to develop their own identities (11). Another example is that many Native American languages do not have an imperative voice (9). Indeed, one of the things that may be challenging to outside researchers is fully respecting the fact that, like all peoples, each Native American has the capacity to make his or her own decisions.

Another possible pitfall is to view Native Americans as analogous to other minority groups in the US. While there are certainly areas of overlap with other minorities, the issue of tribal sovereignty tends to predominate over traditional civil rights when dealing with Native Americans. Tribal sovereignty has been recognized under Article I, Section 8 of the U.S. Constitution and developed and became stronger over the last century through federal law, case law, and U.S. Supreme Court decisions (17, 21). Today the Navajo Nation has jurisdiction over most, but not all legal issues within their reservation land. Among these is the authority to regulate and prohibit research, or even ban non-Navajos from their land (17). The boundaries for sovereignty are both complex and ever changing. We do not try here to explore the legal details, but would point to two recent US Supreme Court rulings that restricted tribal sovereignty rather than expanding it (34, 35). These cases dealt with conduct of non-members of the tribe on non-Indian land within the reservation and search warrants for off-reservation crimes.

A failure to grasp the diversity and complexity of indigenous communities has led some Native Americans to perceive researchers as self-centered individuals, mainly interested in gaining tenure, grants, and prestige (5). Eskimos have even created a word for anyone who “use[s] big words, sound[s] important, and speak[s] fast” – it’s “white man’s disease” (12). Moreover, because many researchers have published sensitive material that according to tradition should only reside in the minds of indigenous people, the community has become cautious with researchers and their studies (6). Some of this material was published with approval under different standards in earlier times or with approval of, for example, one set of elders who may have disagreed with another group about what should or should not be available to the public.

Nevertheless, today’s researcher must navigate the terrain, as it exists today, including whatever residue remains from the past. For this and many other reasons, researchers wanting to work with indigenous communities should consider dedicating much time and effort to getting to know the community, gaining their trust and forging strong relationships based on mutual respect. There is, in our opinion, nothing more convincing than proceeding from the needs and interests of the community and producing results that they can see as beneficial.

Looking Through the Eyes of Researchers

Researchers know that it is unfair to characterize all researchers as being self-centered, but maybe they can see how that feels to them and think for a moment how it feels to be stereotyped as a Native American. It could be said that there are two types of researchers – those who seek to get involved with the community and those who do not (9), although many researchers may fall somewhere in between the extremes. Many researchers have spent valuable time with the community, even learning the language and customs. Many have developed enduring ties with locals who have come to trust them (9). However, it is also true that the interests of researchers and Native communities often diverge. On the most basic level, communities want solutions to their problems while researchers want to advance intellectual knowledge.

Academic training is inculcated with western theories and quantitative thought and a distinct set of values. Researchers are taught to seek the truth and record facts. Truth is usually measured through a set of steps such as the identification of variables, setting of confidence levels, or proving or disproving a null hypothesis (12). Generalizability is important too. If a study’s results are not generalizable, then they are not considered of much value among the scientific community (9). Scientific studies that focus on universal problems are praised and acknowledged more by western society than studies that focus on highly specific problems of a small population (9). It might be a consolation to some that not all researchers believe that science, as described above, is the only way of organizing human experiences (12). Nonetheless, communities participating in research must understand that Western society has developed such scientific methods and that it might be a challenge for researchers to apply their training to a culturally different community.

Researchers today have to face many bureaucracies in order to survive professionally. They must abide by research guidelines established by their host institutions; federal, state, and local governments; and their granting agency in addition to the various levels of approval by the tribes (5). Cases of conflicting requirements arise frequently. Restrictions that must be dealt with include ethical rules overseen by institutional review boards of the host institution, financial restrictions by the funder and the host institution, programmatic restrictions of the funder and reporting requirements. Communities may not understand that there are limits to what researchers can do (9).

Academic researchers are usually under additional pressure to bring in grants and to publish in order to stay employed or to be promoted. Simply the process of writing proposals, a majority of which are rejected, consumes precious time and energy. Data analysis and the writing and publishing of manuscripts also takes far longer and requires more work than most people outside of academia imagine. The time from finishing the first draft of a paper to seeing it in print is usually measured in years.

In Navajo Country these pressures meet up with “Navajo Time”, which moves more slowly and with less of an incessant pace than the research world. The result can be a cultural clash between researchers who “need” things to be done yesterday and Navajos who do not value such time pressure. Researchers planning to work in the Navajo Nation should be prepared for the process of seeking approvals and getting things done in general to take longer than they might otherwise expect.

The Navajo Experience

One Native American tribe that has long been studied and written about is the Navajo Tribe. The Navajo people – the Diné – have strived to honor their ancestors in attempting to preserve their traditions and way of life; however, history demonstrated this to be a difficult task. Historically “white people”, often through the official actions of the US Government, have oppressed Indigenous Americans and Navajos.

The 1863-1864 Carson campaign against the Navajos, which marked their defeat militarily, resulted in the destruction of crops and livestock, the deaths of Navajos who resisted, and starvation of the few who survived (15). This event was followed by what the Navajos call the *Long Walk* – a four hundred mile exile to Fort Sumner, New Mexico. The long walk happened in the dead of winter in 1864 and was endured by some 8,000 Navajo captives. During their internment, deaths persisted due to malnutrition, harsh weather, and diseases introduced by the US Government and to which the Navajos lacked immunity. In 1868 a treaty was signed between the U.S. and the Navajos that allowed them to resettle in designated lands in exchange for peace (15,16). The peace treaty included the provision of sheep and cattle, as well as seeds and agricultural equipment so that they could start anew.

Today, it is remarkable that the Navajo Nation has become the largest Native American tribe in the U.S. It spans three states: Utah, New Mexico, and Arizona and is closest in

size to West Virginia (14). In the 1990 U.S. Census, more than 200,000 members were living on or near the Navajo trust lands (14). The Navajo Nation strives to be economically self-sufficient – a major task, given that the Diné still have high poverty and unemployment rates.

Navajo Perspective on Health

The view of health and what causes illness varies from culture to culture and from individual to individual (11). Navajos tend to view health as all encompassing, although there is a wide range of individual views among Navajos. In the main, Navajos see health and disease as manifestations of events in the environment. In the Navajo culture, a person's health is affected not just by the actions of others, but also by the words of others (10). The Navajo phrases *hózhooji nitsthakees* and *hózhoojí saad*, which mean “thinking and speaking in a positive way,” reflect this view. This could have implications that researchers should take into consideration. For example, researchers might have to be especially sensitive when describing possible risks of research.

The Navajo Area IHS website provides a descriptive list of cultural issues that may affect medical care of the Diné. Most of these issues are applicable in research. The website is <http://www.navajohealthjobs.ihs.gov/glossary.asp>.

The Navajo Nation Government

To understand how research is regulated in the Navajo Nation, one must have some understanding about tribal sovereignty. Unlike most other ethnic groups in the US, Navajos and other tribes have their own governments. Officially established in 1923, the Navajo government is a relatively young. Every 4 years, the Navajos elect a tribal President, Vice-President, and Council delegates (18). The tribal government has 3 branches, each with its own head – executive, with the Honorable President as head; legislative with the Speaker of the Navajo Nation Council; and judicial with the Chief Justice (19). The Navajo Nation is also divided into political entities called chapters, which serve and resolve issues within their local communities, in ways similar to counties or municipalities (20). There are 110 chapters in the Navajo Nation each with a representative on the Tribal Council as well as a local elected leadership.

The Indian Health Service (IHS)

In 1921 the Snyder Act was passed, authorizing federal funds for the provision of health services to Federally recognized tribes (21). The gains in health care during the 1930s were, however, largely lost during and after World War II and the medical community's long-standing critical view of traditional Navajo medicine men persisted (15). In 1955, responsibility for Indian health was transferred to the Public Health Service. The Indian Health Service replaced the Division of Indian Health in 1970 (15). Five years later, the Indian Self-Determination Act of 1975 (Public Law 93-638) allowed tribes the option of taking charge of health programs to serve their own people (17, 21). Today, the IHS seeks, in its own words, to “*assure that comprehensive, culturally acceptable personal*

and public health services are available and accessible to American Indians and Alaska Native people” (21).

The IHS has 12 regional administrative offices, including the Navajo Area IHS (NAIHS). The NAIHS serves Navajos, but also the Southern Band of San Juan Paiutes, the Hopi and the Zuni Reservations, given that these reservations are geographically close to one another. Navajos receive health care from 6 hospitals, 7 health centers, and 12 health stations. (21) The Navajo Division of Health (NDOH), which was created by the Navajo Nation in 1977, is also a key player in the health care delivery system. The NDOH provides a variety of health services for people of all ages and their families. It has five agency offices at different geographic locations throughout Navajo Country. (21)

Navajo Health Research Review Board

The Navajo Area IHS (NAIHS) and the Navajo Nation conduct a limited amount of research involving the Navajo people compared to outside universities. Since 1989 Navajo Nation law has required that all ethnographic research conducted on Navajo Nation lands to be authorized by a formal permit that is issued by the Historic Preservation Department. In addition, the Navajo Nation and the NAIHS have IRBs, although the Navajo Nation IRB is relatively new. Since 1974 federal law has required that required the establishment of IRBs (13). The Navajo Nation IRB is called the Health Research Review Board (HRRB). Up until March 1996, any health researcher seeking to conduct a study in the Navajo Nation had to obtain approval from the NAIHS IRB and the IRB at IHS Headquarters (24; **personal communication, Marlene Long Jasperse, August 1996**). Today the Navajo Nation HRRB reviews proposed research involving Navajos and the IHS IRB is no longer the board of record for studies in the Navajo Nation. Researchers can also contest decisions of the tribe in the Navajo Nation court system.

The powers of the Navajo Nation HRRB include: (25)

- 1. Review and approval or disapproval of research proposals.**
 - 2. Review of manuscripts prior to publication.**
 - 3. Negotiation of procedures, methodologies, and approaches to research and publication with researchers.**
 - 4. Request of assistance from other persons with specialized knowledge. In research involving vulnerable subjects (prisoners, children, etc.), inclusion in the HRRB of individuals who have a particular concern for these subjects.**
 - 5. Adoption of appropriate rules and procedures.**
 - 6. Coordination with other appropriate boards and committees including other IRBs and the Historic Preservation Department (for activities which may also be subject to Cultural Resources Preservation Act).**
-

Both the NAIHS IRB and the Navajo Nation HRRB have regulations and guidelines that dictates ethical codes to be followed in research. Given that the IHS is a federal agency, its IRBs follow the federal policy for the protection of human participants in research, provided in Title 45 of the Code of Federal Regulations, Part 46 (45 CFR 46) (23). In compliance with these regulations, the IHS has filed a Multiple Project Assurance (MPA), in which it agrees to abide by the regulations (24). The MPA further defines the responsibilities of the Headquarters and Area IRBs.

The Navajo Nation, on the other hand, adopted the Navajo Nation Health Research Code in 1995 to “*govern all medical, health, behavioral, social science, and other studies that are conducted within the jurisdiction of the Navajo Nation to provide protection, beneficence and justice for individuals and communities participating in research activities*” (25). To ensure such protection, this code established the HRRB. The Navajo Nation has also adopted the Navajo Nation Privacy and Access to Information Act in 1999 to ensure “*a means to access records and information relating to the operation of the Navajo Nation while preserving the privacy interests of individuals and entities*” (26).

The Navajo Nation Health Research Code further defines the review procedures to be followed by the HRRB. According to the Research Code, the HRRB must continually review any research being conducted in the Navajo Nation. If conditions change once a research project has begun, the HRRB may require the researcher to make any necessary changes. The HRRB also has the power to revoke any research permit or limit the scope of research activities. On the other hand, researchers who are denied a permit may request reconsideration of their application. (25)

Defining Health Research

Given the generally broad view of health held by many Navajos (see earlier), it is perhaps surprising that the Navajo Nation Health Research Code defines research in a very traditional Western framework. The Health Research Code defines “research” as:

...the use of systematic methods (including, but not limited to note taking, interviewing, video and audio taping) to gather and analyze information for the purpose of proving or disproving a hypothesis, concepts or practices, or otherwise adding knowledge and insight in a particular medical or psychological discipline... (25)

Under the IHS it appears that the definition of health was relatively narrow. Despite the above definition from the HRRB, we know from personal experience that the HRRB considers ethnographic studies that mention health to be under its jurisdiction. According to the chairperson of the HRRB, any publications or research that involve Navajos, irrespective of whether it involves human participants and regardless of the precise subject matter falls under the jurisdiction of the HRRB. Further, the chair reports that the role of the HRRB is to insure that such publications or research do not depict Navajos in a derogatory way (personal communication Beverly Becenti-Pigman, September 2001).

For example, another board member confirms that the HRRB would consider program evaluation that is presented publicly or published as well as investigative journalism to be under their jurisdiction (personal communication, Mark Bauer, October 2001). We understand that there is currently a legislative initiative to revise the Health Research Act seeking to extend it beyond health research (personal communications, Beverly Becenti-Pigman, Mark Bauer and Peter Noyes, September--October 2001).

As a point of comparison, the Hanford Cultural Resources Laboratory in Washington State has also been grappling with the problem of defining what constitutes research that involves humans in terms of ethnographic contact with Native American Tribes located near their facilities. They have exempted stakeholder meetings, field trips, participation in project activities not involving human research, taking photographs during non research activities, document recovery and general interviews that do not identify the individual as not requiring consent forms. They do not distinguish, however, between ethnographic and health research (30)

Pre-publication Review

One distinctive feature of both the NAIHS and the Navajo Nation is that they require researchers to submit manuscripts for review and approval prior to publication (25, 27,28). Moreover, if a researcher plans to present orally the results of a study, the presentation materials must also be submitted for review and approval (27, 28). Certainly there is a distinction between prohibiting research and halting or restricting release of findings of approved research. Some researchers might view the latter as infringing on academic freedom. In recent years there has been growing controversy about corporate influence and control over release of research findings that they do not like (35), albeit, the primary concern with corporate influence is the vast amounts of cash that they provide to researchers (36), something that is clearly not a concern with respect to the Navajo Nation.

According to the Navajo Nation Health Research Code, the HRRB is to review manuscripts for “*technical content and validity, organization of content, readability, as well as assurance that they are consistent with the goals, intent and policies of [the] Code*” (25).

The Navajo Tribal Government views their regulations as a protection against being stigmatized by research reports harmful to the Navajo people. For example, it has been reported that Navajos were stigmatized by material published during the Hantavirus Pulmonary Syndrome epidemic in 1993 (17). Researchers were asked not to mention the specific locations on the Navajo Reservation in their publications; however, two research articles named locations. Events that followed, including media coverage describing it as a “Navajo disease”, led to many Navajos feeling an invasion of privacy and public discrimination (17).

Members of the HRRB report that the primary goal is for the board to have something to say about what is written about Navajos rather than to censor findings and that the

Navajo HRRB actively seeks positive relationships with researchers (personal communications, Mark Bauer, September 2001; Mike Everett, May 2001). Recommendations for researchers and Tribes include written formal agreements about manuscripts prior to conducting research (29).

Comparison of the IHS and Navajo Nation Research Guidelines

The adoption of the Health Research Code may be another step towards survival and self-determination of the Navajo Nation. The Nation is seeking more control over the research being conducted within its territory. Prior to the adoption of the Navajo Nation Health Research Code, the NAIHS provided researchers with a *Project Approval Form* that listed pre-conditions required for IRB review (27). Today, researchers must contact the Navajo HRRB Program to obtain an application form (28). There is no expedited review by the Navajo HRRB, something allowed by the IHS and most other IRBs. In rare emergency instances the HRRB has completed review in under a week (personal communication, Peter Noyes, September 2001). All applications go before the full board for discussion and consideration at one of their monthly meetings. The principal investigator is expected to appear in person when their case is considered.

Given that the Navajo Nation Health Research Code has been adopted quite recently, the Navajo Nation is still drafting its research guidelines into a detailed handbook as of this writing (2001). What has been written does not appear to be much different from the NAIHS in terms of the role of the affected community since both the NAIHS and the Navajo Nation require researchers to consider community needs and feedback in research. Both require approval from the affected chapter or chapters (27,28). The differences seem to be mostly in the area of how each board interprets their regulations.

There are, however, several conditions that the written Navajo *Application Guidelines* require that were not part of the NAIHS *Project Approval Form* (27, 28). On the other hand, there are other conditions that were included by the NAIHS in their application form that the Navajo Nation did not. A comparison of the requirements is given in the table below. We feel that it should not be assumed that because these conditions are not officially printed in the Navajo form, that the Navajo HRRB does not enforce them.

Differences Between the Navajo Nation and the NAIHS Research Guidelines: (25, 26, 27,28)

Navajo Nation	Navajo Area IHS
- Not written to have expedited review. (25,26,28)	- Had expedited review and approval, but only with national IHS IRB concurrence. (27)
- Requires quarterly progress reports. (28)	- Required annual progress reports. (27)

<ul style="list-style-type: none"> - Requires support letter from institution where research will take place. If a school: require support letter from principal/superintendent and resolution from area school board. (28) - Requires support letter and/or chapter resolution from Navajo chapters/communities affected. (28) 	<ul style="list-style-type: none"> - Required approvals from other groups or entities such as Tribal org/other. (27)
<ul style="list-style-type: none"> - Informed consent form must state: ...contact information in the event of research-related injury to participant... ...contact person for the Navajo Division of Health... (28) 	<ul style="list-style-type: none"> - No such requirements are in writing, but required by federal law. (27)
<ul style="list-style-type: none"> - Requires an explanation of how technical assistance will be provided to community by writing grant proposals, conducting training session, developing educational materials,... (28) 	<ul style="list-style-type: none"> - No such requirement is in writing. (27)
<ul style="list-style-type: none"> - Particularly sensitive projects and those that use experimental devices/drugs would be referred to outside reviewer. (28) 	<ul style="list-style-type: none"> - Particularly sensitive projects required the approval of the Health and Social Services Committee of the Navajo Nation Council. (27) - Projects that use experimental devices/drugs required the approval of each affected service unit pharmacy and therapeutics (P&T) committee and the Area P&T Committee. (27)
<ul style="list-style-type: none"> - Not stated explicitly, but covered by federal regulation. (25,26,28) 	<ul style="list-style-type: none"> - No further data analysis than that mentioned in consent form was permitted unless permission was obtained from participants or IRB. (27)
<ul style="list-style-type: none"> - Not stated explicitly, but covered by federal regulation. (25,26,28) 	<ul style="list-style-type: none"> - For sensitive topics, participants had to be informed of limits of guarantees of confidentiality. (27)

- Not stated explicitly, but covered by federal regulation. (25,26,28)	- Monetary compensation could not be listed as benefit and had to be included elsewhere in consent form. (27)
- Not stated explicitly, but covered by federal regulation. (25,26,28)	- Required consent forms to be at an understandable English level. (27) - Technical terms had to be avoided. (27) - If desired by participants, consent form could have been in Navajo language. (27) - Required participants to be given a copy. (27)
- Not stated explicitly, but covered by federal regulation. (25,26,28)	- Required questionnaires to include essential, minimum information. (27) - Required interviewing to be culturally appropriate, with sensitivity and respect. (27)
- Not stated explicitly, but covered by federal regulation. (25,26,28)	- IRB approval was not to be considered a blanket approval for ancillary research activities. (27)
- Not stated explicitly, but covered by federal regulation. (25,26,28)	- Required findings to be presented in aggregate form. (27) - Community/chapter identifiers could not be included. (27) - Tribal identity was also sensitive. (27)

Navajo Healing Project

A study that may illustrate what is considered subject to HRRB approval is the Navajo Healing Project. Articles produced by the project compare and contrast different Navajo healing traditions, including Christianity, traditional medicine, the Native American Church and western medicine (33). This project was approved by the HRRB. It used ethnographic methods, but addressed issues of health. It would seem that ethnographic research that is in similar would need to seek approval from the HRRB.

The Experience of the Navajo Uranium Miner Oral History Project

In 1995 one of us (Brugge), serving as project director, approached the NAIHS IRB about approval for collecting oral histories and photographs of Navajos affected by uranium mining. We were directed to the tribe's office for historic preservation to obtain an ethnographic permit and not required to undergo full IRB approval (personal communication, Mike Everett, October 1995). The oral histories and photographs were collected and a book and exhibit produced from them (31, 32). Subsequently, in the preparation for this paper, we learned that the HRRB considered the oral history project to be under its jurisdiction and that we were expected to submit manuscripts and presentations to them for pre-publication review. This suggests to us that during the transfer from IHS to the Navajo Nation there has been a shift in interpretation of what ethnographic research requires approval of the IRB. Alternatively, it is possible that our application, arriving during the transition to the HRRB, simply "fell between the cracks".

In addition to review of products of the oral history project, we were asked to submit this ethics paper for review as an application separate from the oral history project. This paper does not involve any research with humans, relying instead on secondary sources, the academic literature, public documents issued by the Navajo Tribe, personal communication with the HRRB and consultation with our academic colleagues. Thus, this seems to us to be an example of the HRRB requiring publications pertaining to Navajos, but not involving human research to be reviewed. While we have sought accuracy through consultation with the HRRB, we also wonder if there is any conflict of interest in having the HRRB formally review a paper about its work.

Conclusion

There is a need for communities to be protected in research. Given that Native American communities, such as the Navajo Tribe, are extensively studied and have been stigmatized by research, it is critical to have an established ethical code for researchers to follow. The Navajo Nation has taken the initiative to protect its people by adopting the Navajo Nation Health Research Code and establishing the HRRB. Although the written guidelines may not seem as explicit as the NAIHS guidelines, the Navajo Nation is taking firm control over research.

For researchers, this means that they will need to seek approval from their own IRB, from the HRRB and possibly also gain an ethnographic permit from the Navajo tribe. They should plan accordingly. The reader is probably as aware as we are that there is a trade-off between the amount of review required and productivity. We feel strongly that the primary objective must be protecting Navajo participants in research and that research progress must come second.

It seems to us that the HRRB may be expanding the definition of which research and which published materials must be reviewed by the tribe. At a minimum, researchers will need to seek approval from the HRRB for any health related research even if they are not doing conventional medical studies (e.g. the oral history project). There will be no expedited review and researchers will be required to get approval directly from the

affected chapters. It also seems likely that non-health research (such as ethnographic research that does not deal with health) is or will soon be included under the jurisdiction of the HRRB. Less clear, but possible is that the HRRB will seek to review many published materials that discuss Navajos even if they were produced from secondary sources or were not written as part of what is traditionally considered research.

Acknowledgements

The Authors wish to thank Charlotte Frisbie for her valuable critique of an early draft and ongoing comments as the manuscript developed. Peter Noyes provided another valuable critique. Several other members of the HRRB, Mike Everett, Mark Bauer and Beverly Bicenti-Pigman answered key questions asked by the authors.

References

1. Attneave CL. Who has the responsibility? An evolving model to resolve ethical problems in intercultural research. *American Indian & Alaska Native Mental Health Research*. 1989;2(3):18-24.
2. Chrisman NJ, Strickland CJ, Powell K, Squeochs MD, Yallup M. Community partnership research with the Yakama Indian Nation. *Human Org* 1999; 58:134-141.
3. Cook K. Use science, but trust our own knowledge. *Native Americas* 1995;12:64.
4. Herbert CP. Community-based Research as a Tool for Empowerment: The Haida Gwaii Diabetes Project Example. *Canadian J of Pub Health*. 1996;87:109-12.
5. Mihesuah, DA. Suggested guidelines for institutions with scholars who conduct research on American Indians. *Amer Indian Culture & Research J*. 1993;17:131-39.
6. Mihesuah DA, ed. *Natives and academics: Researching and writing about American Indians*. Lincoln: Univ of Nebraska Press, 1998.
7. Norton IM, Manson SM. Research in American Indian and Alaska Native Communities: Navigating the Cultural Universe of Values and Process. *J of Consult & Clin Psych*. 1996;64:856-60.
8. Schell LM, Tarbell AM. A Partnership Study of PCBs and the Health of Mohawk Youth: Lessons from Our Past and Guidelines for Our Future. *Environ Health Perspect*. 1998;106(suppl 3):833-40.
9. Wax ML. The ethics of research in American Indian communities. *Am Indian Quart*. 1991;15(4):431-456.
10. Carrese JA, Rhodes LA. Western Bioethics on the Navajo Reservation: Benefit or Harm? *JAMA*. 1995;274:826-29.
11. Connors JL, Donnellan AM. Walk in Beauty: Western perspectives on disability and Navajo family/cultural resilience. In: *Resiliency in Native American and immigrant families*. California: Sage Publications, 1998:159-182.
12. Wronka JM. "Science" and indigenous cultures. *Humanistic Psych*. 1993;21:341-353.

13. Dunn CM, Chadwick G. Ethics and Federal Regulations. In: *Protecting Study Volunteers in Research – A Manual for Investigative Sites*. Boston: CenterWatch, Inc., 1999:15-32.
14. <<http://www.dcd.navajo.org/pops.htm>> *Division of Community Development – Population Statistics* (visited July 2001)
15. Trennert RA. Army Doctors – Western Medicine Comes to the Navajo. In: *White Man’s Medicine: Government Doctors and the Navajo, 1863-1955*. Albuquerque: Univ of New Mexico Press, 1998:19-37.
16. <http://www.lapahie.com/Dine_Treaty.cfm> *U.S. Treaty with the Navajos, 1868*. (visited June 20, 2001)
17. Freeman WL. The role of community in research with stored tissue samples. In: *Stored tissue samples: Ethical, legal, and public policy implications*, ed. Weir R. Iowa City, IA: Univ Iowa Press, 1988: 267-301.
18. <<http://www.americanwest.com/pages/navajo2.htm>> *Explore the Navajo Nation* (visited June 20, 2001)
19. <<http://www.navajo.org/nhomepg.html>> *Welcome to the Navajo Nation* (visited June 20, 2001)
20. <<http://navajocentral.org/faq2.htm>> *Navajo Land FAQ’s** (visited June 20, 2001)
21. <<http://www.ihs.gov>> *Indian Health Service* (visited June 20, 2001)
22. American Indian Law Center, Inc. *Model Tribal Research Code*, 3rd ed. Albuquerque, NM: American Indian Law Center, Inc., 1999. Also available through <<http://www.ihs.gov/nonmedicalprograms/research/irb.htm>> (visited June 20, 2000)
23. <<http://www.ihs.gov/nonmedicalprograms/research/irb.htm>> *Title 45 of the Code of Federal Regulations, Part 46* (visited June 20, 2001)
24. <<http://www.ihs.gov/nonmedicalprograms/research/irb.htm>> *The Indian Health Service Multiple Project Assurance (MPA) for Compliance with DHHS Regulations for the Protection of Human Subjects (45 CFR 46) as Amended* (visited June 20, 2001)
25. *Approving the Navajo Nation Health Research Code*, Navajo Nation Council Resolution CO-106-95. Requests could be made to the Navajo HRRB Program, PO Box 1390, Window Rock, AZ 86515 or call 520-871-6925.

26. ***Adopting the Navajo Nation Privacy and Access to Information Act, Navajo Nation Council Resolution CAP-48-99.*** Requests could be made to the Navajo HRRB Program, PO Box 1390, Window Rock, AZ 86515 or call 520-871-6925.
27. ***Navajo Area Indian Health Service, Research and Publications Committee and Institutional Review Board (IRB) – Project Approval Form, revised 5/21/95.***
Requests could be made to the.....??????
28. ***Navajo Division of Health/Navajo Research Program, Navajo Nation Health Research Review Board (HRRB) – Application and Application Guidelines.***
Requests could be made to the Navajo HRRB Program, PO Box 1390, Window Rock, AZ 86515 or call 520-871-6925.
29. **Freeman WL. *Tribal Review of Manuscripts: Suggestions for Tribal Councils and Researchers.* Draft #3, Oct. 17, 1996.** Requests could be made directly to Dr. William Freeman at WFreeman@HQE.ihs.gov or call 301-443-0578.
30. **Prendergast E. *Historic Preservation: An Unusual Way to Protect Human Subjects in Research.*** Protecting Human Subjects. US DOE. Summer 2001 at www.science.doe.gov/ober/humsubj/newslett.html.
31. **Brugge D, Benally T.** Navajo Indian voices and faces testify to the legacy of uranium mining. *Cultural Survival Quarterly.* 1998; 22(1):16-19.
32. **Brugge D, Benally T, Harrison P, Austin-Garrison M, Stilwell C, Elsner M, Bomboy K, Johnson H, Fasthorse-Begay L.** The Navajo Uranium Miner Oral History and Photography Project. In *Dine baa hane bi naaltsoos: Collected papers from the seventh through the tenth Navajo Studies Conferences.* J Piper, ed. Navajo Nation Historic Preservation Department, Window Rock, AZ. 1999:85-96.
33. **Csordas T.** Introduction to the Navajo Healing Project. *Medical Anthropology Quarterly.* 2000; 14:463-475.
34. **Nevada et al. v. Hicks et al.** Certiorari to the United States Court of Appeals for the Ninth Circuit. No. 991994. Argued March 21, 2001. Decided June 25, 2001.
35. **Atkinson Trading Co., Inc. v. Shirley et al.** Certiorari to the United States Court of Appeals for the Tenth Circuit. No. 00454. Argued March 27, 2001. Decided May 29, 2001.
36. **Shenk D.** Money + science = ethics problems on campus. *The Nation.* March 22, 1999: 11-18
37. **Bodenheimer T.** Uneasy alliance – Clinical investigators and the pharmaceutical industry. *New England Journal of Medicine.* 342, 2000:1539-1544