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Making Research Trustworthy for Native Americans

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Goal: To learn what research approaches are considered respectful and trustworthy by Native American populations.

Ethical and scientific justification. The Federal Regulations of human research and other ethical guidelines did not prepare us for what we have learned, by trial and error, about conducting research on Native American populations. If research with these populations is to be conducted validly and respectfully, the ground rules need to be learned inductively, and ideally shared with other investigators.

Ethical objections or barriers. Many Native Americans live on reservations where their tribe is a sovereign government. Researchers have to consider first gaining permission to conduct research on the reservation, usually by presenting the research to the tribal council and getting a resolution supporting the project. While some tribes have research ethics committees, many do not. Thus, the researcher also has the ethical obligation to help the tribes develop a system for reviewing the research for human participants protection.

Given the history of exploitation of American Indian tribes by the government (broken treaties, relocation programs, forced acculturation), there is a long-standing distrust of the federal government on reservations. This is particularly true with respect to research funded by government agencies and conducted by outsiders. Based on this, and broken promises by researchers who have come before, there is a healthy skepticism about why the data are being gathered and how they will be used. It is clear that research with indigenous communities needs to be based on collaboration, yet procedures that place the approval of final protocols with external agencies undermines this collaboration. For example, the UNL ethics committee requires the University logo on almost all informed consent forms. This suggests the University as the sole responsible entity, and hence arouses ill feelings in many Native American research participants.

Current problem solving. What has evolved is that the informed consent letters for Native American groups are allowed to have a more familiar symbol at the top of the letters, one that is approved by a local advisory board to represent the partnership between the Tribes and the University (e.g., a dream catcher for one tribe). When native field researchers are trained, this needs to be done in a style that accommodates the culture of the tribe. This means that internet training is definitely out (i.e., CITI), even when internet access is available. Face-to-face is the only way such training can occur effectively and respectfully, and it needs to be done with a great deal of respect and latitude for questioning.

The fundamental principles of informed consent, confidentiality, and other human research protections are consistent with Tribal customs and practices, but they need to be presented and reviewed in culturally-appropriate contexts. The University of Nebraska–Lincoln (UNL) has developed projects that address these ethical concerns by providing assurances concerning how the data will be used, and what will be written. The UNL re-

quests that the Tribal Council appoint an advisory board for the research project. UNL researchers restrict access to the data to only the approved project personnel, and assure the tribes that no one will merge tribal data with other data to make comparisons across racial groups (for example, to suggest that some problems are more prevalent or severe among American Indians). They also assure the tribes that they will see the summary of the research first. Applied research reports, with lay presentations of data summaries in pie charts, bar charts and basic tables, are prepared for each reservation. These reports are presented to the Tribal Council and advisory board. Any research prepared for publication from the project is sent to the advisory board members for review prior to submission. If tribal advisory board members raise any issues about cultural appropriateness of the research, UNL researchers pledge to review it and respond, prior to submitting for publication.

Suggested empirical questions. Science is understood to be a cumulative endeavor that develops through a peer reviewed literature. In research on Native Americans, there is an incipient literature that emphasizes the importance of collaborative approaches between scientists and the communities they aspire to study (e.g., Noe, Manson, Croy, McGough, Henderson & Buchwald, 2006; Mohatt & Thomas, 2006). Yet, in much research in traditional cultures, each researcher or institution begins somewhat anew. It would be highly ethical and scientifically appropriate to begin to build a literature, in print and on line, fostering development of cumulative knowledge and expertise in this area. That literature should move beyond broad generalities to the specifics of what is appropriate.

1. What literature exists on effective and respectful research approaches with traditional populations within the North American continent? Is there a literature on which a review of that methodology could be based?
2. What questions have guided the University of Nebraska researchers, and others who have studied traditional populations within the North American continent, in their inductive learning of effective and respectful approaches? How might these questions be formulated more broadly to guide other researchers?
3. What organizations would be interested in pooling new information, perhaps via a list serve and updating an online manual as new methodology evolves?

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