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More Tips: What If a Cooperative Extension Professional Must Work with Native American Institutional Review Boards?

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Abstract

This article focuses on working with tribal IRBs to conduct research or evaluations of projects on tribal lands. It is a follow up to a series of four recent articles designed to help Extension Professionals navigate the university IRB process. The authors use their experience with a community assessment project conducted in one small, remote community located on the Navajo Nation to illustrate some of the issues and tips for success.

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Introduction

This is the second follow up to a series of four recent articles designed to help Extension Professionals navigate the university Institutional Review Board (IRB) process (Brown, Martin, & Weigel, 2004; Martin, Weigel, & Brown, 2005; Weigel, Brown, & Martin, 2004; Weigel, Martin, & Brown, 2005). The first follow up was on working with more than one IRB at a time (Betts, Peterson, & McDonald, 2005). This article focuses specifically on working with tribal IRBs, in addition to your university IRB, to conduct research or evaluations of projects on tribal lands.

Research on tribal nations is regulated by an IRB, which is responsible for reviewing and approving research involving humans in tribal areas. Some tribal nations have established their own IRBs, with regulations and procedures that may vary from one to the other. In other cases an Area Research Committee (ARC) formed through the Indian Health Services (IHS) is responsible for such reviews. This article describes some common points to consider when Extension professionals are working with tribal review boards. The authors' experiences with the Navajo Nation Human Research Review Board (NNHRRB) are used to illustrate each point.

Most of the steps in the tribal IRB approval process are similar to those encountered with any other institutional review board. However, there may be many more entities that must provide approval, more meetings to attend, and more letters of support that need to be solicited. Three primary issues in the tribal IRB process are:

- Addressing the study's relevance to the community and the tribe,
- Describing the benefits to the community and the tribe, and
- Negotiating ownership of data.

Issues and Tips

Relevance to the Community

In any evaluation of a community program it is critical to ensure *authentic participation and collaboration* of community members (McTaggart, 1989). A tribal IRB requires documentation that the community in which the research is being conducted understands the study fully, supports it, and gives its official approval. This may entail acquiring supporting resolutions from the local tribal governance and letters from local agencies or organizations with which you are working.

The NNHRRB, which we went through to conduct a community assessment in one small, remote community located on the large Navajo Nation, required letters from local health boards in the area as well as a letter from the CEO of the regional health board. Obtaining approval meant traveling some distance to attend multiple meetings of various tribal agencies, such as health boards, the Chapter Council, and the tribal IRB, to make formal requests. We also had to obtain approval from the Navajo Nation Historic Preservation Department.

To help garner support and assure relevance, a community assessment committee was formed that included interested community members and others who represented:

- Agencies,
- Non-profit organizations,
- A local church and school,
- Tribal government, and
- Extension.

Committee members shared in the responsibility of obtaining the required documents, often acting as liaisons to various agencies, attending agency meetings as representatives of the evaluation project, and answering questions. This level of involvement also contributed to a sense of ownership and investment in the success of the community assessment.

Benefits to the Community

Tribal IRBs are not only concerned with the risks and benefits to the individual participant, but also to the community and tribe, especially how the research will contribute to the improvement of the health status of Native people. The IHS Indian Health Manual advises that:

- The research be consistent with the goals and objectives of the Department of Health Services, the Indian Health Service, and tribal groups involved.
- The research does not significantly detract from or interfere with the provision of health services to American Indians or Native Alaskans (IHS Indian Health Manual).

The NNHRRB specifically requires an explanation of how the research will benefit the Navajo Nation. One of the initial discussions of the community assessment committee revolved around how the information from the assessment would be used. Furthermore, at the conclusion of the community assessment, when the report was written, it was important to involve committee members in the process, especially in terms of drawing conclusions, determining any implications associated with the findings, and presenting the results.

Ownership of Data

Using data for reports, articles, and conference presentations is a matter of who owns the data. What happens with the data after collection is a delicate matter that may require some negotiation and consultation with the tribal IRB and your institution's legal department.

While the IHS Indian Health Manual does not specifically address the issue of ownership of data, it does state that, "The ARC may take whatever action is necessary to assure that the research, once approved, is being conducted in accordance with the approved proposal." Furthermore, the Model Tribal Research Code (American Indian Law Center, 1999, p.17) states that, "Tribal regulations may require in some cases that researchers sign a contract agreeing to certain tribal rights and prerogatives which will protect tribal interests . . ."

We consulted with our university legal department and developed an agreement with the NNHRRB allowing the university to retain the right to use the data for non-commercial teaching and research purposes. The NNHRRB was still able to review and provide comments on any proposed dissemination. Practically speaking, it is critical for the researcher to establish at the start his or her intentions for use of the data. In the case of the community assessment, there was an informal agreement between the researchers and the community assessment committee that the report would belong to them and the decisions around dissemination were their responsibility.

Conclusion

As Extension professionals increase work with diverse audiences, we must protect human subjects within the context of their Native cultures. A key to successful navigation of a tribal IRB is to emphasize the risks and benefits to the community and the tribe, not just to the individual participant.

Here are some good resources for preparing tribal IRB protocols:

U.S. Department of Health and Human Services--Indian Health Service--The Federal health program for American Indians and Native Alaskans. This site lists the area/tribal IRB chairs.
<http://www.ihs.gov/MedicalPrograms/Research/areairb.cfm>

Portland area Indian Health Service IRB--has the responsibility to review, and the authority to approve or disapprove, all research activities that use IHS facilities, data, staff resources, or funding in the Portland, Oregon area.
<http://www.npaihb.org/epi/irb.html>

Research Ethics and Environmental Health--provides articles and case studies concerning research in diverse communities.
<http://www.researchethics.org/articles.asp>

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