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Building Research Capacity With Members of Underserved American Indian/Alaskan Native Communities

Permalink

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Journal

Health Promotion Practice, 16(3)

ISSN

1524-8399

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Publication Date

2015-05-01

DOI

10.1177/1524839914548450

Peer reviewed

**TITLE: BUILDING RESEARCH CAPACITY WITH MEMBERS OF UNDERSERVED
AMERICAN INDIAN/ALASKAN NATIVE COMMUNITIES: TRAINING IN
RESEARCH ETHICS AND THE PROTECTION OF HUMAN SUBJECTS.**

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Acknowledgements: "The authors gratefully acknowledge the support of the many participants in the educational sessions who provided feedback during the training sessions, reviewed the manuscript and made many thoughtful suggestions for how to improve it." This project was part of a larger project funded by NIH grant #1RC4DK089859-01.

INTRODUCTION

The protection of human subjects is a topic of vital importance in American Indian/Alaskan Native (AI/AN) communities. Past research efforts insensitive to the cultural norms and the protection of human subjects within AI/AN communities have left many tribal nations wary and cautious about participating with University researchers. However, these same communities are deeply committed to improving the lives and welfare of their families and tribes, and recognize the potential benefits of collaboration. To address these concerns a research ethics education program was developed using a community based participatory research (CBPR) model as the foundation to integrate University research norms, expectations and human subjects protections with tribal norms, expectations and human subjects protections. CBPR has been described as a collaboration between a community and university to conduct research and take action (Minkler and Wallerstein, 2003). Particularly in underserved communities, CBPR can empower communities to define priorities, to collect and present research, and ultimately find solutions to improve their quality of life in meaningful ways. CBPR has been used with some success in collaborations between AI/AN communities and University collaborators (Castleden and Garvin, 2008; Gray et al., 2010). Using this approach for ethics training can help ground research relationships between AI/AN communities and University researchers in a mutual understanding about how research is ethically best conducted.

BACKGROUND

The development of this research ethics education training program was part of a larger project to train AI/AN communities in research methods. This NIH funded project consisted of a partnership between the University of California, Davis (UCD) with two Indian health clinics and three Northern California Indian tribes. The new project anticipated that AI/AN community

members, in CBPR fashion, having an active role in formulating the research questions. In addition, it involved these individuals in data collection, primarily through administration of surveys, as well as their consideration of whether a tribal research oversight board was needed that would supplement research review by Institutional Review Boards (IRB). Since these community members would be researchers themselves, they required IRB certification and it was both this regulatory requirement, and the plan to have the communities create a mechanism for local oversight of research that served as an impetus for the CBPR-based approach to research ethics learning that is the focus of this study.

The need for research ethics curricula tailored for community members involved in research has been addressed in part by Project TRES (Training in Research Ethics and Standards), an NIH-funded training program developed for community health workers involved in research (Terpstra et al., 2011). This is a self-guided course that lacks the interaction provided by the collaborative approach that was the foundation for our CBPR training project in research methods. While we were able to locate a Collaborative Institutional Training Initiative (CITI) research ethics course designed for University researchers working with AI/AN communities, and a research ethics course designed for community researchers in general, both from the University of Arizona, we could find no other material, published or otherwise in the public domain, of community research ethics training courses for AI/AN community researchers.

METHODS

The research ethics training program consisted of a tailored research ethics curriculum based on the CITI courses offered by the UCD IRB, and a round table seminar to discuss the curriculum. CITI is a self-administered course designed primarily for University researchers

who are mandated to complete formal training in human subjects research protections ([https://www.citiprogram.org/about us](https://www.citiprogram.org/about-us) accessed 12-3-11). However, there were many reasons to question whether the self-administered CITI course was appropriate for community researchers in AI/AN communities: the course history module did not address past research ethics problems in AI/AN communities, an important oversight that had to be addressed; the content presumed a familiarity with research and college-level reading; and the online format was new to some community members who had little or no Internet experience.

Development of CITI course for AI/AN community researchers

In an effort to both certify community researchers and provide some preparation to communities to consider the extent of community oversight of research conducted locally, two curricula were offered in conjunction with the CITI courses required by the UCD IRB. It was deemed critical to modify the standard CITI course in the Social and Behavioral Sciences directed towards UCD researchers to better meet the needs of the AI/AN community researchers. This module was reviewed with an eye toward the community stated preferences regarding the focus of health related research in their community, basic principles of research ethics of which anyone interested in completing research needs to be aware, and additional material that would address previous problems with research completed with AI/AN communities (Table 1). From the course on Social and Behavioral research the following modules were retained: 1) Introduction and Belmont report; 2) History and Ethical Principles; 3) Defining Research with Human Subjects; 4) Assessing Risk in Social and Behavioral Sciences; 5) Privacy and Confidentiality; 6) Informed Consent; 7) Research with Children; and 8) Research in Public Elementary and Secondary Schools (Table 1). Modules 1-6 were retained because they contained the core elements of research ethics of which everyone involved with research with

human subjects should be aware. The modules for research with children (7) and research in schools (8) were retained because one of the communities was going to be involved with a school fitness education program as part of this project. It was anticipated that additional research projects might be developed that focused on health/fitness/nutrition education programs for children, so these modules would be relevant for that research.

Table 1 about here

The following modules were removed from the CITI course on Social and Behavioral Sciences: 1) The Regulations and the Social and Behavioral Sciences, 2) Research with Prisoners, 3) Internet Research, and 4) International Research (Table 1). These modules were removed because they contained mostly regulatory content aimed at University researchers and University oversight (module 1), because they were not relevant for the type of research that the AI/AN trainees anticipated completing in their communities (modules 2 and 3), or were just inapplicable (module 4).

The curriculum supplemented the CITI certification course with additional research ethics materials, which also helped to better prepare local communities to consider whether a community-based research oversight review board might be useful. The additional material was included in an effort to provide learners with a robust foundation in the basic ethical principles of biomedical research set forth in *The Belmont Report*, how those principles inform IRB and other regulatory aspects of research oversight, and how those principles at times fail to take into full account ethical issues that frequently arise in the context of research with AI/AN communities. The following modules were added as part of the course: 1) Group Harms and 2) Conflicts of Interest (Table 1). The module on group harms was included because many of the examples of research that had a negative effect on AI/AN communities affected the community as a whole,

rather than an individual. For example, a study on alcohol use in an Alaskan Native community resulted in the community receiving a lower bond rating, and jeopardized the community's ability to obtain funding for community development projects (Foulks, 1989). The module on Conflicts of Interest was included because it was important that community trainees be aware of all the regulations to which University researchers are subject as part of the need to establish a foundation of trust when completing research. Finally, the History module was supplemented with case studies relevant to AI/AN communities. These studies included the Barrows alcohol study (Foulks, 1989), the Havasupai DNA study (Harmon, 2010), the Nuu-chah-nulth arthritis study (Wiwchar, 2004), and the Yakama cancer study (a positive case study provided by the University of Arizona). While the course was tailored for the AI/AN community researchers, clinic personnel participating in the project were also required to pass this CITI course. The UCD IRB supported the modifications represented by this curriculum. On the one hand, dropped components were not relevant to the community members. On the other hand, the new curriculum included many enhancements, such that learners were able to engage substantive research ethics topics not normally covered in the standard required CITI-based course.

The second curriculum offered as part of the research ethics training program was the UCD module for participants serving on the Social and Behavioral Sciences IRB. While we believed it was important to modify the CITI course for community researchers, we believed that it was equally important to not modify the CITI course for the UCD IRB members, as the community members taking this course were potential participants on the UCD Social and Behavioral Sciences IRB.

Training program

The novel contribution of this research ethics training and certification program was the

presentation of the curricula through a round table seminar using CBPR principles of collective participation. The advantage of using this method over a more traditional Lecture/Discussion approach is that it makes the “training” less a passive learning process to pass the course, and more an active learning discussion focused on how research can be ethically conducted within communities by community researchers in conjunction with University researchers. The round table seminar was developed and delivered by the University academic partners with administrative support from clinic staff. It addressed the key ethical considerations of the three groups most involved in the ethical conduct of research: a) those who conduct the research, so time was spent focusing on the ethical responsibilities of researchers; b) those who oversee research, so time was spent addressing the role, activities and significance of IRBs in assuring the ethical conduct of research; and c) those on whom research is conducted, so there was also considerable focus on identifying and exploring the rights and interests of research participants, especially how researchers and IRBs best respect research participants’ rights and protect their interests, as well as the collective interests of their communities.

The seminar was broken down into two parts. For the first part of the seminar discussion was centered on a one-page handout summarizing how the principles set forth in the Belmont report generated specific IRB functions and researcher responsibilities. For example, discussion focused on how the principle of respect for persons leads IRBs to assure that research participants are able to exercise their right to grant voluntary informed consent, which in turn presupposes researchers fulfilling their obligations to provide adequate disclosure to research participants of information relevant to their decision about possibly participating in research. Handouts were also provided on how to log-on and register for the CITI site, the individual CITI modules, and the AI/AN case studies.

This facilitated research ethics discussion then provided context for the second part of the curriculum: reviewing, discussing and completing the CITI modules. The primary aim of this part of the curriculum was not to summarize the information in the modules or to “teach to the test.” Instead, as each of the CITI modules was addressed, the aim was to engender discussion about them through the lens of the ethical principles of research stipulated in the Belmont Report. The instructors wanted most of all for the community members to master understanding of the rights and interests of the people they would be working with in their future research, as well as their responsibilities as researchers to adequately address those rights and interests.

Throughout the sessions, much effort was made to highlight issues of special relevance to research within the AI/AN communities. During the discussions in the History module case studies involving research in AI/AN communities were especially important and served to introduce topics, such as group harms, not recognized in the Belmont Report nor frequently well addressed by university IRBs. Discussion of these case studies, as well as examples drawn from their own current or planned research surveys, supplemented the group discussions of the CITI modules and helped illustrate the challenges of ethically conducting research in rural AI communities.

As part of the collaborative process, local health clinics and staff who have community outreach experience assisted in the delivery of the curriculum. They served as local hosts for the learning activities, providing space and a terminal for each person to take the on-line course; identified participants in the early stages of the overall project who became the community researchers; and they served as advisors to the university-based research ethics instructors throughout the course of the research ethics activities. Their participation helped lend credibility to the university faculty and they were able to contribute to discussions about local concerns and

history.

The training program was initially offered as a two-day course. The first day was an informal, facilitated discussion in research ethics. The second day was organized around the CITI modules approved by the UCD IRB for certification purposes. However, based on feedback and experience with the course, we subsequently altered our approach so that the seminar and CITI course could all be completed in one day. At the beginning of the session the participants were walked through how to register with CITI at the CITI registration site. In addition, handouts of all registration pages were provided so that the participants could reference them while registering, especially those with more internet experience who wanted to jump ahead. At the end of the training session a debriefing session was held. During the debriefing session the clinic and community members were asked to describe what they liked about the training and what they felt could be improved. Each seminar was delivered at the home community of each tribe, except one of the IRB trainings that was completed at one of the clinics that served two of the AI/AN communities. Participants could take the course ahead of time or after the training program, but were required to pass the course if they wished to participate in survey development and implementation. A couple participants passed the course ahead of time, but still participated in the discussions during the research ethics training seminar.

DISCUSSION

A total of five trainings were completed during the spring and summer of 2011. The first three were for community members who would be conducting social science research with human subjects. The final two trainings were for those community members who were taking the CITI course to participate as IRB members as part of the development of a possible community research oversight board. All participants who started the CITI test during the

research ethics training passed the test at the end of the training sessions. On average it took 2.5 hours to 4 hours to complete just the CITI course when training consisted of two days. For the training sessions that consisted of one-day it took between four and five hours. A total of seven clinic personnel and 29 AI/AN community researchers were certified in the UCD CITI community researcher module. A total of 12 community members were certified in the UCD Social and Behavioral Sciences IRB member module.

Based on the debriefing sessions, the community members liked the group discussion, learning together, and not being “preached to”. The groups noted in particular that they liked the informal structure and felt at ease asking questions and discussing topics important to them. One of the groups commented that it did not feel like the training took five hours. With respect to the materials, the groups liked having the handouts of the summary of the Belmont report, the CITI course material, and CITI registration pages. They especially liked having the AI/AN case studies and using them to facilitate discussion of issues important to the participants and their community. The main criticism came from the group that completed the 2-day training. They wanted to log onto the CITI site on the first day and have all handouts in advance of the training for those who wanted to review them beforehand.

The group sessions described here were supplemented in many instances by additional work by learners, both collectively and individually. Some individuals read the CITI module materials either before or after the group sessions. Based on questions and comments made during project planning meetings with University researchers, some of the communities continued to discuss the reading materials, as well as some of the topics discussed in the group sessions, at their subsequent group meetings held between the visits from university researchers. Thus, the description of the group sessions does not capture the full extent of individual and

group preparation and follow-up regarding research ethics. The sessions served as a catalyst to some extent for additional research ethics learning and development.

Despite the success of the curriculum in leading to IRB certification and in catalyzing ongoing consideration of research ethics by some of the participants, a notable challenge arose with knowing the proper time to introduce a research ethics curriculum. One of the communities that participated in the curriculum has continued to invest extensive time in research ethics and oversight as they consider the need for a mechanism for local review of human subjects research in their community. This effort is occurring at the same time that they are conducting their own research, which means that they are becoming both more knowledgeable about research and the importance and challenge of conducting it ethically. As a result, their appreciation of research ethics has grown considerably, raising the question as to whether the training sessions would have been more impactful if they could have been conducted later in the project, after the participants were more knowledgeable about both research itself and the ways it can impact their community.

In reality, there is not much room for flexibility on this point since, in order to carry out research, the individuals require IRB certification. Nevertheless, it highlights both the need for and value of ongoing focus and consideration by communities on the ethics of research. The kind of curriculum we have described is, by definition, time limited and designed to meet research sponsor and institutional mandates, mandates that often poorly match the needs and opportunities of those subject to them. Ideally, it should be possible to supplement the initial sessions by ongoing interaction between university research ethics faculty and community members. The realities of research funding make this ongoing interaction unlikely, however.

CONCLUSIONS

We offer the following conclusions regarding research ethics education in preparation for IRB certification to others who are contemplating partnering with community-based researchers.

1. Approach research ethics education as group resource development and capacity building rather than individual training and certification. University-based researchers typically approach the need for IRB certification as one of several recurring training requirements for university-based individuals. As such, the training can become bureaucratized and focused on “getting certified” so that one can move on to the “more important” work of doing research. There is no need to squeeze community-based researchers into this individualistic model, though. They may not be “stand alone” investigators in the sense that most university researchers are. Instead, they are among a cadre of individuals who have decided to join with university researchers to learn new skills so that they can conduct important research together. Consequently, viewing research ethics education as a group task affords the opportunity to wed learning about research itself with learning about the ethics that guides research and shapes the responsibilities of those who conduct it. We think this approach is preferable because community members learning how to conduct research for the first time will not have the benefit of the more extensive educational time-frame of university researchers and the acculturation into research and its ethical norms, so a substitute for this process of acculturation can prove valuable. Although either approach will lead to IRB certification, viewing research ethics learning as an opportunity for group resource development provides these additional significant benefits.

2. Be prepared to commit sufficient time and faculty resources to make research ethics training a true partnership in the same manner that research is envisioned as a partnership. For learning to be most effective, it needs to be relevant to the learners and their immediate tasks at hand, as

well as reflective of their particular communities and the research legacy of their communities. This means that university faculty members need to be willing and able to invest time in the community to learn about previous research and how community members think the research affected the community. Do they perceive that there is a legacy of perceived benefit from research conducted by universities and others or is the legacy one of perceived exploitation instead? Discussion informed by this sense of local history provides a reference point for both University and community researchers, as well as practices to emulate or avoid as the case may be. It is also useful to begin the initial stages of developing a research project using CBPR before the training in research ethics occurs so that community members can situate discussion of ethical principles and responsibilities in the context of specific future tasks and activities.

3. *Community members are motivated learners.* Even University researchers taking the CITI research ethics course for the first time will need to spend time and effort on taking the course. A natural assumption is that since University researchers needed to take time and care to complete the course, it would be significantly more difficult for community members to take the course. We found that once the discussion in research ethics occurred, the community members became familiar with the content, vocabulary and terminology used in the field and completed the CITI course in a manner comparable to University researchers taking the CITI course for the first time.

4. *Be comfortable with discussing issues or concerns regarding current or past University research within the community, even if the issue is a negative reflection on the University community.* Communities are not isolated units; rather, they are active people, some of whom

will have participated in research with other University researchers and formed expectations and concerns about continuing to participate in projects. They will also probably be aware of some, if not all of the problems previous researchers have caused, even if they are unfamiliar with specific cases. By being open about the negative cases, space is provided for community members to voice their concerns about research within their community. It is important, however, for University trainers to not be the person to resolve the concern; rather, they should facilitate a discussion on potential options that will ultimately be decided independently by the community.

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Table 1. A comparison of the courses for University researchers and AI community researchers in the Social and Behavioral Sciences.

Module	University Researchers	AI Community Researchers
Introduction and Belmont Report	X	X
History and Ethical Principles	X	X
Regulations and Social and Behavioral Sciences	X	
Defining Research with Human Subjects	X	X
Assessing Risk in Social and Behavioral Sciences	X	X
Privacy and Confidentiality	X	X
Informed Consent	X	X
Research with Children	X	X
Research in Public and Elementary Schools	X	X
Research with Prisoners	X	
Internet Research	X	
International Research	X	
Group Harms		X
Conflicts of Interest		X