

THE NATIVE PEOPLES TECHNICAL ASSISTANCE OFFICE
NATIVE AMERICAN RESEARCH LECTURE SERIES



Community-based Participatory
Research

Presented by Dr. Jennie Joe

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KEY POINTS FOR RESEARCHERS
WHEN CONSIDERING A COMMUNITY-BASED RESEARCH PROJECT WITH NATIVE
AMERICAN COMMUNITIES

There are certain attitudes and perceptions to keep in mind when considering developing a research project with a Native American community. From Dr. Joe's extensive field perspective, she's often heard:

- "We've been researched to death"
- "They study us and our problems but the research does not benefit us or the community; it only benefits the researcher and once the study has ended, we never see the researcher again."
- Many studies conducted in the past have focused on the negative, not on the positive.
- "People don't even come to our community; they just look at us from afar."
- Helicopter syndrome: researchers "bail in – exploit – then bail out."
- Native people have been under the microscope for some time and are seen as having certain "unique" characteristics that are attractive to researchers.

NEW TRENDS IN HEALTH RELATED RESEARCH

Along with the aforementioned sentiments, many factors have led to major changes in the modern Native American research arena resulting in a shift in local research policies. Many tribes are taking control of their own health programs. As a result there is a need for *evaluative research* to determine, for example, if certain health-related interventions are really working.

Tribal governments, tribal community colleges and tribal organizations are now listed on requests for proposals (RFP's) as eligible to apply for grant funding. Additionally, many tribes now have their own epidemiology centers where they are able to conduct data analysis on health trends in their communities enabling them to more reasonably plan for future health care costs. Tribes are taking a proactive stance on developing health care solutions through their own research intervention and prevention studies. Examples of these types of studies include the "Pathways" study for prevention of heart disease; smoking cessation studies; diabetes prevention research including clinical trials involving the use of fish oil; and the Beata insulin study utilizing the saliva of the Gila Monster with the Gila River Indian Community. (For more information on these programs, contact Dr. Joe.)

Another important public health trend in Native American communities is the integration of alternative medicine programs into community health care systems. The Pascua Yaqui Tribe, Gila River Indian Community, San Carlos Apache Tribe and the Alaska South Central Foundation all have cutting edge programs where traditional practices and approaches have been re-integrated into model tribal health care programs.

There are new challenges in the tribal health care/research arena. As health-care problems are more complex, a *multidisciplinary approach to health care research* is mandated. For example, diabetes treatment often requires the expertise of a team of clinicians, psychologists, endocrinologists, et al. A research project in this discipline would also require the expertise of a community research design specialist. This multidisciplinary approach not only reduces the burdens of an individual researcher, each discipline brings a different focus on the problem resulting in a better understanding and synthesis of perspectives and whole solutions.

Tribal communities whose members have been involved in long-term *longitudinal studies* (for example diabetes research with the Pima Indians) have grown "restless" at the lack of viable solutions after years of scientific studies. Communities now apply pressure on funding agencies and institutions for *prevention studies*.

THE COLLABORATIVE PROCESS

From Dr. Joe's perspective, most Native American communities limit consideration of research proposals that are deemed beneficial to the community. The Native American Research and Training Center (NARTC) (under the direction of Dr. Joe) gets involved in programs that are requested by communities, as community support is vital to a project's success. It is always extremely important to focus on programs important to the community, and where the outsider researcher deeply shares that interest. While it is not always possible to find an absolute solution to an issue, the community can nonetheless come away with a better understanding of the problem.

Research partnerships should also include integrated, meaningful efforts to increase research capacity in the community. This can occur in a variety of ways, including designation of a co-principal investigator in the community, and hiring and training of community members and Native students in interviewing, data collection and data analysis, and analytical software applications. With these "capacity builders" firmly integrated into research proposal design, many of Dr. Joe's community partners have gone on to conduct subsequent research studies in their communities.

RESEARCH ORIENTATION VS. METHOD

The new trend in research today involves the foundational principles of "partnership" and "equity." Dr. Joe expresses this as an "orientation" rather than a research methodology. Partnerships with a "buy-in" from the community and an integrated capacity building component, re-informs and fosters tribal self-determination. Native communities are the first and foremost authorities on their own abilities to accurately assess their strengths and needs and their fundamental rights to act upon them. Researchers from universities are outsiders and are cautioned against inflated ideas of superior ways and knowledge.