

K. RESOURCE SHARING

Data Sharing Plan. The National Institutes of Health has instituted a data sharing policy to facilitate more wide-spread use of information collected in NIH-funded research. This is a policy that we support. However, we propose a limited and more restrictive plan for data sharing for the proposed Phase II of the Healing of the Canoe project as it is a collaboration with two federally-recognized and sovereign Tribes.

There are specific concerns among AIAN communities about research, primarily based on past history that has led to suspicion and reluctance to participate in research with academic partners. In addition, research guidelines for AIAN communities indicate the importance of respecting and protecting AIAN community knowledge, some of which may be sacred. Because of these concerns, and in light of their status as sovereign nations, AIAN Tribes have begun to assume right of ownership of data collected from research within their communities. Additionally, in our work with the XX Tribe and our proposed inclusion of the XX Tribe, we are dealing with quite small tribal communities where there are concerns about privacy and confidentiality. In our Phase I NCMHD CBPR study (Healing of the Canoe 5R24MD001764), the University and the XX Tribe (via the tribal attorney and Tribal Council) came to an agreement concerning the rights to and ownership of data. The data are jointly owned by the two parties and both have access to them. However, the University partners agreed that they would include the Tribe in reviewing the outcome of data analyses, interpretation of results, and drafts of presentations and/or publications derived from the data before anything is made public. This approach is consistent with recommendations about conducting research with AIAN communities by groups such as the National Congress of American Indians and the Work Group on American Indian Research and Program Evaluation Methodology. This policy and these procedures were formalized in the Memorandum of Understanding between the XX Tribe and University and are also written into the Memoranda of Understanding for the current proposal between the University and both the XX and XX Tribes.

As such, we do not feel that it is possible to provide open and unrestricted access to the data. Rather, we propose a limited data access plan. Requests for data, with an outline of the data requested and the analyses that are being proposed, can be submitted to the PI (Dr. Donovan), who will review the request and forward it to the XX and XX Community Advisory Councils or Tribal Councils for their review and approval. If the participating Tribes both approve the request, then arrangements will be made to provide the requested data. This procedure is consistent with the NIH guidelines, which indicate that data should be made as widely and freely available as possible while safeguarding the confidentiality of the data and privacy of participants.