Research Review Checklist for American Indian/Alaska Native Communities

Regulation of research is becoming an increasingly important issue for many American Indian/Alaska Native (AI/AN) communities. Through whatever mechanism and process they choose, AI/AN communities should carefully regulate research projects throughout all phases: in the initial stage of reviewing proposals, while the research is ongoing, and finally in dissemination and publication of the research findings. The National Congress of American Indians Policy Research Center (NCAI PRC) has developed the following checklist as a guide for reviewing research projects from beginning to end.

Components of research proposals

Researchers should be asked to provide a detailed proposal when they approach an AI/AN community about conducting a study. Possible components of a proposal might include:

___ Narrative of research proposal:
   ___ Background, literature review
   ___ Research question(s)
   ___ Recruitment procedures
   ___ Informed consent procedures
   ___ Incentives/compensation procedures (if any)
   ___ Data/specimen collection procedures
   ___ Data storage/handling procedures
   ___ Data analysis procedures
   ___ Plan for publication/dissemination of data

___ Informed consent form:
   ___ Clear, understandable language
   ___ Background and significance of study
   ___ Description of research procedures
   ___ Confidentiality procedures
   ___ Options for data/biological specimen handling (if applicable)
   ___ Separate checkboxes for individuals to opt in or out of specific aspects of the study (e.g., having biological specimens stored for future research, etc.) (if applicable)
   ___ Description of risks and benefits of study
   ___ Alternatives to study participation
   ___ Right of individuals to refuse study participation or to withdraw at any time
   ___ Information on compensation in the event of injury
   ___ Contact person for questions about the study
   ___ Signature line if individual agrees to participate

___ Budget and funding sources:
   ___ Detailed budget for research project
   ___ Copies and status of grant applications submitted
   ___ Information on data ownership and sharing requirements of potential funders
   ___ Funding and/or in-kind resources being requested from the AI/AN community
___ Funding and/or in-kind resources available to the AI/AN community

___ Professional qualifications of research team:
   ___ Résumés for researchers and research staff
   ___ Copies of relevant previous publications by researchers
   ___ Letters of support from researchers’ institutions or departments

**Review of research proposals**

As communities review research proposals, they may wish to consider the following questions:

___ Do the potential benefits of this study outweigh the potential risks?
   ___ For the community as a whole
   ___ For individual community members

___ Does the community have adequate control over data/biological specimens in the following areas?
   ___ Collection
   ___ Use
   ___ Storage
   ___ Destruction

___ Is there a contract or other legal tool that ensures the community has adequate control over data/biological specimens?

___ Is there a trusting relationship between the researcher and the community?

___ Is there an avenue for community input and feedback during the research project?

___ Is the community treated as an equal partner in the research project?

**Monitoring ongoing research**

Once a research project has been approved, the community may wish to continue monitoring the project through requiring regular reports from researchers. The following components may be included in interim or final reports provided by researchers:

___ Clear, understandable language

___ Summary of current findings

___ Resulting recommendations to community for improvements in policies/services

___ Benefits the study provided to participants and community
___ Problems that occurred in the research study (if any) (e.g., delays in the research plan, unexpected reactions participants had to a study drug or research protocol, etc.)

___ Timeline for anticipated follow-up steps (e.g., future proposed research studies, manuscripts that may be submitted for publication).

___ Report of how results have been disseminated in the community (e.g., articles in community newspaper, presentations at community meetings, additional funding proposals).

Review of publications

While there are challenges in reviewing research publications, doing so ensures that AI/AN communities are informed about the research findings and how those results will be portrayed to the scientific community and the public. Community review policies for publication manuscripts should be geared towards protecting the community from stigma but should avoid putting up unreasonable roadblocks for researchers trying to publish their findings. It is ultimately beneficial to both the community and the researcher if a study is completed successfully and the data are published, because then other AI/AN communities, researchers, and policymakers can learn from the findings. Thus, in reviewing publications, communities may benefit from considering these questions:

___ Do proposed publications represent the community without unfair stigma?

___ Has the community tried to constructively support researchers’ needs for publication?

In sum, the best way of ensuring that AI/AN communities benefit to the greatest extent from research projects is for communities to be involved throughout a research study. Through creating a comprehensive research review process and detailed guidelines for review of research projects, AI/AN communities can facilitate successful partnerships with researchers. For more information on reviewing research projects, please see the NCAI PRC paper, “Research Regulation in American Indian/Alaska Native Communities: A Guide to Reviewing Research Studies” (http://www.ncaiprc.org/research-regulation-papers).