

Research Review Checklist for American Indian and Alaska Native Communities

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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>).

