

ANSC RESEARCH ETHICS SAMPLE MOA

Patricia Cochran

www.nativescience.org



AFN BOARD ADOPTS POLICY GUIDELINES FOR RESEARCH

AFN conveys to all scientists and researchers who plan to conduct studies among Alaska Natives, that they must comply with the following research principles:

- Advise Native people who are to be affected by the study of the purpose, goals, and timeframe of the research, the data-gathering techniques, the positive and negative implications, and impacts of the research.
- Obtain the informed consent of the appropriate governing body.



- 
- Fund the support of a Native Research Committee appointed by the local community to assess and monitor the research project and ensure compliance with the expressed wishes of Native people.
 - Protect the sacred knowledge and cultural/intellectual property of Native people.
 - Hire and train Native people to assist in the study.
 - Use Native language whenever English is the second language.

- Guarantee confidentiality of surveys and sensitive material.
- Include Native viewpoints in the final study.
- Acknowledge the contributions of Native resource people.
- Inform the Native Research Committee in a summary and in non-technical language of the major findings of the study.
- Provide copies of studies to the local library.



Memorandum of Agreement

INTRODUCTION

- ❏ The [Name of Project] is a partnership of the people of the [Name of Community] and researchers of [Name of Research Organization]. In this document these groups are referred to as the Partners.
- ❏ The community is represented by the [Name(s) of Community Organization and Community Researchers] and the researchers by the [Name(s) of Researchers].
- ❏ The partners will work cooperatively and collaboratively in the design, implementation, analysis, interpretation, conclusion, reporting and publication of the experiences of the project. Each partner provides ideas and resources that come from the experience, knowledge and capability of all its members. Together, through respect for each other, consultation, and collaboration, they significantly strengthen the project and its outcomes. All partners of the project share an understanding that community based research is a powerful tool for learning about the community while contributing to the community in which it is being conducted.
- ❏ Collaborative research acknowledges that there must be respect for the scientific and social integrity of the project. Each group has obligations towards the other partners.



PURPOSE OF THE CODE OF ETHICS:

- The purpose of this code of ethics is to establish a set of principles and procedures to guide the partners to achieve the goals and objectives of the project. The code outlines the obligations of each of the partners through all of the phases of the project, from the design of the research through to the publication and communication of the experiences of the project.

POLICY STATEMENT:

- The sovereignty of the community to make decisions about research in the community is recognized and respected. The researchers should maximize the benefits to the community as a whole and to individual community volunteers. Research should empower the community to support community goals of health and wellness, to improve its conditions and to fulfill its traditional responsibility of caring for the generations to come.



PRINCIPLES:

- ❏ The community must be involved as a full partner in all aspects of the research. Continuous consultation and collaboration should characterize the partnership.
- ❏ The strengths and culture of the community, including community researchers and staff as well as material resources, must be respected and utilized whenever possible.
- ❏ Written permission must be obtained from the partners before beginning the research projects.
- ❏ Permission from all individuals participating must be obtained prior to collecting personal information.
- ❏ The confidentiality of all individuals must be respected. If necessary, the community involved may choose to remain anonymous when reporting the results.
- ❏ All research results, analyses and interpretations must first be reviewed by the partners to ensure accuracy and avoid misunderstanding.
- ❏ All data collected belongs to the community and must be returned to the community.
- ❏ The partners must all be involved in making decisions about the publication and the distribution of all or parts of the research results.
- ❏ The community must agree to the release of information.



OBLIGATIONS OF THE PARTNERS

OBLIGATIONS OF THE RESEARCHERS:

- To do no harm to the community.
- To involve the community in active participation rather than passive acceptance.
- To ensure the design, implementation, analysis, interpretation, reporting, publication and distribution of the research are culturally relevant to the community and in agreement with the standards of competent research.
- To undertake research that will contribute something of value to the community in which the research is being conducted.
- To impart new skills to community members.
- To help to address any issues that are raised as a result of research.
- To provide expertise to scientifically answer questions that emerge from the community.
- To promote academic diffusion of knowledge through written publications and oral presentations. This includes the documentation of the undertaking of the project and of the results.
- To be guardians of the data until the end of the project and to return that data to the community at the end of the project.
- To be involved in any future analysis of the data after the data has been returned to the community.



OBLIGATIONS OF THE COMMUNITY RESEARCHERS:

- Community researchers are regarded as the Project Staff and those Co-investigators who are employed within the community. In addition to the obligations listed for researchers, the community researcher is obligated:
- To maintain a long-term relationship of trust in the dual role of caregiver, educator, and researcher: this will only be possible if the needs of the community are always considered as the first priority in any decision.
- To communicate with researchers during all phases of the research.
- To arrange for researchers to meet with the partner Committees and/or Board of Directors, and any other local organizations to implement and promote the project.
- To facilitate supervisory meetings of the Intervention and Evaluation teams.
- To participate in all phases of the project, review all research results, analyses and interpretations for accuracy and present information to the community.



OBLIGATIONS OF THE COMMUNITY PARTNER:

- To represent the community through their respective organizations.
- To be updated by the Project Staff on a determined basis to support the development and offer analysis of the activities to ensure compatibility with the project goal and objectives.
- To meet with the Project Co-investigators to maintain awareness and to offer recommendations concerning the research aspect of the project.
- To communicate with representatives of other communities to share ideas and program development for benefit and involvement.
- To serve as the guardian of all evaluation data after the completion of the project.
- To receive all requests for the use of the data by other researchers after the completion of the project.
- To approve or write a disagreement to the interpretation of the data analysis.



AUTHORSHIP GUIDELINES

INTRODUCTION

■ The purpose of the project is to investigate the research questions described in the protocol. Since this project is unique, the results will be of interest to many other communities. For this reason it is necessary to share the experience of the project with the largest audience who might benefit from it. Part of the research process includes the communication of research results to other people and organizations in similar areas of research.

AUDIENCE

■ Communications will be directed at four general audiences:

■ Health, Education and other officials

■ Scientists and Researchers

■ The Community Council or governing body

■ The community, at large.

■ Health, education and other officials are those people providing services or working on programming and planning. They will be interested in how the project was developed and implemented as well as the outcome of project efforts. Scientists and researchers will be interested in the methods used, the process of the program, the impacts measured, and the answers provided to the research questions. The community at large is everyone who participated in the project as well as those who are generally interested in the project goals.

PRINCIPLES

- All aspects of the project can be considered as worthy of communication. All communication pertaining to the project will follow generally accepted ethical standards. The principles include:
- Anonymity: Results to be presented in a grouped, not individual manner.
- Confidentiality: All personal information provided by individuals will be made anonymous whenever possible and remain confidential unless otherwise determined by the individuals.
- Priority of Communities Involved: The communities participating will be the first to review and receive results and the first invited to provide input and feedback on the results.
- Respect: Consideration for the communities and all participants must be observed in all communications.



PROCESS

- Results from research projects usually are presented in the following ways:
- Articles in scientific journals, referred to as "a paper".
- Oral presentation of "a paper" at a scientific conference or meeting.
- Oral presentation to the community at large.
- Written document to the community at large.
- Teaching examples.
- For scientific journals and oral presentations at scientific conferences and meetings there is a standard process involved. It is therefore possible to outline the steps from idea to final communication and outline the responsibilities for those involved with the authorship. However, these points should also apply to communications to the community. From here on the word communication will be used to describe both oral presentations and written papers.





It will be the responsibility of the project partners to ensure that the staff and investigators who have made significant contribution to the project can qualify for authorship. These are people who have worked directly on the project. However, being involved only in data collection or delivery of a program will not be sufficient for authorship.

The Idea:
All ideas for communications must be presented to the partners before writing begins.

Preparing the Communication:
The first author of an article (i.e. the person whose name appears first on the article) will assume the major responsibility for preparing the article. The first author will assume most of the writing responsibility. Other authors contributing to the communication will appear in descending order. This order will depend on the contribution made to the subject of the communication and the preparation and writing of the communication, including hunters and elders, in the body of the document and the author's section.

Submitting a Communication:
All authors on the paper must approve of the final version before the paper is submitted to the journal, conference, etc. Furthermore, final versions of all papers must be approved by the partners before submission.

 **Peer Review:**

Communications may be reviewed by scientific and community people considered knowledgeable in the subject of the communication. This peer review process may result in suggested changes of the communication in order for publishing the article in the journal of interest. All the authors of the communication must approve any changes made in the review. This will be done by a letter to the editor signed by all the authors.

 This next section deals with special communications **Abstracts:**

An abstract is a short summary of the content of a communication. When someone wants to present a paper at a conference, an abstract will be sent to the conference organizers. The abstract will then be used to decide if the communication will be accepted for presentation. In case of a late call for an abstract, the partners should be contacted as soon as possible. If there are no objections, the abstract should be sent immediately. The preparation of the communication will proceed following the steps outlined previously.

 **Responsibility of Communication by the Partners:**

It is part of the shared responsibility of the partners to prepare communications for the community and the scientific community. Those who have more of an interest in them would appropriately prepare communications for the community: likewise for communication to the scientific communication. This should not limit the authors to one or the other.



EVALUATION GUIDELINES:

CODIFICATION, DATA ENTRY AND DATA CLEANING

- The activities organized by the project should ensure that the data collection process is in accord with the host community values and norms, and competent scientific practice.
- Participation in the evaluation activities is voluntary for the people in both communities. The people who express the desire to withdraw will be able to do so at any time.
- All information or data collected on individuals will be kept strictly confidential. An identification number will be given and the names of participants will be removed. A file containing names and identification numbers will be kept for future follow-up. Only the Project Coordinator will have access to this file.
- For reasons of confidentiality, the person responsible for coding the collected information should not have access to the names of the participants. The names of the participants should be removed prior to data coding.
- The coordinator is responsible for the quality control of the data coding and entry.



PROCESS FOR APPLICATION TO RESEARCH IN CONJUNCTION WITH THE PROJECT:

- ❏ The researcher and community need to meet for the purpose of discussion and approval of the research idea and the protocol involved. To meet this end, the following steps will be followed to make application:
- ❏ A letter is sent to one of the partners to request a meeting to discuss the research proposal. This letter is to include a summary description of the proposed research, a time frame for research, reporting, and the expected conclusion.
- ❏ The recipient of the request is responsible to: distribute the material to the other partners within one working week of receipt of the letter, establish a meeting with the partners and the researcher, and send a copy of the Code of Research Ethics to the applicant to allow for preparation.
- ❏ If there are no objections from any of the members of the partners to the research proposal, formal written consent is to be sent within thirty (30) days of the meeting.
- ❏ In the event of any objections, a second meeting with the proposed researcher is to be held within two working weeks for discussion on the objection.
- ❏ The researcher must agree to comply with all aspects of the project Code of Research Ethics. The proposal will be rejected if the researcher refuses to comply with any aspect.
- ❏ All partners will review and discuss the completed research document(s) before publication. This review is to take place thirty (30) days following receipt of the research document(s).
- ❏ If there is any dissent, the dissenter is responsible to write and present a written response at this meeting. The dissent is to be included with the submission of the research document(s)

