The Social Transition in the North: collection and data access protocols

Susan M. Means
Institute for Circumpolar Health Studies (ICHS), University of Alaska Anchorage

ABSTRACT
Objective. These protocols were designed to provide access to the Social Transition in the North (STN) collection and data set.
Method. Staff at the (UAA) Institute for Circumpolar Health Studies (ICHS) reviewed, organized, inventoried, and cataloged the STN collection.
Results. Most of the materials in the collection are available from the UAA Archives and Manuscripts Department, Consortium Library. Documents and data containing sensitive information are maintained by ICHS to assure confidentiality of research participants.
Conclusion. These access protocols allow researchers to obtain access to this valuable data set consistent with US research policy while protecting the integrity of the data and the confidentiality of the participants.

Keywords: Alaska and Russian Indigenous communities, archives, data set.

INTRODUCTION
The STN study was prompted by concerns in both countries about the quality of life in rural, Native villages where health status generally lags far behind national norms, poverty is common, and the prospects for future prosperity are clouded by factors such as rapid population growth and uncertain political support for social and developmental programs.

The study approached these problems by looking at child rearing in the family environment, based on the assumption that what children are learning today sets the stage for what families will be like in the future. Thus, the study was to "look at the family environment today as a way to see what the future may bring. [Investigators were] especially interested in looking at resilient children and families. These are the ones who may experience problems, but who weather them effectively and then thrive. They can tell us a lot about possible solutions to demoralizing social and economic problems in rural areas." The target areas for the study were northwest Alaska, the Aleutian-Pribilof Islands of Alaska, and Chukotka and Kamchatka, Russia.

The intent of the STN study was to investigate a narrow set of fundamental sociological questions that were clearly related to problems in human/environmental relationships, community viability, and rapid social change. It was to examine demographic transition, epidemiologic transition, and domestic
transition in a sample of Alaskan and Russian Far East communities that were matched along certain dimensions to permit controlled comparisons.

In late August and early September of 1995, the STN research team of Steven L. McNabb, William (Bill) W. Richards, Aleksandr (Sasha) I. Pika, Richard G. Condon, and W. Penn Handwerker were conducting field work in Chukotka in the Russian Far East. This was the final year of the four-year project. On the evening of September 7th, an incident occurred that claimed the lives of 14 individuals, including Dr. McNabb, Dr. Richards, Dr. Pika, and Dr. Condon. At that time, most of the data collection for the STN project had been completed and the Principal Investigators (PIs) were preparing for the analysis phase.

By the end of 1996, the original grant from the National Science Foundation (NSF) was closed out. In mid-1996, the Alaska Native Science Commission (ANSC) applied for and received a grant from NSF's Office of Polar Programs to "conduct a series of workshops and working sessions to coordinate the scientific data and results of the [STN] project." Under the terms of NSF OPP-9633690, ANSC was to serve as the successor institution and coordinate the activities of a senior advisory group to oversee completion of the STN project. The ANSC was to convene meetings, facilitate archiving of project materials, manage the budget, and help produce a final report. The specific objectives were to assemble at one site and catalog the data already gathered by the STN project, bring the research in progress to some conclusion, and establish directions and plans for future research.

In 1999, ANSC applied for and received a follow-on grant to hold a workshop on the topic of Social Transition in the North as part of the 1999 American Association for the Advancement of Science (AAAS) Arctic Science Conference. The workshop was to present, in detail, the current status of the STN archive by surveying the contents of the archive in order to orient the scientific and educational community on how to obtain access to it. In addition, individuals presenting at the workshop were to use selected data sets from the archive to illustrate and present the breadth of data available.

**Transition of the Collection to UAA**

With the move of ANSC from the UAA campus, stewardship of the STN materials was placed into question. Following a lengthy discussion with ANSC, it was decided to release the STN collection to the Institute for Circumpolar Health Studies under the auspices of a National Institutes of Health (NIH), National Center for Research Resources (NCRR) grant (P20 RR16430). ICHS was expected to assemble a team to examine the STN collection to determine the extent of the materials and develop a protocol for their use. On October 30, 2002, some 44 boxes of STN collection materials were delivered to ICHS.

In November 2002, ICHS staff began reviewing, organizing, inventorying, and cataloging the STN collection in preparation for transferring certain document sets to the UAA Archives and Manuscripts Department, making some data sets and documents available to qualified researchers, and evaluating other materials for possible posting to the Arctic Health website (http://www.arctichealth.org), which is sponsored by the National Library of Medicine and UAA.

**Initial STN Collection Inventory**

*Original Research Project & Informed Consent:* The collection was reviewed for pertinent original STN project documents, such as informed consent protocols and other administrative documents, to determine the extent to which Institutional Review Board (IRB) approvals were sought and awarded during the initial research effort and the extent to which these records may affect the availability of the STN collection to the wider research community now and in the future.

*Limitations on Use:* The original STN proposal to NSF contained neither a specific section on human subjects protection, nor apparent limitation to the use of the research data consistent with the original aims of the project. The original aim was to "examine demographic transition, epidemiologic transition, and domestic transition in a sample of Alaskan and Russian Far East communities that are matched along dimensions that permit
controlled comparisons." However, the proposal abstract contained a provision that urged the sharing of data with affected communities. It stated "... results of this project will form a basis for continuing international collaborative efforts in areas of native health and social change, and will be applied to immediate needs of residents through cooperation with native residents and organizations such as the Association of Peoples of the North (Russia) and the Alaska Federation of Natives."

Human Subjects Review: The original proposal was reviewed and approved by the Human Subjects Division of the University of Washington’s Grants and Contracts Services, Dr. McNabb’s home institution. The project was considered exempt in both a certification of exemption and a protection of human subjects assurance / certification / declaration follow-up review.

Informed Consent & Confidentiality: The researchers advised both interviewers and subjects regarding the need for confidentiality and the importance of research ethics. The Interviewer Confidentiality and Ethics Statement described the manner in which questionnaires and unique individual identifiers were to be treated. Interviewers were required to sign the agreement prior to interviewing. Respondents were also provided with informed consent forms. These forms were signed by both the respondent and the interviewer. They do not appear to restrict the use of the data obtained during the research project. However, they reiterate the obligation that research reports will be given to local agencies and representatives.

Conclusion & Recommendation: ICHS staff concluded that proper IRB approval procedures were followed during the original research effort. The cognizant IRB was the University of Washington. Both interviewers and subjects were advised of their rights and obligations to protect confidentiality and grant informed consent. The only obligation that appears to direct the use of the data is the pledge to share the findings with affected communities. This is consistent with NSF Principles for the Conduct of Research in the Arctic.

It was recommended that the original Interviewer Confidentiality and Ethics Statement be modified to form the basic certification for proper use of the STN collection in the future, and that ICHS proceed with archiving of the STN collection, to make it available for use by other researchers. With that, the STN collection project team began to develop an access protocol in preparation for making the collection available to the research community.

Stakeholder Review and Comment
In late April 2003, the draft protocol was distributed to individuals identified as STN collection stakeholders. The stakeholders were asked to review the draft protocol and provide comments. The comments received were synthesized and incorporated into the final access protocol as appropriate.

Protocol for Accessing the STN Collection
Regardless of background, credentials, or past experience with the original STN research project or materials, all researchers wishing to conduct new research using the STN collection are required to work under rigorous standards of confidentiality and research ethics. In order to use the STN documents and data for new research, a researcher must comply with the access protocols specified in the Researcher Confidentiality & Ethics Statement.

How to Access the STN Collection
The bulk of the STN collection is located at the University of Alaska Anchorage Consortium Library, in the Archives and Manuscripts Department. Certain sensitive documents and data (i.e., materials containing personal identifiers) remain in secure storage at ICHS, UAA. Individuals who have questions about the STN collection, the access protocol, or how to access the collection materials and data sets should contact Dr. Brian Saylor, Director, ICHS, UAA, 3211 Providence Drive, DPL 404, Anchorage, Alaska, 99508. Dr. Saylor can be reached by phone at 907.786.6567 or by email at anbls@uaa.alaska.edu.
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Susan M. Means
Institute for Circumpolar Health Studies (ICHS)
University of Alaska Anchorage (UAA)
3211 Providence Drive, DPL 404
Anchorage, AK  99508
Researcher Confidentiality & Ethics Statement

Researchers desiring access to the Social Transition in the North (STN) collection are required to work under rigorous standards of confidentiality and research ethics. Specific requirements that must be satisfied are:

1. Agree to keep all documents, questionnaires, data files, etc. containing personal identifiers of any kind in strictest confidence. Further, agree to handle such documents with great care and maintain them under lock and key to ensure adequate security when they are being used.

2. Agree to abide by the Alaska Federation of Natives (AFN) Guidelines for Research, which can be found at http://www.ankn.uaf.edu/afnguide.html.

3. Agree to abide by the National Science Foundation (NSF) Principles for the Conduct of Research in the Arctic, which can be found at http://www.nsf.gov/od/opp/arctic/conduct.htm.

4. Agree to share research findings with affected communities, consistent with the NSF Principles for the Conduct of Research in the Arctic.

5. Prepare an Institutional Review Board (IRB) plan in accordance with the University of Alaska Anchorage (UAA) Human Research Subjects Policy and Procedure, which can be found in the UAA Faculty Handbook, Chapter VI. (http://www.uaa.alaska.edu/oaa/research/irb.pdf). Submit the draft IRB plan to the UAA IRB for evaluation and approval.

6. Complete one of the following training courses in the protection of human research subjects, or an equivalent training course:
   1. University of Alaska Anchorage training course in the protection of human research subjects, which can be found at http://hosting.uaa.alaska.edu/research/319.cfm, or
   2. U.S. Department of Health and Human Services, Office for Human Research Protections (OHRP) Human Subject Assurance Training, which can be found at http://137.187.206.145/cbtng_ohrp/cbts/assurance/login.asp. Attach evidence of training completion to the IRB plan submitted to UAA.

7. When applicable, contact and coordinate with the appropriate IRB and/or Human Subjects office for the geographic region / subject population encompassed by the proposed research.

8. Agree to acknowledge the original STN research team of Dr. Steven L. McNabb, Dr. William W. Richards, and Dr. Aleksandr I. Pika, and cite the original NSF project entitled Comparative Study of Social Transition in the North: Alaska and Russian Far East (NSF OPP-9496351) in all papers, presentations, publications, or other intellectual properties produced as a result of using the STN collection.

Acknowledgement Signature

Since confidentiality and research ethics are a special issue of trust, we ask that you sign this form to show that you have read and understood these statements. Your signature indicates that you agree to abide by these statements.

Name (printed): __________________________________________  
Signature: __________________________________________
Date: ____________________________________________
