

# BUILDING A COMMUNITY-BASED PARTICIPATORY RESEARCH CENTER TO INVESTIGATE OBESITY AND DIABETES IN ALASKA NATIVES

Bert B. Boyer <sup>1</sup>, Gerald V. Mohatt <sup>1,2</sup>, Cecile Lardon <sup>2</sup>, Rosemarie Plaetke <sup>1</sup>, Bret R. Luick <sup>1</sup>, Scarlett H. Hutchison <sup>1</sup>, Gabriela Antunez de Mayolo <sup>1</sup>, Elizabeth Ruppert <sup>3</sup>, Andrea Bersamin <sup>4</sup>

<sup>1</sup> Institute of Arctic Biology, University of Alaska Fairbanks

<sup>2</sup> Department of Psychology, University of Alaska Fairbanks

<sup>3</sup> Yukon Kuskokwim Health Corporation, Bethel, Alaska

<sup>4</sup> Nutrition Department, University of California, Davis

Received 23 Feb 2005, Accepted 4 May 2005

## ABSTRACT

The Center for Alaska Native Health Research (CANHR) is a community-based participatory research project aimed at understanding current risk factors for obesity, diabetes, and cardiovascular disease in Alaska Natives living in Southwest Alaska. We utilize a multidisciplinary approach that includes assessment of genetic, nutritional and behavioral risk factors and their interrelationships with one another in the overall development of disease. The design of the CANHR project involved community participation in the development, implementation and interpretation of research results. We have developed a participatory research program that is designed to be culturally appropriate, relevant to community needs and interests, and respectful to our participants. This manuscript describes the organizational development of our CANHR study and the procedures employed in its progression to date. (*Int J Circumpolar Health* 2005;64(3):281-290.)

**Keywords:** Native American, Yup'ik, Cup'ig, Eskimo

## INTRODUCTION

Past research efforts with Native people have rarely asked for their collaboration or contribution in the design, conduct, analysis and interpretation of research conducted in their communities. This process, whereby outsiders enter a community to exploit its resources, in this case its intellectual property, has been

described as “colonizing,” and offers scant useful feedback to the communities (4). Fortunately, some work is being pioneered with a more collaborative approach (1-3).

Ethical guidelines for research with ethnically and culturally diverse communities in general (2, 5, 6), and for research with American Indian and Alaska Native communities specifically (6-8), strongly recommend

community involvement. Besides the inclusion of community collaboration in the research process, these guidelines also advocate for Native ownership of the research process, data and outcomes. Furthermore, increasing evidence suggests that a research process based on collaboration with the research communities is necessary to produce results that are appropriate, relevant and respectful, as well as being more likely to be accurate and effective (1, 2, 9-11).

Within this context of participatory research, two avenues exist for generating research questions and the research process. In the first model, the community itself generates the questions and designs the methodology (3). In the second approach, the researchers generate questions and go to the community to discover if community members share the questions, as well as the goals of the researchers. During this process, a collaborative approach assumes that changes in methodology, refinements of questions, and involvement in identifying avenues for dissemination, will take place with the partnering community. It is this second method that the Center for Alaska Native Health Research (CANHR) chose. We will describe this process and how it has achieved a sense of a shared research agenda with the health corporation and the villages involved in this research.

### **The question**

The Center began with the question that we generated: why are rates of obesity and diabetes increasing faster in indigenous peoples than in non-indigenous groups? Unlike the idea of beginning with a question that is of the highest priority for the region, we examined data indicating the existence of an important health

disparity that could present a significant risk for the population. In the 1960s, Dr. James Neel proposed that, in hunter-gatherer populations, a “thrifty genotype” evolved that facilitates efficient storage of calories when they are abundant and spares burning of calories when they are scarce (12). The environment in which indigenous groups reside is increasingly modernized, resulting in more abundant food resources and a more sedentary lifestyle. Additionally, the macronutrient composition of their food supply has changed. Although the obesity epidemic is not limited to Native Americans, the devastating increases in body weight and diabetes among some Native groups suggest that its root cause is complex, and is due to more than simply reduced activity and overeating. Evidence suggests that the trigger for the development of obesity and diabetes results from the interaction of susceptibility genes with obesigenic environmental conditions. The CANHR study was designed to investigate the interactions between genetic and environmental risk factors contributing to excess body weight, diabetes and cardiovascular disease in Alaska Natives. Our first step was to determine whether our concern was shared by the Alaska Native population and their health system. This process was essential to making our work truly collaborative in nature.

### **The setting**

In order to lay the foundation and background to the approach taken by the CANHR team, it is essential to understand how health care is delivered to Native communities throughout Alaska. The current population of Alaska Natives residing in the state exceeds 120,000 and there are 229 federally recognized tribes.

Many of these settlements have only remained in a fixed location for the last century, and most villages are composed of fewer than 500 people. Within the tribal groups, there are significant cultural and linguistic variations. Each of the villages is typically organized around a hub village that is, in most cases, much larger than the smaller villages. There are 13 Native regional profit corporations. Alaska Natives develop health policies and provide health services to the villages within their region, through separate, non-profit health corporations. Most of these health corporations have an ethics committee, or a human studies committee, to examine the appropriateness of research in their regions. The CANHR team works closely with a health corporation in Southwest Alaska.

In addition to the village and regional structure, there is a statewide structure involved in health care and health policy. The Alaska Native Health Board (ANHB) and the Alaska Native Tribal Health Consortium (ANTHC) often provide health policy and applied research guidelines. Each has representatives from each of the health corporations. The consortium is directly responsible for the Alaska Native Medical Center in Anchorage, the statewide hospital for Alaska Natives in need of specialized care unavailable in their local health clinics and for urban Natives who live in Alaska. The ANHB and ANTHC are key players in policy and the determination of research needs in Alaska Native communities. Lastly, the Alaska Native Science Commission and the Alaska Center for Rural Health have been involved in assisting Native communities in defining research priorities, intellectual property rights, and culturally appropriate methodologies for research in Native communities.

Our CANHR study is based in a region in Southwest Alaska that is roughly the size of Oregon, and has over 20,000 Alaska Natives residing in approximately 50 rural villages, with an average of about 500 inhabitants per village (ranging from villages with populations of under 100 to over 1000). The regional center has a population of over 5000 and is the seventh largest city in the state. In this region, the indigenous Yup'ik language is still the first language learned by most of the population, and people engage in subsistence practices to generate much of their food. The culture of this region is considered one of the most intact of all of the indigenous groups in Alaska.

The remoteness, geographical barriers, cultural diversity and road-less nature of rural Alaska presents researchers with significant logistical challenges that increase the costs of conducting research with Alaska Native communities. Maps and numerical distances do not show that, year round, almost all villages can only be reached by plane, or by boat in the summer and snowmobile in the winter. Weather is variable and may change suddenly. When researchers work in a rural area, they may find that they have to wait several days to get into, or out of, a village, or to move from one village to the next. Additionally, because CANHR is working with cultural groups who are firmly anchored in a kinship and personal, face-to-face milieu, researchers must spend time in the villages and regional centers to make themselves known to, and accepted by, the people.

#### **The CANHR project**

Several environmental risk factors may contribute to excess body weight, diabetes and cardiovascular disease in indigenous people.

These risk factors are thought to include, but are not limited to, the balance between the consumption of subsistence and healthy market foods, levels of physical activity, stress and coping styles, cultural identity, access to healthcare providers, and socioeconomic status. CANHR supports three multidisciplinary research projects aimed at elucidating genetic, behavioral and nutritional risk factors, as well as the interaction between genetic and environmental factors. In addition, we are initiating the development of culturally appropriate methods for the prevention and reduction of obesity, diabetes and cardiovascular disease. We provide participants with immediate indi-

vidualized feedback in a booklet listing their body measurements and laboratory values, with detailed explanations of what the test results mean. Results of the CANHR study are also shared with the participating villages, in order to emphasize the collaborative nature of the research. Thus, study results are shared in two steps: immediate individual feedback, and through a presentation of the overall village health statistics to the tribal council.

**Core research resources**

We have developed three research cores that support the research projects and overall goals of the center (Figure 1). Our *Epidemiology*

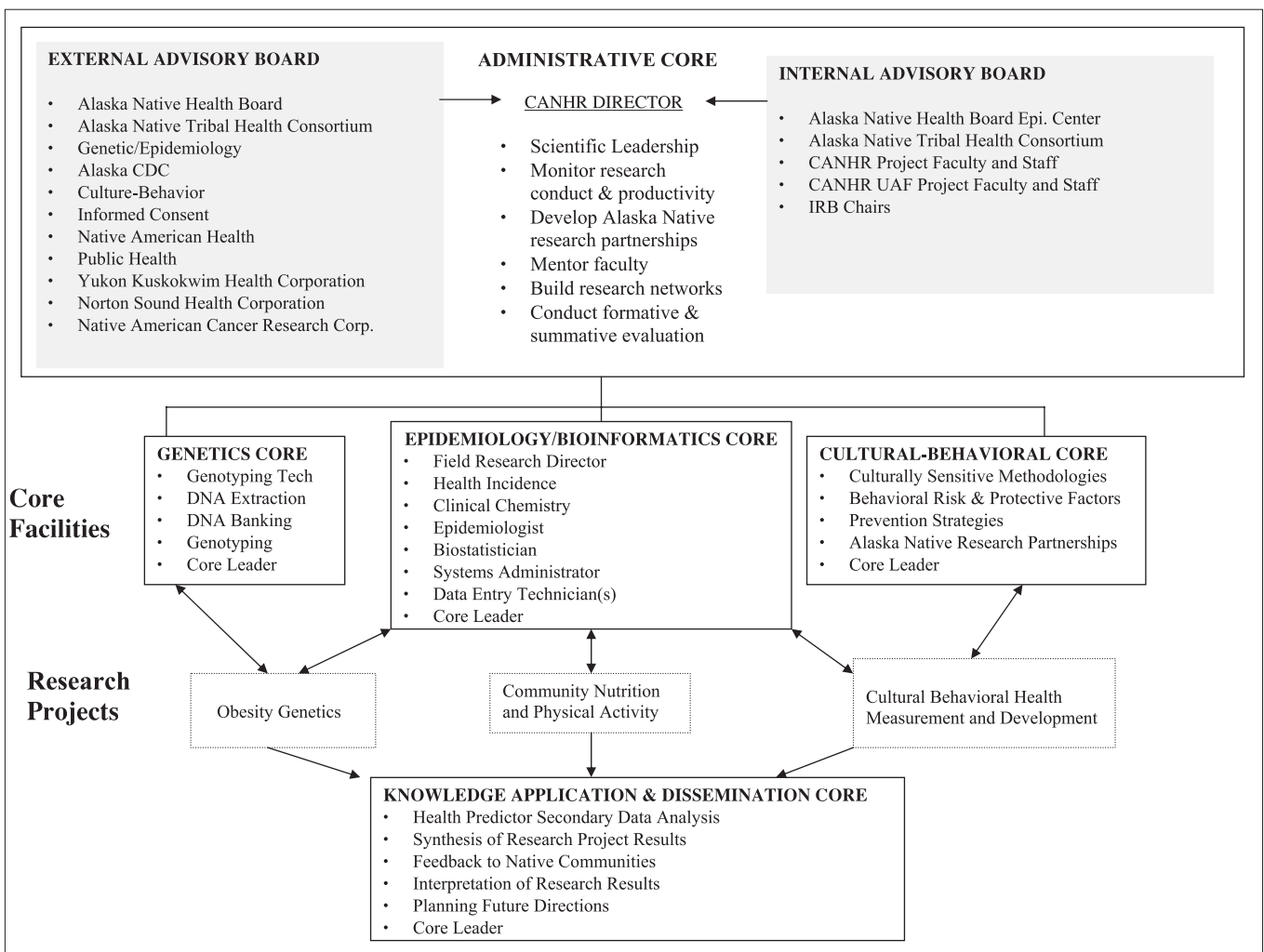


Figure 1. CANHR research cores.

and *Bioinformatics Core*, lead by a genetic epidemiologist, is involved in study design, data management and quality control, data analysis, statistical consulting, as well as the field collection logistics of the Center. The Epidemiology and Bioinformatics Core also provides necessary hardware and software for the data management and statistical analysis for all members of the Center. Additional responsibilities include working with the Center Director to prepare presentations of study results to the research community.

The CANHR *Genetics Core* facilitates collection, storage and analysis of plasma, serum and DNA samples. Analyses include genotyping for a human genome-wide scan and candidate gene analyses. In collaboration with the Epidemiology and Bioinformatics Core, the Genetics Core is responsible for the development of a sample management plan that insures sample integrity and security.

In order to develop the knowledge base of our Center's research scientists in areas of cross-cultural research, CANHR has developed a *Cultural-Behavioral Core*. This core assists the Center in developing sound working relationships with state agencies involved in Alaska Native health, reviewing proposed studies, and developing culturally meaningful presentations to tribal councils. The Cultural-Behavioral Core is also involved in expanding current research and knowledge for the development of culturally relevant and appropriate health promotion interventions and prevention strategies in Alaska Native populations. Overall, the Cultural-Behavioral Core serves as our central resource to facilitate community-based participatory research and health promotion projects, as well as to transfer knowledge back to participants and the community in a

culturally appropriate manner. Additionally, the Center has established a *Knowledge Application and Dissemination Core* that works closely with the Cultural and Behavioral Core to prepare materials and creates culturally based ways of presenting materials. They also analyze existing data sets to assist the Center in planning for future studies and in interpreting the data we are collecting.

### **The research process: developing expertise and understanding through community partnerships**

To work with Alaska Native groups, CANHR researchers and staff developed an understanding of Yup'ik cultural traditions that includes a culturally appropriate protocol for contacting and collaborating with communities and establishing trusting and lasting research partnerships. First, a legacy of mistrust had to be addressed to overcome varying degrees of resistance in some Native communities regarding the participation in health research projects. Some individuals felt that previous researchers working in rural Alaska had exploited Native communities in several ways. During the course of our study we have heard comments like: "*What do you want to study us for now?*" or "*We must be the most over-studied population in the world!*" "*Researchers in the past have promised to come back and explain their findings to communities, but very few have returned.*" Other researchers in Alaska have violated local ethical norms by disseminating their findings to news outlets before asking for permission from their participants, often providing very negative representations of Alaska Native communities (13). Similarly, indigenous communities residing in regions outside of Alaska

were promised that research was only going to be conducted on certain diseases, only to find that the scientists making these promises distributed their biological material to other laboratories to investigate different diseases to which they did not consent (14). In genetic research, participants have heard rumors about cloning, or selling biological material. As a result, participants are increasingly concerned about the potential for exploitation in research, including cultural misrepresentation and “biopiracy” and the negative exposure associated with the Human Genome Diversity Project (15). All these negative connotations associated with research involving indigenous groups need to be faced and worked through in order to develop a successful and trusting partnership with Native communities.

### **Overcoming barriers: The CANHR approach**

Initiating our research involved a series of stages designed to ensure that a community-based participatory paradigm organized our work. Our first phase began by meeting with the regional medical director and other health corporation executives to explain our goals and to obtain permission to conduct research in the region. Following approval from the health corporation president, we again met with the regional medical director and his staff several times over the next year to discuss and refine our research goals and identify potential villages that might be willing to participate. At this point, the health corporation embraced the idea, provided that the communities were willing and interested in participating.

The local tribal councils in the villages proposed by the medical director were subsequently contacted by letter to inform them

about the CANHR study and to ascertain their willingness to meet with representatives from our research team for a discussion of our projects. CANHR met with village council at least twice, and once with the community at a village community meeting. During the council meetings, we explained the project and asked for permission for a larger team of investigators to visit the village to make a community presentation to all interested residents. Approximately 4-6 investigators returned at a later date to take part in a community presentation of the CANHR study, visit the tribal council, participate in local dances and other community activities, give presentations on science and health-careers to the school children, and generally interact with the community for 2-3 days. Before leaving, we presented a draft resolution for participation to the tribal council Administrator that could be used, or modified, to express their interest in having the CANHR study conducted in their community.

Once a community and their tribal council approved the CANHR study in their village, we hired a part-time bilingual research assistant in their village to help explain the research project to community members. This was especially useful to those community members who spoke primarily Yup'ik. In addition, the local research assistants proved invaluable as liaisons between community members and the CANHR team. For example, about 1-2 weeks prior to our visit to collect health data, the local research assistants posted notices throughout the community to announce our arrival. They also helped to facilitate setting up the rental of a building that we could conduct our study in. Finally, our local research assistants acted as translators in explaining the CANHR project, consenting interested participants in

Yup'ik and translating for our physician when explaining test results.

Applying this approach, we conducted our research in 7 locations, stayed in each village for approximately one week at a time for data gathering, and recruited individuals over a 6-month period. We believe that strong working relationships and research partnerships were integral to our successful entry into the communities in which we work with. The effect of our approach to involve our participants in our research may be best illustrated in our low drop-out rate of 21 participants out of 798 in the 7 locations (3%). In order to develop trusting relationships with community members, it takes careful planning, sensitivity to the participants' concerns, continual two-way communication between participants and researchers, an ability to anticipate potential problems and misunderstanding, a commitment to protect participants from discrimination, and an openness and perceptiveness to cultural norms with which we were not familiar.

#### **Facing the issues of genetic research**

Since our project involved genetics research, we assumed that we needed not only to make a substantial investment in genetic education for our Alaska Native community leaders and health corporation representatives, but also to enhance our understanding of Native American genetics research concerns. To address this need, we subcontracted Dr. Linda Burhansstipanov, Executive Director of Native American Cancer Research (<http://natamcancer.org/>), to conduct a genetic education workshop. Dr. Burhansstipanov previously developed the Genetic Education for Native Americans (GENA) program and

delivered the two-day (10 hour) workshop to approximately 40 directors of the health corporation board, tribal council members and village representatives. The GENA workshop covered basic cell biology, a review of genetic concepts, including inheritance, cultural traditions, risks and benefits, and the Human Genome Project, as well as cultural issues related to genetic research and guidelines for culturally respectful genetic research. The GENA workshop was extremely beneficial for both the CANHR scientists and the community leaders, as it opened a dialogue about the potential problems and ways that the community could protect itself and the way that researchers need to proceed to insure such protection.

#### **Logistics**

Our CANHR project takes place in small villages that do not have a formal hospital facility. While local clinics are present in each village and are generally staffed by 2-3 paraprofessional health care workers, the clinics are small, very busy, and generally crowded with equipment. Therefore, it was essential that we provide all personnel and supplies needed to collect data in the participating communities. The CANHR team generally conducted the health study in a local community center. Equipment included consent and data collection forms, printers, laptops (for collecting and analyzing diet recalls and drawing family trees in the field), anthropometric instruments to conduct body measurements, including a bioimpedance analyzer (Tanita TBF-300A), supplies and instrumentation to draw blood samples, conduct on-site analyses of blood lipids and glucose, as well as to process and freeze the blood components.

Our staff included the principal investigators of the behavioral, genetic and nutrition projects, a field research coordinator, a phlebotomist, a physician, a local field research assistant, and other field workers, including postdoctoral fellows and graduate research assistants, who helped with various aspects of data collection and blood processing. The field research coordinator, who is a registered nurse, participated in all aspects of organizing the field trip as well as data collection, and is involved in the dissemination of the results back to the communities. In addition, the field research coordinator acted as the direct supervisor of our field research assistants in each village. We also hired a bilingual research coordinator within the regional health corporation to act as a liaison between the University, the health corporation and the participating villages. A postdoctoral fellow on the genetics project processed the blood samples in the field for DNA extraction, and froze aliquots of plasma and serum for additional laboratory measurements. This individual also entered pedigree information into our database. Four team members were trained to collect diet information. Finally, a physician checked out the participants, explained their laboratory and body composition results to them, and provided dietary recommendations to participants.

### **Data collection**

The CANHR team collected health data by directly interviewing participants and through self-administered questionnaires, as well as by obtaining body measurements and collecting blood samples in the field. After blood samples were drawn, the blood was immediately tested with two pieces of equipment: a Cholestech

LDX lipid analyzer, which measures triglycerides, total cholesterol, HDL, LDL, and glucose, and an HbA1c Analyzer (Bayer DCA 2000+) to assess long-term blood glucose maintenance by estimating glycosylated hemoglobin levels. These results were explained to each participant when they checked out. Individuals with lab values outside the regional health corporation guidelines were referred to the health-care provider for their village. The remainder of the collected blood samples were processed into serum, plasma, packed red blood cells, or DNA, and were frozen in the field. The samples were shipped to our university laboratory, and were assayed for the abundance of several hormones, metabolites, cytokines, vitamins and minerals.

Information about health history and family structure was also collected through a personal interview. Physical measurements, included sitting blood pressure and pulse, height, weight, percent body fat, and four circumferences and four skin-fold measurements to determine the regional distribution of body fat. These measurements were explained to the participants, and referrals were made for individuals whose values were outside the established regional health corporation cutoffs.

Our diet and physical exercise team collected 24-hour food recalls and three-day food records to assess nutrient intake. A Native Yup'ik speaker, in addition to three others, was certified to collect the recalls and assist with the translation and identification of Native foods. The diet and physical exercise team also monitored three-day activity periods with belt-worn pedometers and accelerometers. The analysis of an individual's reported diet and activity levels was explained to each participant.

Behavioral health and wellness beliefs and practices also contribute to disease in Native populations and are being investigated using self-report questionnaires. A measure of well-being based on Yup'ik cultural beliefs was developed for this study. Other measures assessed social support, perceived stress, personal and communal mastery, cultural identity, and coping styles.

### **Progress to date**

Applying a cross-sectional study design, approximately 30% of eligible individuals in the villages participated in the first phase of the study. We have visited two villages a second time and doubled the number of participants in both of these villages. We assume that any measurable success to date has largely been based on our efforts to stay in constant contact with the communities we are working with, and to listen to participant concerns and needs, while sharing meaningful health information with the individual participants and the community in general. Thus, the project is designed in such a way that participants have been active collaborators. By keeping our participants informed as to what we were trying to accomplish, and by giving them regular feedback on our results, we plan to build a lasting and trusting research partnership with the community members.

To further explore ways to make research data useful to Alaska Native communities, we are conducting a health promotion project in one village. The purpose of this project is to engage members of the community in a more in-depth exploration of our data and to set goals for health improvements based on these results. A community health promotion team

is working with the research team to design, implement, and evaluate a program geared towards increasing behaviors that are likely to have a positive effect on the community members' weight and cardiovascular health. This approach aims not only to make research more immediately useful to communities, but also to develop local expertise in basic research and health promotion skills that can be used to address a variety of health issues in the community.

We have also established a formative evaluation process to monitor the Center's progress. We have two external evaluators who monitor our work with the communities and prepare annual and more frequent reports regarding our progress. This includes ascertaining the communities' familiarity with our work, the effect of data gathering on individuals' behavior, their satisfaction with our approach, and their understanding of genetics research. In order to ensure that participants have a process in place that is likely to lead to active informed consent, we are evaluating the degree to which the consent forms and process are understood. Our goal is to create a research process that aims at active informed consent at both the individual and community levels. As we have mentioned, this demands an enormous time commitment. Our feeling is that, unless we evaluate our research, our procedures and overall project will not be acceptable and effective for Native communities. Given the health disparities that these communities experience, good research to explore why such disparities exist, and what can be done to reduce them, is critical. Ethically, we should create a context and process for research that is both available and acceptable to Alaska Native communities.

### Acknowledgements

The CANHR study is funded by a grant from the National Center for Research Resources at the National Institutes of Health (P20 RR16430, to Dr. Gerald Mohatt). The CANHR team would like to express its sincere appreciation to all of our study participants and their communities for welcoming us and teaching us so much about the Yup'ik way of life. Quyana!

### REFERENCES

1. Strickland CJ, Chrissman NJ, Yallup M, Powell K, Squeoch MD. Walking the journey of womanhood: Yakama Indian women and papanicolauou (PAP) test screening. *Public Health Nurs* 1996;13:141-150.
2. Fisher PA, Ball TJ. The Indian Family Wellness project: an application of the tribal participatory research model. *Prev Sci* 2002;3(3):235-240.
3. Mohatt GV, Hazel KL, Allen J, Stachelrodt M, Hensel C, Fath R. Unheard Alaska: culturally anchored participatory action research on sobriety with Alaska Natives. *Am J Community Psychol* 2004;33(3-4): 263-273.
4. Smith LT 1999. *Decolonizing methodologies: Research and indigenous peoples*. New York: Zed Books.
5. 1993. American Psychological Association Office of Ethnic Minority Affairs: Guidelines for providers of psychological services to ethnic, linguistic, and culturally diverse populations. *American Psychologist* 48:45-48.
6. Council of National Psychological Associations for the Advancement of Ethnic Minority Interests (CN-PAAEMI): Guidelines for research in ethnic minority communities. 2000. Washington, D.C.
7. Code of research ethics. 2001. In Alaska Native Science Commission.
8. Guidelines for respecting cultural knowledge. 2001. In Alaska Native Science Commission.
9. Edwards RW, Jumper-Thurman P, Plested BA, Oetting ER, Swanson L. Community readiness: Research to practice. *J Community Psychol* 2000;28:291-307.
10. Parker-Langley L. Alcohol prevention programs among American Indians: Research findings and issues. In: *Research Monograph No. 37: Alcohol Use Among American Indians and Alaska Natives; Multiple Perspectives on a Complex Problem*. NIH Pub. No. 02-4231, 2002: pp. 111-140.
11. Rowe WE. Changing ATOD norms and behaviors: A Native American community commitment to wellness. *Evaluation and Program Planning* 1997;20:323-333.
12. Neel JV. Diabetes Mellitus: a 'thrifty' genotype rendered detrimental by progress? *Am J Hum Genet* 1962;14:352-362.
13. Manson SM. Barrow alcohol study: Emphasis on its ethical and procedural aspects. *Am Indian Alsk Native Ment Health Res* 1989;2:5-6.
14. Dalton R. When two tribes go to war. *Nature* 2004;430:500-502.
15. Holtug N, Salzano, Hsia YE, et al. Symposium on The Human Genome Diversity Project Politics Life Sciences 1999;18(2):285-337.

*Bert Boyer, Ph.D.*  
*Center for Alaska Native Health Research*  
*Institute of Arctic Biology*  
*311 Irving I Bldg.*  
*Fairbanks, Alaska 99775*  
*Email: bert.boyer@uaf.edu*