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Author manuscript

*Prog Community Health Partnersh.* Author manuscript; available in PMC 2023 February 13.

Published in final edited form as:

*Prog Community Health Partnersh.* 2010 ; 4(4): 325–330. doi:10.1353/cpr.2010.0012.

## Community-based participatory research in a large cohort study of chronic diseases among Alaska Native adults

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### Abstract

**Background:** In 2001, the National Cancer Institute (NCI) funded a project to develop methods to recruit American Indian and Alaska Native (AI/AN) adults for a prospective cohort study of chronic disease risk and protective factors.

**Objective:** We describe how the use of community-based participatory research (CBPR) principles led to more effective study design and implementation in a study in Alaska.

**Methods:** CBPR elements included collaboration between researchers and tribes at all stages of the project, capacity building through training AI/AN staff in research methods, and knowledge dissemination through presentations, newsletters, and individual and community health feedback based on results of the study.

**Results:** Between March 2004 and August 2006, 3,821 AI/AN adults from 26 Alaskan communities enrolled in the study. Retention in the study is high, with over 88% of participants successfully completing a 2-year follow-up questionnaire.

**Conclusions:** CBPR methods have facilitated effective development of study methods, recruitment and retention. Efforts are on-going to continue work with this unique AI/AN research participant community.

### Keywords

Alaska Native people; community-based participatory research; prospective cohort; research; methodology; chronic disease

### Introduction

In 1954, the Parren Report documented significant health disparities among Alaska Native (AN) people, which led to the initiation of studies focusing on tuberculosis, other infectious diseases, and infant and maternal morbidity and mortality.<sup>1,2</sup> Although infectious diseases were the primary cause of death among AN people through the 1950s, infectious disease rates have since declined, and rates of chronic diseases have increased. Chronic diseases

are now responsible for 5 out of the 10 leading causes of death among AN people.<sup>3</sup> Key health disparities or particular academic interests drove the research agenda, not priorities identified by AN communities themselves. Until the 1980s, there were no policies or procedures to ensure the protection of AN research participants or promote the dissemination of research results among community members. Because of this history, there has been a growing call for research with AN communities to follow specific research principles and become more participatory.<sup>4,5</sup>

## Background

For years multiple prospective studies have been on-going to address disparities in cancer and other chronic diseases among multiple ethnic and racial groups. Because no study included meaningful numbers of American Indian and Alaska Native (AI/AN) people, in the 1990s the National Cancer Institute (NCI) solicited interest from multiple researchers with experience working with AI/AN people. Those interested were encouraged to submit linked R01 grants targeting health disparities in cancer and chronic diseases among AI/AN people. At a regular meeting of all regional Tribal Health Directors in Alaska, staff researchers distributed a concept paper describing the nature of the study and potential risks and benefits. The regional Tribal Health Directors provided enthusiastic support and recommended submission of an application. In 2001, NCI provided funding to the Alaska Native Tribal Health Consortium (ANTHC), the Navajo Nation, and the Black Hills Center for American Indian Health. The University of Utah acted as the coordinating center for this effort. In Alaska, 3 regional tribal health organizations (THOs) collaborated on the study with ANTHC.<sup>6</sup>

ANTHC was formed in 1997 as a statewide non-profit, health services organization owned and operated by AN people to provide health services to members of the 229 tribes throughout Alaska, primarily through small clinics in each community. The ANTHC has a Self-Governance Agreement (the Alaska Tribal Health Compact) with the Indian Health Service for management of all statewide health services formerly provided by that agency.

Herein, we describe the lessons learned in conducting the Alaska portion of the study using community-based participatory research (CBPR) methods to increase collaboration between researchers, communities and Tribal leaders; build research capacity among AN people; and disseminate research findings to tribal communities and leadership. We describe the challenges of piloting a large prospective study in an Alaskan population dispersed in small, remote and geographically widespread communities, and the benefits that the CBPR approach gave for increasing effectiveness of study recruitment, retention, and community-wide health promotion.

## CBPR Methods

### Tribal and researcher collaboration

The CBPR approach reflects a profound shift to a more egalitarian balance between researchers and study communities.<sup>7-10</sup> Collaboration with regional THO staff, Tribal leadership, and local experts impacted multiple aspects of this study. Each of the three

THOs contributed research questions to the study, including questions on depression, the household environment (mold, type of heat source, cigarette use in the home), and local foods and activities such as hunting marine mammals, berry picking, or smoking fish and meat. One region requested that the questionnaires include audio in the local language (Yupik) as well as English. THOs were also instrumental in developing the protocols for the medical measurements, including a decision not to measure skin-fold thickness or thigh circumference due to space limitations in small communities and resulting privacy concerns. Additionally, because of a desire to provide health feedback directly to participants, the study did not draw blood for later analysis but instead provided a finger stick fasting blood glucose and lipids test that gave immediate health information to the participant and local healthcare providers.

After development of the protocol, the Alaska Area Institutional Research Board, the National Indian Health Service Institutional Research Board, the Tribal health research and ethics committees, and the governing boards of each of the participating regional THOs reviewed and approved the study design, instruments, and research questions. Regional coordinators then made presentations to local Tribal Councils. Out of the 27 councils approached, 26 signed resolutions allowing the research study to enroll Tribal members in their community.

One of the most important elements of CBPR is sharing power between researchers and communities, and one of the ways that power is manifested is the names that are used to describe things.<sup>11</sup> Often investigators chose the project name, not the community that is being researched. In this study, a Tribal Advisory Board, which included respected Tribal elders and Tribal health board members, chose the logo and name of the study, *Education and Research Towards Health* (EARTH), after a contest was held among Native artists. All study materials, such as newsletters and reports, included the logo and name of the study. It was also included on small give-away items such as baseball caps, T shirts, and water bottles to help build a sense of community among study participants and staff members. Tribal recommendations determined the type of study incentives, such as the use of cash incentives instead of checks or gift certificates due to the lack of banks in the majority of the small, remote communities where participants lived.

Another element of power sharing is the sharing of study resources. The ANTHC received the grant from the NCI and then set up subawards with each of the THOs involved in the study. Each organization made their own decisions on hiring of staff and allocation of funds for participant recruitment and study materials, while the ANTHC acted as the coordinating center to compile and report data back to the funding agency. All four organizations worked in concert to meet study objectives and use resources efficiently.

This study also expanded standard methods of recruitment (flyers, radio announcements, presentations to boards, health providers and community groups) to include home visits by local recruiters. Research team members lived and worked in the community for blocks of time ranging from 1 to 8 weeks. During that time they participated in community events such as bingo nights, traditional dance presentations, pow-wows and other Tribal gatherings. The Chief Executive Officers of the ANTHC and Southcentral Foundation showed tribal

support at a leadership level by allowing AI/AN employees to participate in the study during work hours.

### **Capacity building**

Among other CBPR principles, the EARTH Study sought to build on the strengths and resources of the community and increase AI/AN capacity to do research. The regional study teams included a coordinator, 2 to 4 research assistants and local Tribal members in each community who acted as liaisons to engage other community members in the project. The majority of study team members were of AN descent, and many were bilingual in the Native language of their area. More than 30 AI/AN people completed training in research methods as part of this study. Several local recruiters went on to become research assistants, and one research assistant obtained a Master's degree in Public Health while working with the study.

### **Knowledge dissemination**

Another important CBPR principle that is oftentimes neglected is to disseminate knowledge gained from research to all involved partners, including those who participated in the research.<sup>4,12</sup> One of the goals of the EARTH Study outlined in the original study proposal was to develop methods to provide rapid feedback to individuals and communities to monitor health and plan health programs at the community level. To ensure that study participants and tribes learned the results in a timely manner, staff put extensive effort into data collection and management. Audio-assisted computerized questionnaires and touch screen monitors eliminated separate data entry. These methods, coupled with an immediate entry of medical measurements and blood tests, allowed the generation of an individualized 4-page health report based on participant responses. Staff discussed the report with each participant at the end of the study visit. The report focused on encouragement for positive health behaviors reported, while also indentifying modifiable health behaviors. Participants with laboratory values over recommended levels were referred for follow-up to providers and appropriate programs (i.e. diabetes program) and a copy of the participant feedback was put into their medical chart.<sup>6</sup>

Along with direct dissemination of individual health results to each participant, the study team created a health report for each community and for each of the 3 participating regional THOs. The community report included key study findings of interest to tribal members, including information on medical measurements, diet, weight, physical activity, and tobacco use. These summary health reports went to healthcare providers and Tribal Councils of each participating community. Study staff gave formal presentations to communities and THOs. Biannual study newsletters also kept participants informed about current enrollment numbers, study findings, and health tips and recipes. There was not a study website designed for participants as many small communities lacked reliable Internet service during the study period. Each THO received a regional detailed data book and a summary databook. The summary databook was posted on the Internet after all THOs gave their approval. Along with these data-sharing projects, regions have requested additional data analyses such as a health status report specific to Alaska Native elders.

Researchers often face the pressure to publish study results in peer-reviewed journals in order to sustain funding. A CBPR approach demands that communities be equal partners in data dissemination as well as all components of the research process.<sup>13</sup> Previously, researchers have published results of studies conducted in AI/AN communities without first sharing those results with community members.<sup>14</sup> In keeping with the tenets of CBPR, a tribal committee at each of the three THOs and ANTHC review all manuscripts to ensure that sensitive information is not included and that data are correctly interpreted prior to submission to scientific journals. This process takes time but is necessary to ensure that all collaborating partners have a voice in the data dissemination process.

## Results

### Participant recruitment and retention

The potential for increased participation by community members is a primary reason researchers are drawn to CBPR methods.<sup>15</sup> By employing CBPR methods, the EARTH Study was able to enroll 3,821 AI/AN people, making it one of the largest study cohorts in Alaska. The study interview took on average 2.5 hours to complete and was often conducted in small spare rooms due to space limitations in rural and remote communities. Despite the length of enrollment and space limitations, over 95% of Alaskan participants who started the initial interview completed all components of the study visit. Enrollment ranged from 2% to 49% (median 29%) of those eligible for participation in each community. A larger proportion of persons in smaller communities participated in the study.

Prospective studies face an additional difficulty over cross-sectional studies as they must retain a large group of participants over a long period of time to retain statistical power and avoid response bias.<sup>16,17</sup> One benefit of the CBPR approach used in this study was increased participant retention. Two years after initial enrollment study staff contacted participants for a follow-up telephone interview. Retention was high: Over 88% of participants completed the follow-up questionnaire. The amount of effort required to successfully contact participants was comparable or better than follow-up rates reported in other populations.<sup>18–20</sup>

One important aspect of CBPR is the need to establish and maintain trust between local community members and researchers.<sup>21</sup> In this study, research staff who conducted the follow-up calls were often those who had also enrolled the participants and collected the baseline data. On the call, participants frequently made it clear that they remembered the caller and made positive comments about their experience. One participant wrote a short note to the study team saying: “I absolutely love what you are doing for Natives all over Alaska.” Another participant credited the study with educating him on the importance of always wearing a float coat, which he believed helped save his life when he later went overboard in a boating accident. Over half (57%) of participants said they had made health improvements after enrolling in the study. Although anecdotal, these examples show the sense of participant community formed over the course of the study. The largest source of friction between community members and the study researchers was when the study funding was discontinued at the federal level. Study participants enjoyed receiving the newsletters

and reports but expressed disappointment that the study wasn't going to continue in their community again in the near future.

## Discussion

Despite the well-meaning intentions of researchers, the research climate and culture in the United States imposes significant barriers to those who aspire to CBPR. Such barriers include the lack of planning grants or funding for establishing relationships with communities early in a project. In addition, current research funding climate tends to devalue the expertise of tribal leaders and indigenous health care providers, and instead often defines funding eligibility based on formal degrees, graduate training, numbers of publications, and academic appointments. The pressure to rapidly present or publish study findings, and the importance of these in securing continued funding is directly counter to the expectations and desires of the population involved in the study. Most minority populations rightfully expect that the most important outcome of research is to improve the health of the population. Many individuals participate knowing that there may be no immediate benefit to them personally, but they participate anyway because of potential benefit to their families and community. They also rightfully expect to be the first to hear the results of a study and to be involved in the interpretation of findings. Researchers who respect this approach are still judged by the number of manuscripts accepted or already published in scientific literature, and therefore will appear to have not been successful. The limited pool of highly trained tribal researchers, the necessity of maintaining high levels of delivery of services in underfunded, understaffed settings with frequent turnover of personnel are internal issues that add to the challenge of conducting research on AI/AN health disparities. Following CBPR goals in research targeted at reducing health disparities will require a paradigm shift in the time allowed for research projects, the definition of "successful" research, and enhanced training for local experts to carry out the research.

## Conclusions

This paper has described efforts to conduct a large, prospective, cohort study incorporating CBPR principles. One limitation of our project is that there was no formal evaluation of how successfully the research team actually met that goal. We used process measures of tribal involvement as well as more traditional measures of study success: Enrollment of a large proportion of persons eligible, high completion rate of all components of the study after consent, and high response rates on follow-up 1 or more years after enrollment. Additional evaluation of "success" is based on spontaneous positive comments from participants, Tribal organizations, and Tribal leaders, and the continued interest, enthusiasm and commitment of tribal persons employed by the project team or who voluntarily participated as experts and advisors. The benefits of this study included the AI/AN people trained in health research; the almost 4,000 AI/AN individuals recruited in Alaska who learned about their personal health and risk factors; and the communities and THOs that received health education and economic benefits by having a study in their area. We believe that dedication to CBPR principles and methods contributed to the large number of persons who chose to participate in the study, the high response rate on follow-up, the number of AI/AN persons who gained

experience from involvement in the conduct of the study, and the positive impression of the study from participants and tribal leaders.

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