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Determined by the Community: CBPR in Alaska Native Communities Building Local Control and Self-Determination

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RUNNING HEAD: CBPR IN ALASKA NATIVE COMMUNITIES

Determined by the Community: CBPR in Alaska Native Communities Building Local
Control and Self-Determination

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Abstract (250 words)

Objectives: Past research conducted with Alaska Native communities involved researchers entering the community to gather data then leaving with that data never being returned or presented or the researchers to be heard from again. The communities were not made aware of the findings, how the data was used, or where the information was published. This method of research resulted in significant mistrust of researchers by tribal communities. This article will briefly describe the context and history of research with Alaska Native people; provide an overview of the complex approval process for research through two case studies; highlight the relevant principles of Community-Based Participatory Research (CBPR) when working with tribal communities; and our own experiences with the tribal approval process.

Methods: Using a case study format, the authors provide a guide to the complex approval process in working with tribal communities and the relevance of Community-Based Participatory Research (CBPR). This is based on their experiences with the approval processes in a dissertation study and a community-based Elder Needs Assessment project.

Results and Conclusions: Drawing from their personal experiences and understanding of the tribal approval process, the authors discuss the benefits and challenges associated with conducting research with tribal communities in rural Alaska. They also provide recommendations for future researchers on how to work effectively with tribal communities, from entry into the community through dissemination and publication of information.

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Introduction

Historically, organizations, agencies, and individuals have conducted research in tribal communities with mixed results. Past research in Alaska rarely resulted in positive outcomes or strong relationships between communities and researchers. This is not to say that all research with tribal communities has been negative; there have been positive outcomes for tribal communities as a result of research, such as the development and implementation of culturally appropriate programs and services targeting priority issues determined by the community. Despite some of the benefits of research, the deleterious effects to the indigenous communities have far outweighed the good and have made it necessary for Alaska Native communities to develop regulations and guidelines to assist researchers in working respectfully with tribal communities. These documents are examples of tribal communities exercising their sovereign status and taking control of how research is implemented and disseminated in their own communities. Based on our experiences, we provide recommendations for future researchers planning to work with tribal communities in the State of Alaska. This paper hopes to provide justification for the necessity of extended timeframes and flexibility for conducting culturally responsive and responsible research with Alaska Native communities.

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Discussion

History of Research with Alaska Natives

Much of the past research conducted with tribal communities was coined “helicopter research,” because researchers would enter the community, gather data, and then leave the community taking the data and findings with them. Researchers never informed communities how the data was used or published, which created significant mistrust. One research study conducted in Alaska played a pivotal role in shaping the way communities view researchers, as well as providing ample justification for the complex guidelines and approval process for working with tribal communities in the state. The Barrow Alcohol Study (Foulks, 1989) is an example of what can go wrong with this type of research approach. The goal of the Barrow Alcohol Study (BAS) was to understand the relationship between alcohol and accidental death, suicide, and violence in the community and to identify preventative community interventions (Foulks, 1989). The research was conducted with inadequate consideration of the context and culture of the community. The scholars publicly published questionable findings without regard to the impact it would have on the community (Wolf, 1989), and stigmatized an entire community by omitting the cultural, social, historical, and political factors that contributed to the context of Alaska Natives (Foulks, 1989; Wolf, 1989). The work did not have adequate representation from the community; only one point of view was truly represented in their advisory groups. The scientific and community advisory groups met separately and never communicated with each other or the community; the study was divorced from local community input, and dissemination occurred prior to meaningful

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community presentations and discussions (for a full critique of the study see *Am Indian Alaska Native Mental Health Res.* 1989; 2(3)). The BAS has served as a cautionary tale for researchers working with cultures outside of their own and has illuminated the importance of research participants' rights, potential negative effects of data misuse, and the consequences of poor conceptualization of research findings. The researchers did not achieve their reported aims and also unnecessarily and unrightfully stigmatized the entire community.

In the State of Alaska, both the Alaska Federation of Natives (AFN) and the Social Sciences Task Force of the Interagency Arctic Research Policy Committee (IARPC) have developed guidelines and principles for researchers conducting research with tribal communities in the North (Alaska Native Science Commission, 1993; Interagency Arctic Research Policy Committee, 1995). In accord with these principles, Mohatt (1989) suggests a participatory model of research with Alaska Native communities where the researchers include community members in all aspects of the research process. This collaborative approach to research (Mohatt, 1989) described and then put into action by Mohatt et al., (2004), sits in stark contrast to the previously mentioned BAS, which involved only one segment of the community rather than the entire community. The juxtaposition of these two studies, their outcomes, and the community perceptions of them highlight important contrasts between the two approaches: one reflects the older, scientific method of research that is common among the mainstream culture, and the other study is more aligned with current principles and research regulations developed for researchers in the Arctic (Alaska Native Science

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Commission, 1993; Interagency Arctic Research Policy Committee, 1995). Mohatt's research (Mohatt et al., 2004) did three things differently that set them apart from the BAS. First, they had broad community input rather than just a select few people from one area of the community; second, they engaged community advisors throughout the research process rather than utilizing separate scientific advisors; and third, there were multiple levels of review in Mohatt's study prior to disseminating interpretations of the data. These three things ensured the research process, data analysis, and findings were reflective of the community's values, and these specific things are echoed in the literature on Community-Based Participatory Research which are outlined in the next section of this paper.

Community-based Participatory Research

Community Based Participatory Research (CBPR) is a research approach conducted as an equal partnership between community members, organizational representatives, and researchers (Israel et al., 2010; Mohatt et al., 2004). A set of principles has been developed directly related to CBPR and they serve as guidelines for researchers working collaboratively with communities. There are 11 CBPR principles, which include the following:

1. Recognizes community as a unit of identity.
2. Builds on strengths and resources within the community.
3. Facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.

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4. Fosters co-learning and capacity building among all partners.
5. Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners.
6. Focuses on the local relevance of public health problems and an ecological perspective that attends to the multiple determinants of health.
7. Involves systems development using a cyclical and iterative process.
8. Disseminates results to all partners and involves them in the wider dissemination of results.
9. Involves a long-term process and commitment to sustainability.
10. Openly addresses issues of race, ethnicity, racism, and social class and embodies cultural humility.
11. Works to ensure research rigor and validity but also seeks to broaden the bandwidth of validity with respect to research relevance.

(Israel et al., 1998, 2005; Minkler & Wallerstein, 2008).

We would like to highlight the CBPR principles relevant to the case studies discussed in this paper which illustrate the iterative process of formulating the research study, gaining approval, and conducting research in Arctic communities from the perspectives of two distinct cultural regions of rural Alaska. The first case study highlights the approval process from the beginning of a dissertation study and engaging the community throughout the entire process, including survey development and dissemination (Principles 1 & 3). The author approached the Bristol Bay region to conduct the study and worked with each individual community to seek and acquire

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approvals prior to engaging in data collection. The second case study highlights an Elder Needs Assessment project that originated in the communities of the Norton Sound southern sub region and the authors were approached to conduct the Assessment within a CBPR framework. Each of the sub-regional communities had voiced support for the project before the Assessment began and they provided support that enabled the authors to successfully complete the Elder Needs Assessment. Both of these case studies emphasize the importance of developing and establishing relationships with each community and treating them as co-researchers throughout the entire process (Principles 3 &4). They also highlight the importance of community support and engagement and building relationships to ensure the projects are culturally appropriate and reflective of the communities (Principle 10).

The first two principles of CBPR acknowledge the community as a unit of identity and builds on the strengths and resources within participating communities. The third and fourth principles, facilitating a collaborative, equitable partnership with co-learning in all phases of the research (Minkler & Wallerstein, 2008), were also instrumental. To obtain entry into the community and meet with Elders, the tribal councils and local Elder Coordinators served as excellent resources with firsthand knowledge of their community and residents. The fifth CBPR principle, achieving a balance between knowledge generation and intervention (Minkler & Wallerstein, 2008), was addressed as the communities discussed how they would use the members' knowledge on how to age successfully and how to improve programs and services to promote aging in place. Principle eight (8) was also addressed in these projects in that the

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results were disseminated to the participating communities and other interested parties in the region. To further illustrate, the two case studies consisted of a set of core principles of community-based participatory research (CBPR), such as being participatory and cooperative (Principle 3), being a co-learning and community empowering process (Principles 3 & 4), and achieving a balance between data collection and action (Principle 8) (Israel, Eng, Shulz, & Parker, 2005; Minkler & Wallerstein, 2008).

These two case studies have moved effective, community-based research forward in the Bristol Bay region and Norton Sound southern sub region and demonstrated the fact that community-based research can be done effectively, in a timely manner, and that communities can remain involved after the data are gathered and disseminated. It is the hope that future research will continue in these communities and the relationships will strengthen in each region. In addition to adhering to the CBPR principles outlined above, these projects both went through tribal approval processes that are unique to each region. The following sections of the paper will discuss in further detail the approval processes for each case study and what was required to engage in community-based participatory research.

Alaska Native Cultures

The State of Alaska is home to 11 Alaska Native cultural groups and 229 federally recognized tribal communities, each culturally and geographically distinct and unique. Each cultural group segments the State into regions and they have their own subsistence lifestyle, language, culture, and values. Most rural communities have tribal sovereignty and their own unique relationship with the federal government, consisting of

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federal policies and regulations in place to protect the well being of the community and its members. All these unique relationships between communities and the federal government make it complicated to work collaboratively on research projects, but provide the necessary protections. Additionally, the size of Alaska and the remote locations of most tribal communities off the road system makes it challenging, and costly, to conduct research in Alaska. Researchers engaging in Alaska Native health research within the State must navigate a complex, multi-level tribal approval process. The next section of this paper will briefly describe the tribal approval process required when conducting health research with tribal communities.

Approval process for research in Alaska

The Indian Health Service (IHS) has responsibilities for delivering health care services for American Indian and Alaska Native people and the regional IHS Institutional Review Board (IRB), referred to as the Alaska Area IRB (AAIRB), provides human subjects review of health-related research projects with tribal communities. In addition to the AAIRB, university researchers have their own university IRB that also reviews for human subjects protections. Once researchers receive AAIRB and University IRB approvals, they must also work with the regional health corporations. These corporations were established with the passage of P.L. 938-638, the "Indian Self-Determination and Education Assistance Act of 1975," which authorizes tribes and organizations to contract and operate federal service programs within the Bureau of Indian Affairs (BIA) and Indian Health Service (IHS)(Bureau of Indian Affairs, www.bia.gov). Most regional health corporations also have a review board and approval process, and finally, each

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community has a tribal council with its own governing board and approval process that is required before researchers can work in communities. It is important to note authority originates with the tribe; the regional health corporation serves at the permission of the tribe, and both can determine the IRB that will have governing authority for their region. When conducting research with tribal communities, the authors recommend presenting the proposed study to the tribe for informal support before starting the approval process.

The process and timeline for approvals can be time consuming and complicated. When proposing to conduct research in Alaska, the process often begins with the AAIRB, followed by the regional health corporation and affiliated university IRB approvals, with final approvals occurring in the tribal councils of each individual community you wish to collaborate with during your project. As described, the process seems fairly linear and straightforward; however, each level of approval may require modifications and revisions that then need to be resubmitted to the previous levels. This iterative process of approval and project modification can be laborious and time consuming. This can become particularly complex when working with communities in multiple regions of Alaska, each with distinct values and ideas about how research should be conducted in their region and community and adding additional levels of approval.

The two case studies in this paper illustrate the iterative process of formulating, gaining approval, and conducting research in Arctic communities from two perspectives. The first case study is based on one of the author's dissertation study, highlighting the top-down approval process from the beginning of the study and engaging the community throughout the entire process. The second case study illustrates a project that originated

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in the community and the authors were approached to conduct the study in a CBPR framework with prior approvals to visit the communities. These two case studies highlight the importance of community support and engagement and nurturing relationships with each community to ensure the project is culturally appropriate and reflective of the communities.

Alaska Native Successful Aging

The first case study is the author's dissertation, which was a qualitative, in depth analysis of successful aging among Alaska Native Elders in the Bristol Bay region of SW Alaska (Lewis, 2009). This is the home region of the author, so he had access to communities as an insider but worked in new communities to be considered as an outsider by the AAIRB and UAF IRB and avoid bias in his data collection procedures.

Within the perspectives of CBPR, this dissertation began by determining whether the research study was important and beneficial to the communities in Bristol Bay. Before contacting individual communities, the author spoke with the Bristol Bay Area Health Corporation (BBAHC) Ethics Committee about the proposed project in January 2008. Appendix 1, the dissertation timeline, outlines each step of the dissertation to illustrate the complex and time consuming approval process associated with this form of research. Once the author received BBAHC approval to conduct the study, the University of Alaska Fairbanks IRB application was submitted for approvals.

Once the BBAHC Ethics Committee approved the project and believed it would be an important contribution to the region they provided a list of approved communities, all located in culturally distinct areas of Bristol Bay in order to reflect the cultural

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diversity of the region, and the process of establishing rapport with each community commenced.

In addition to receiving BBAHC approval, the author submitted the dissertation research proposal to the AAIRB for their approvals. Upon receiving AAIRB approval in December 2008, introductory letters were sent to the traditional village council Presidents of the selected communities to explain the purpose and goal of this research (January 2009). Follow-up phone calls were made to answer any questions and schedule visits with the traditional village councils and Elders selected to participate in the study. In person meetings with traditional councils in participating villages began in November 2008 and interviews with the nominated Elders in each community were completed in January 2009.

Upon arrival in their community, respondents were interviewed in their homes, tribal office, or wherever they felt most comfortable. Visiting with the Elders, their family, and community was crucial to establishing rapport and trust with the Elders and help them open up and share, which was critical to the success of this project and it being reflective of their experiences. This process of rapport building took place on the individual participant level as described above, through to the community level with presentations to the tribal councils and communities, and up to the regional level with the regional health corporation approval and involvement.

This case study provides an example of using a CBPR framework for a dissertation study from the inception of the research, and seeking approvals from the appropriate tribal governing authorities from the beginning through to the publications

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and professional presentations given today. Appendix 2 illustrates the time consuming nature of conducting CBPR with tribal communities in rural Alaska. Figure 1 below illustrates the layers of the tribal approval process for the dissertation study, which outlines how researchers seek approval when working in this specific region of Alaska. As discussed earlier, if one level of tribal review does not approve, or modifies the study, the researcher(s) is required to go to the previous step and resubmit their application with the recommended modifications.

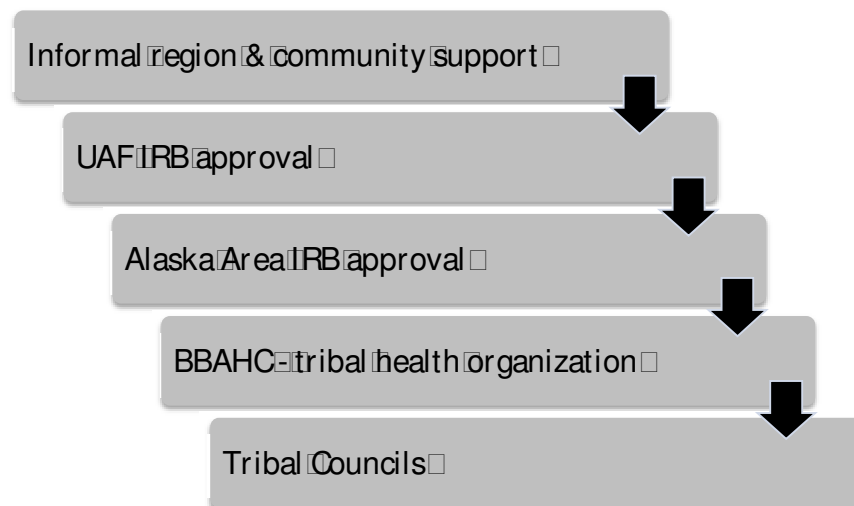


Figure 1: Dissertation Tribal Approval Process

All procedures of the dissertation study were structured through a CBPR framework and each participating community was actively engaged throughout the entire study, which is illustrated in Appendix 2 (Lewis, 2011). The participating communities in this project served as co-researchers and contributed to the implementation, development, and dissemination of the findings. The communities, and Elders, were invited to be as involved in the research process as they wanted or felt was necessary to ensure they were adequately represented.

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It is important to note the tribal approval process differs for graduate students and professionals when submitting applications to the AAIRB and the University IRB. For the dissertation study, the author first sought and received UAF IRB approval and then submitted the approved application to the AAIRB. Professionals and other researchers must first receive Alaska Area IRB approval before submitting their application to the respective tribal health organization. Receiving informal regional and community support for your research project makes this process flow more smoothly and avoid delays and significant revisions. The successful aging dissertation study required up-front approvals, but the Elder Needs Assessment the authors conducted required approvals further into the project. The next section of this paper highlights the Elder Needs Assessment project and the process required to conduct a successful, community-initiated project.

Norton Sound Southern Sub-region Elder Needs Assessment

The second case study illustrates the CBPR process from a grassroots approach where the community reached out to address a community concern. The Norton Sound Southern sub region engaged the two authors to assess the long-term care and housing needs of their local Alaska Native Elders and to gain an understanding of the wishes and desires of the Elders themselves through the use a CBPR framework. Rather than approaching the community to conduct a study (as in the first case study), the idea, development, and funding of this project was a direct result of the sub-region communities coming together, pooling their resources, and developing a partnership with

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the authors who had the necessary skills and experience to explore the community and Elder needs in a culturally appropriate manner.

The approvals in this project came after the initial start of the project because the authors were asked to direct the assessment project after the funding and community support had been acquired. This case study involved a year long, two-phase Elder Needs Assessment conducted to determine the existing and needed services to keep Elders in their home and communities. The first phase of this project consisted of a quantitative, biomedical, assessment of the Elders' health care needs with a total of 134 Elders (n=134), utilizing the Administration for Native Americans (ANA) Assessment survey tool. This phase of the project provided a comprehensive picture of the health status of Alaska Native Elders (Inupiat Eskimo and Yup'ik Eskimo) in the five sub-regional communities.

The second phase of the project consisted of a qualitative, in-depth questionnaire focused on the specific health and long-term care needs of the Elders. We conducted in-depth interviews with a total of 22 Elders (n=22) in the five participating communities. This phase of the assessment provided a more detailed picture of not only the health and long-term care service needs of Elders in each community, but also the way in which the Elders would like those services to be delivered.

Once the initial data was collected the authors sought input and approval on how to present the findings, and in which format each participating community would like to see the results disseminated. The results were brought back to the communities in the forms of a formal presentation to the community, a final report to the tribal councils, a

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newsletter for the participants and community members, and a conference poster. We traveled to each community with the poster to solicit feedback, edits, and changes and receive final approval prior to presenting at the Gerontological Society of America (GSA) Annual conference in 2011. This process enabled each community to provide their input and comments directly on the poster and have discussions on the presentation, which we incorporated prior to the GSA conference presentation; the same process holds true for journal publications written on this project. This project continues to use the same process used to seek approvals for future publications and presentations. Unlike the first case study where community approvals were sought prior to the research project starting, the Elder Needs Assessment project required approvals after the initial project began and then during and after the project.

Case Studies Summary

Where these two case studies are similar is their need for building and fostering relationships with the participating communities. To ensure the communities were invested in the projects and they reflected their experiences, the authors spent time getting to know the communities, visiting with Elders and family members, and spending time in each community on multiple occasions. Over the two years of these projects, we were trusted and supported by the communities to bring the voices of their Elders to the forefront and ensure accuracy of the findings and analyses. Without building and sustaining these relationships through the CBRP framework, the success of these projects and their continued growth would not have been possible.

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It is important to note that when conducting CBPR with tribal communities, approvals go beyond the initial approvals to start a project. Approvals must be received throughout the life of the project, such as the tribal councils reviewing and approving any publications or professional presentations using their name(s) or data. In order to receive these approvals, the relationships are important to maintain during and after the project and to keep the community abreast of the development of the project and how the data is being used or presented. Not only does maintaining these relationships demonstrate respect, culturally appropriate and ethical research, but improves the communication and any future research projects in the region and/or community.

Conclusion - Recommendations

Over the past few years, researchers in Alaska have made significant progress in establishing trusting relationships with tribal communities, which has allowed community members to become more invested and active in community-based research. As more tribal communities come to understand the benefit of research that includes community involvement, we will see more collaborations developing between researchers and tribal communities. We have learned the value and importance of CBPR when working with tribal communities and that it requires us as researchers to work in a flexible, iterative fashion, and that this work cannot be rushed. Working with the AAIRB and regional health corporations at each level of tribal approvals cannot be rushed if it is to be done properly and everyone's interests are incorporated into the study. Through the tribal approval process we have also learned that local knowledge and culture must be respected and integrated into the research, the establishment of trusting relationships is

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crucial, and research must respect and reinforce sovereignty and self-determination. All of these lessons have demonstrated that this all takes time and patience on the part of the researcher and the community involved.

In order to respect the cultural values and traditions of each tribal community, we needed to include their knowledge, cultural values, and experiences when designing and implementing the research study. It is also important to develop and maintain relationships with the tribal councils in each community to seek their input, ideas, as well as changes throughout the life of the project. Middlebrook et al., (2001) concluded that programs work best if they are both culturally relevant and developed with major community, or local, input. Based on our experiences, we would advise working closely with the communities and tribal councils to be sure they are comfortable with the project, have been given the opportunity to provide their input, and continue to feel engaged throughout the research process. We feel it is particularly important to incorporate the culture, language, and history of the communities into the study when feasible, paying attention to the sociocultural influences on the community.

Researchers cannot effectively force change on the community; we must instead work in collaborative partnerships and build community capacity to elicit the change they want in ways that are sustainable beyond researcher involvement (CBPR Principle 9). It is important to recognize and take into consideration the special relationship (IHS, Office of Tribal Self Governance)(Allen et al., 2011) of tribal communities with the federal government and the impact this has on the overall tribal approval process. As researchers continue to work collaboratively with tribal communities, it will be important to

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remember to involve a broad range of community collaborators, such as the regional health corporations, tribal councils, Elders, and community members. This involvement should occur during the formulation of the research project and study methodology to the writing and publication of findings (Burhansstipanov, Christopher, & Schumacher, 2005).

Our last recommendation is to have patience and not rush the process. Research studies take time in Alaska, but the final products are solid in that the community, region, and State support them as being representative of their community and its members. In the end, research with Alaska Native people is about building, maintaining, and respecting relationships at all levels of the research process.

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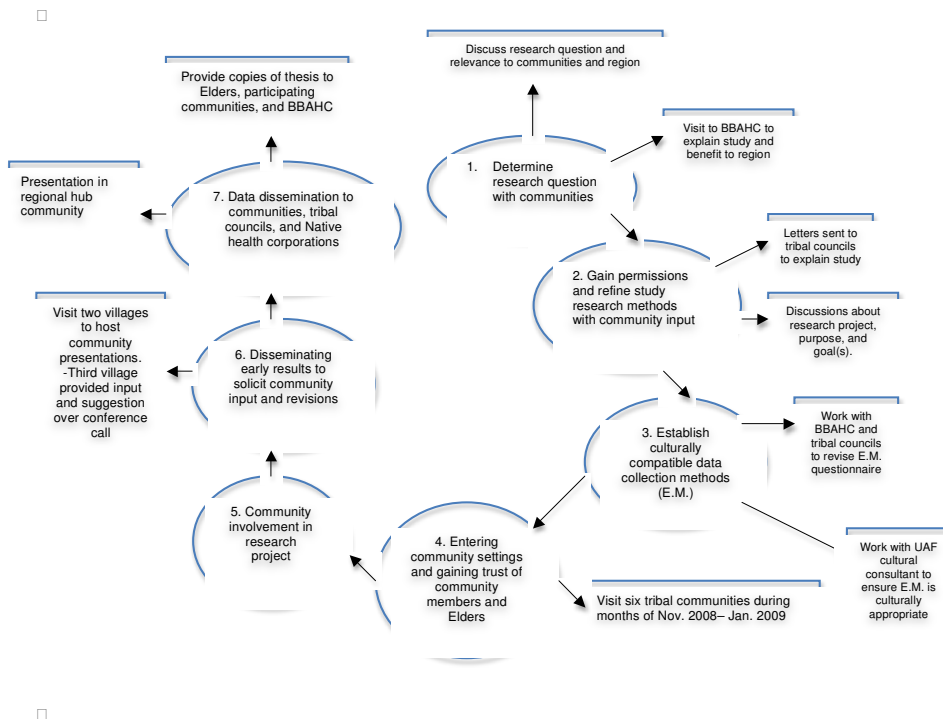
Appendix 1: Dissertation Timeline

Dates	Activity
August - December 2007	Dissertation pilot study conducted
January – March 2008	Initial meetings with BBAHC
April 2008	Project presentation to BBAHC Ethics Committee (Dillingham, AK). Project approval received (April 25, 2008)
April – June 2008	Consultation with approved tribal communities (research methods, research question, travel schedules, elder nominations)
July 2008	UAF IRB approval received
December 2008	Alaska Area IRB approval received
January – October 2008	Establish rapport with approved communities, survey development in collaboration with BBAHC and communities, fieldwork schedules arranged, tribal approvals signed
November 2008 – January 2009	Data collection in six approved communities
January – June 2009	Data analysis and write-up of findings
June 2009	Data dissemination/ three community presentations

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September 2009	Dissertation defense
October – December 2009	Edits and copies of dissertation sent to each participating community, its members, BBAHC

Appendix 2: CBPR Process: Developing a co-researcher methodology (Lewis, 2011)



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