LESSONS FROM THE RIVER: IDENTIFYING FACTORS THAT INFLUENCE THE COMPREHENSION OF GENETICS RESEARCH IN A YUP’IK ESKIMO COMMUNITY

By

Kathleen McGlone West

RECOMMENDED:

__________________________________________________
Dr. Kelly Fryer-Edwards

__________________________________________________
Dr. Kim Hopper

__________________________________________________
Dr. Bert Boyer
Advisory Committee Chair

__________________________________________________
Dr. Richard Boone,
Chair, Department of Biology and Wildlife

APPROVED:

__________________________________________________
Dr. Paul Layer
Interim Dean, College of Natural Science and Mathematics

__________________________________________________
Dr. Lawrence K. Duffy
Dean of the Graduate School

__________________________________________________
Date
TITLE PAGE

LESSONS FROM THE RIVER: IDENTIFYING FACTORS THAT INFLUENCE THE COMPREHENSION OF GENETICS RESEARCH IN A YUP’IK ESKIMO COMMUNITY

A

THESIS

Presented to the Faculty

of the University of Alaska Fairbanks

in Partial Fulfillment of the Requirements

for the Degree of

MASTER OF SCIENCE

By

Kathleen McGlone West, B.A.

Fairbanks, Alaska

May 2009
ABSTRACT

The Center for Alaska Native Health Research (CANHR) follows a Community-Based Participatory Research (CBPR) approach to study genetic, nutritional, behavioral and cultural protective factors for obesity and Type 2 diabetes in Yup’ik Eskimo communities. As a multidisciplinary center, investigators have returned results of many of their research projects to participants and participating communities. However, traditionally, genetics research results are only returned to participants under specific conditions, which are not necessarily compatible with a CBPR approach. I ask how CANHR can improve its dissemination efforts, especially in the area of genetics research. I identify factors that influence how community members receive and understand health information, including genetics information. This study uses a grounded theory approach to qualitatively analyze interviews and focus group discussions with Yup’ik community members, identify themes and construct a theoretical narrative. The primary factors that emerged include communication pathways (ways in which information is transmitted in the community); health beliefs (what people already know and believe about health); and social location (a person’s role in the community). I examine each of these through the framework of a river metaphor to provide recommendations for improving CANHR’s dissemination efforts with the communities, including genetics research results.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>SIGNATURE PAGE</td>
<td>i</td>
</tr>
<tr>
<td>TITLE PAGE</td>
<td>ii</td>
</tr>
<tr>
<td>ABSTRACT</td>
<td>iii</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>iv</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xi</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>xi</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>xii</td>
</tr>
<tr>
<td>PREFACE</td>
<td>xiii</td>
</tr>
<tr>
<td>CHAPTER 1 INTRODUCTION TO STUDY</td>
<td>1</td>
</tr>
<tr>
<td>1.1 The Center for Alaska Native Health Research</td>
<td>1</td>
</tr>
<tr>
<td>1.2 Health Disparities</td>
<td>3</td>
</tr>
<tr>
<td>1.3 Aim of This Study</td>
<td>5</td>
</tr>
<tr>
<td>CHAPTER 2 BACKGROUND AND LITERATURE REVIEW</td>
<td>7</td>
</tr>
<tr>
<td>2.1 Community-Based Participatory Research</td>
<td>7</td>
</tr>
<tr>
<td>2.1.1 Definitions</td>
<td>7</td>
</tr>
<tr>
<td>2.1.2 CBPR Principles</td>
<td>9</td>
</tr>
<tr>
<td>2.2 CANHR as a CBPR Center</td>
<td>13</td>
</tr>
<tr>
<td>2.3 What is Meant by “Community”?</td>
<td>20</td>
</tr>
<tr>
<td>2.4 The Community of Quyana</td>
<td>25</td>
</tr>
<tr>
<td>2.5 Ethics of Dissemination</td>
<td>28</td>
</tr>
<tr>
<td>2.5.1 Introduction</td>
<td>28</td>
</tr>
</tbody>
</table>
3.4.2 Participant Recruitment .............................................................56
3.4.3 Sampling Methods ......................................................................57
3.4.4 Sample Population .......................................................................61
3.4.5 Participant Observation ...............................................................63
3.4.6 Focus Groups .............................................................................64
  3.4.6.1 Overview .............................................................................64
  3.4.6.2 Logistics ..............................................................................65
  3.4.6.3 Obtaining Informed Consent ..................................................66
  3.4.6.4 Note-Taking, Audio Recording, Transcription and Translation 67
3.4.7 Interviews ...................................................................................67
  3.4.7.1 Overview .............................................................................67
  3.4.7.2 Logistics ..............................................................................68
  3.4.7.3 Obtaining Informed Consent of Participants .........................69
  3.4.7.4 Gathering Basic Personal Information ...................................70
  3.4.7.5 Note-Taking, Audio Recording, Transcription and Translation 70
3.4.8 The Interview Guide ....................................................................70
3.5 Analysis ..........................................................................................72
  3.5.1 Data Preparation .......................................................................72
  3.5.2 Analytical Approach ..................................................................72
  3.5.3 Validity and Reliability ...............................................................74
    3.5.3.1 Memoing Process ...............................................................74
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.5.3.2 Triangulation</td>
<td>75</td>
</tr>
<tr>
<td>3.5.3.3 Cultural Auditing</td>
<td>75</td>
</tr>
<tr>
<td>3.6 Reporting Back</td>
<td>78</td>
</tr>
<tr>
<td>3.7 Conclusion</td>
<td>80</td>
</tr>
<tr>
<td>CHAPTER 4 FINDINGS</td>
<td>82</td>
</tr>
<tr>
<td>4.1 Overview</td>
<td>82</td>
</tr>
<tr>
<td>4.2 The River</td>
<td>83</td>
</tr>
<tr>
<td>4.3 Communication Pathways</td>
<td>85</td>
</tr>
<tr>
<td>4.3.1 Learning About Community Events</td>
<td>86</td>
</tr>
<tr>
<td>4.3.2 Language Complexity: Three Age Groups</td>
<td>87</td>
</tr>
<tr>
<td>4.3.2.1 The Fourth Language Group</td>
<td>88</td>
</tr>
<tr>
<td>4.3.2.2 Found in Translation</td>
<td>89</td>
</tr>
<tr>
<td>4.3.3 People Learn Differently</td>
<td>91</td>
</tr>
<tr>
<td>4.4 Health Beliefs: The Water in the River</td>
<td>94</td>
</tr>
<tr>
<td>4.4.1 Synthesis of Health Information</td>
<td>94</td>
</tr>
<tr>
<td>4.4.1.1 The Yup’ik Way of Life</td>
<td>96</td>
</tr>
<tr>
<td>4.4.1.2 A Blended Understanding</td>
<td>97</td>
</tr>
<tr>
<td>4.4.1.3 Different Minds</td>
<td>99</td>
</tr>
<tr>
<td>4.4.2 What is Healthy?</td>
<td>100</td>
</tr>
<tr>
<td>4.4.2.1 Values</td>
<td>100</td>
</tr>
<tr>
<td>4.4.2.1.1 “How you live is up to you”</td>
<td>100</td>
</tr>
</tbody>
</table>
4.4.2.1.2 “When you are sick, be happy” ................................................................. 100
4.4.2.1.3 “Fighting it” ............................................................................................. 102
4.4.2.1.4 Social Bonds ............................................................................................ 103
4.4.2.1.5 “God is watching me” ............................................................................ 105
4.4.2.2 Healthy Foods ............................................................................................ 106
4.4.2.2.6 “What you are raised with is what you like.” ........................................ 107
4.4.2.3 Activity ...................................................................................................... 108
4.4.2.3.7 “It’s about being strong, not sitting around too much.” .................... 108
4.4.2.3.8 “This is a basketball town!” .................................................................... 110
4.4.3 Health Concerns ............................................................................................ 111
4.4.3.1 Cancer ...................................................................................................... 111
4.4.3.2 Diabetes and Diet ...................................................................................... 112
4.4.3.3 Social Ills .................................................................................................... 113
4.4.3.4 Honorable Mentions .................................................................................. 113
4.4.3.5 Participants’ suggestions for future research ............................................. 114
4.5 Social Location: Where a Person Enters the River ......................................... 114
4.5.1 Gender Responsibilities ................................................................................ 115
4.5.2 Leaders vs. Non-Leaders ............................................................................. 117
4.5.2.1 Elders vs. Youth ......................................................................................... 117
4.5.2.2 Elected Officials vs. the General Public ................................................... 120
4.6 Genetics: A Case Study of a New Tributary .................................................... 121
4.6.1 Current Beliefs: The Water ..........................................................122

4.6.1.1 Elders’ Ideas: The Carriers of Traditional Knowledge .................122

4.6.1.2 Middle and Younger Generations’ Ideas ..................................124

4.6.1.3 Infectious Diseases vs. Genetic Diseases ..................................125

4.7 Concluding Remarks: “People Have Different Minds” .....................126

CHAPTER 5 DISCUSSION .............................................................................128

5.1 Recommendations From the River (Figure 4.1) ..................................128

5.1.1 Knowing the Water .................................................................128

5.1.2 Where a Person Enters the River .............................................134

5.1.3 It’s About WHO, Not Just HOW the New Tributary Flows Into the River ......139

5.1.4 On Different Braids in the River .............................................141

5.1.5 Back to the Genetics Tributary ...............................................141

5.1.5.1 Emerging From the Water at the Confluence .....................142

5.2 General Limitations .......................................................................149

5.2.1 Limited Time ...........................................................................150

5.2.2 Qualitative Research in Bilingual Communities ..........................150

5.2.3 Bilingual PowerPoint Presentations .........................................154

5.3 Fieldwork With the Best-Laid Plans .............................................156

5.3.1 Time .......................................................................................157

5.3.2 Integration ..............................................................................157

5.3.3 Flexibility ..............................................................................157
LIST OF FIGURES

Figure 2.1 Levels of "community" represented as CANHR partners ........................................... 23
Figure 3.1 Map of Alaska ........................................................................................................... 51
Figure 4.1 The River ................................................................................................................... 85

LIST OF TABLES

Table 3.1 Characteristics of sample population ....................................................................... 62
Table 4.1 Found in translation: Yup'ik phrases to describe English terms ................................ 91
Table 4.2 Characteristics of someone who lives a good life. ..................................................... 97
ACKNOWLEDGEMENTS

I would like to extend my sincerest thanks to all of the people who have helped me throughout the research process, and my graduate experience. First, I would like to acknowledge my graduate committee, who has provided countless hours of advice from the development of my project to the preparation of this manuscript: Drs. Bert Boyer, Kim Hopper and Kelly Fryer-Edwards. Many thanks are due to the entire Center for Alaska Native Health Research (CANHR) team, especially Dr. Jerry Mohatt, Scarlett Hopkins, Eliza Orr, Michelle Dondanville, Dawniel Dupee, Judy Romans, Ross Newcombe, Dr. Jim Allen, Dr. Nancy Schoenberg, Dr. Elaine Drew, Dr. Diane O’Brien, Diana Campbell, Renee Pasker, Johanna Herron, and Charity Gitschel. I owe a debt of gratitude to the students and faculty of the Center for Genomics and Healthcare Equality at the University of Washington (UW), especially Drs. Wylie Burke, Helene Starks, Rose James, Malia Fullerton, and Sue Trinidad and the students at UW 2007 Summer Seminar. To the Department of Biology and Wildlife and the Resilience and Adaptation Program, I extend thanks for their financial and staff support, especially to Drs. Brian Barnes, Richard Boone, Terry Chapin, and Gary Kofinas and Ms. Carol Piser. Thanks to Drs. Phyllis Morrow (University of Alaska Fairbanks, emeritus) and to Heather Wallace (University of Kentucky) for their consultation. Thanks to the YKHC for their partnership and review of my project proposal and manuscripts, and to the University of Alaska Fairbanks Institutional Review Board for reviewing this study (#07-79). A big thanks also goes to the staff of the UAF Graduate School, who spent many hours formatting this thesis with me, and helping to make sure that I would graduate.

I must also acknowledge my family, friends, fellow graduate students, yoga instructors, local coffee shops for all of their support throughout the last few years, and my incredible husband, Dave, who planned a wedding with me while I was writing my thesis.

And finally, perhaps most importantly, thanks to all who helped me in the Quyana community: the Council members, field research assistants, translators, consultants, teachers and staff of the Quyana school, and of course, my participants. What I have learned from my gracious hosts in the community extends far beyond what fits into these pages.

Quyana!
PREFACE

My Path to Qualitative Research

With my love for Alaska, and an interest in health disparities in medically under-served populations, I found that the Center for Alaska Native Health Research (CANHR) was an obvious place for me to pursue my graduate education. In addition to providing me with an increased background in basic biological sciences, I had the opportunity, under Dr. Bert Boyer, to take part in a cutting edge area of research: conducting genetics research with a Community-Based Participatory Research (CBPR) orientation. I will discuss CBPR more fully in later chapters. I accepted the position that Dr. Boyer was looking to fill: to conduct a study aiming to learn how to return genetics research progress and results to participating communities, which is one of the principles of CBPR that he felt needed improvement in his study.

Thus, I entered my graduate study program intent on gaining more biological understanding, while learning to be a qualitative health researcher. As a student with an interdisciplinary focus, I found it challenging to fit into any particular niche on campus. Thanks to my admission to the Interdisciplinary Graduate Education and Research Traineeship (IGERT) program at the University of Alaska Fairbanks (UAF), I joined a cohort of students who were interested in learning to work from a disciplinary foundation across various fields of study, research paradigms and traditions of thought toward common goals. This seemed like a good fit for me, as I have always intuitively felt that cross-disciplinary collaboration was necessary in community health (and other) fields, and gaining more of an academic perspective on interdisciplinary training seemed appropriate for me.

As a requirement for the IGERT program, all enrolled students must complete a summer internship outside of their home discipline. I spent my internship during the summer of 2007 at
the University of Washington (UW) Center for Genomics and Healthcare Equality (CGHE), a Center of Excellence in Ethics, Legal and Social Implications (ELSI) of Research. While working with this Center, I conducted a literature review on the ethics of genetics research dissemination, how this relates to CBPR, and engaged in countless discussions about how and why we might go about doing this work. I refined the focus of my research during that summer, benefitting from consultation with the many investigators, collaborating from the fields of genetics research, medical ethics and education, communication, anthropology, and others. Together, we developed potential research plans to answer the question, *How might CANHR return genetics research progress and results to the participating Yup’ik Eskimo communities?*

As an intern with CGHE, I participated in a seminar, which reviewed the history of negative research experiences in American Indian and Alaska Native communities, and the importance of reducing health disparities in a manner that is consistent with a code of ethics that includes protection for communities. In our many discussions, CBPR emerged as an ethical approach to conducting health research in Native (and other underserved) communities in the U.S. It not only allows access to the community for the researchers, but it facilitates access to the research process for the community members, and places priority on their issues of concern as well as on direct benefit for the community partners. Our discussions reinforced that for ethical and political reasons, CBPR is the most appropriate way to approach research in the Yukon-Kuskokwim (YK) Delta region of Alaska, where CANHR engages in research. These conversations also highlighted the gap between the theoretical principles of what CBPR strives to be, and what happens in reality, namely that the varied situations in different communities hinder, to various extents, full realization of the above goals from the start of the partnership. These ideas will be addressed more fully in Chapter 2.
A Few Notes on Language

Throughout this thesis, I use many terms that are taken from the Yup’ik language spoken by the residents of the communities in which CANHR has been working. One term that is particularly worth noting is the Yup’ik word *kass’aq* that is used to mean “non-Native person.” While this term is not necessarily a term of endearment, it is widely used in the communities by both Native and non-Native people alike. I refer to myself and my non-Native colleagues, western ideas and ways of life all as *kass’aq* throughout the following chapters. The word *Yup’ik* refers to the ethnicity and culture of the people in the YK Delta. The word *Yupiit*, spelled with no apostrophe, refers to the Yup’ik people.

The word *quyana*, which means “thank you,” is the word that I chose to use to refer to the community in which I conducted my fieldwork. This word is used widely, both in Yup’ik and Inupiaq Eskimo communities, so I felt it was general enough to use without identifying the specific community. Also, in a couple of instances, I use the Yup’ik spellings of some words such as *qayaq*, which means “kayak,” without additional explanation.

Finally, I refer to adults in the community using age classifications that the local people do not explicitly use. The participants reported grouping people based on “knowledge and experience,” acknowledging that the distinct differences among adults with varying levels of knowledge and experience are correlated with age. Though the general public does not separate people according to specific age boundaries, for the sake of the research process I categorized participants into three age groups, based on the People Awakening Project’s classification
I call these age groups “young adults” or simply “young,” (ages 18-30), “middle adults” (ages 30-55) and “elder adults” or simply “elders,” (over age 56).

---

1 This project uses these age limits that were developed for research by a committee of representatives from every major Alaska Native group.
CHAPTER 1 INTRODUCTION TO STUDY

1.1 The Center for Alaska Native Health Research

The Center for Alaska Native Health Research (CANHR) is a multi-disciplinary center at the University of Alaska Fairbanks (UAF), conducting longitudinal studies situated in the Yukon-Kuskokwim (YK) Delta region of southwest Alaska (Boyer et al. 2005). Eleven Yup’ik Eskimo communities to date have participated in studies with the Center, amounting to over 1000 participants in the first five years of its existence. The Center conducts studies of genetics, nutrition, and culture/behavior using mixed methods, to “assess genetic, nutritional and behavioral risk factors” for obesity and Type 2 diabetes (T2D) by “integrating the knowledge of the Center researchers with the local knowledge of community stakeholders and residents” (Boyer et al. 2007a). CANHR follows a Community-Based Participatory Research (CBPR) approach to its development as a research center (Boyer et al. 2005). CBPR and how it applies to the CANHR project will be discussed in greater detail in the next chapter.

During the first 2-3 years of CANHR’s funding, the investigators worked to establish a partnership with the Yukon-Kuskokwim Health Corporation (YKHC), the governing body in the region that provides health care services and research oversight. They then invited local community leaders to participate in a two-day Genetics Education for Native Americans (GENA) workshop hosted by Dr. Linda Burhansstipanov, the Executive Director of Native American Cancer Research (http://natamcancer.org/) and a member of the Western Cherokee Tribe. The goal of the GENA workshop was to introduce community leaders to genetics research in general and provide a basis for evaluating the original CANHR research proposal and determining their own interests in the project. Following the workshop, several leaders chose to invite the CANHR investigators to present the proposal to their communities, of which eight out of nine invited
CANHR to begin conducting the studies in their communities. Most recently, one additional community, which did not choose to be involved in the studies initially, has signed on to the project, and two others have joined for a total of eleven participating communities.

The process that the CANHR investigators undertake to conduct their studies in this region is relatively extensive. First, after gaining UAF Institutional Review Board (IRB) approval, they submit their research proposals (and subsequently any modifications and additions to the protocol, personnel, etc.) to the YKHC Human Studies Committee (HSC) for approval. Once approved, the investigators present their proposal at a Traditional Council meeting in each of the participating communities. This presentation is given in the Yup’ik language by a local translator or the CANHR cultural consultant, Ms. Eliza Orr. Ms. Orr, a current resident of Fairbanks, was born and raised in the YK region and provides translations for all CANHR paper work, interviews, and other research related work. After the presentation, the Council confers to determine whether or not they will support the project. If they do provide their support, then CANHR investigators next present to the public at a community-wide meeting. Once the community public provides their support for participation, CANHR can begin their data collection. At each step of the process, there is communication and collaboration with local community members to ensure cultural appropriateness and acceptability that, according to CBPR theory, leads to a higher quality of science and a level of trust that cannot be obtained through traditional means of conducting scientific research with human participants. While research may be a dirty word in some communities and in other parts of the country (Smith 2005), an idea that will be discussed in Chapter 2, CANHR has attempted, through the above described process, to avoid situations that could lead to stigma, community harm and distrust of researchers by its participating communities.
From its inception, CANHR has attempted to “decolonize” the research process, to borrow a term from Linda Tuhiwai Smith’s book *Decolonizing Methodologies* (Smith 2005). This effort has included steps at each stage in the research process to share decision-making power with community representatives, to encourage two-way communication between the community members and the university researchers, building capacity for research, to ensure that the project addresses local concerns, and to maintain a trusting relationship with the communities. They aim to directly benefit the communities both in the short-term, and in the long-term (Boyer et al. 2007a). Examples of this effort follow. CANHR investigators are currently developing projects in direct response to expressed community interest surrounding cancer prevention. Community research assistants receive training and as such are able to participate directly in the data collection processes. All results are returned to the communities prior to wider publication and public presentation to ensure transparency in the research and to ensure that the information disseminated is not harmful to the community in unforeseen ways.

1.2 Health Disparities

There is a clear concern about health disparities among the various US ethnic and racial groups (Ibrahim et al. 2003). President Clinton launched the Healthy People 2010 initiative in 1998 to end these disparities completely by the year 2010 (Eschiti 2005, Grantmakers in Health 1998, Minkler and Wallerstein 2003, United States Department of Health and Human Services 1998). This concern is further articulated by the director of the Indian Health Service (IHS), Charles W. Grim, regarding disparities in health outcomes specifically among Native and non-Native people in the US: “the elimination of health disparities is an important step in accomplishing the mission of the Indian Health Service-- to raise the health status of American
Indian and Alaska Native people,” (Indian Health Service 2008). The IHS attributes the health disparities to lower economic status on average and poor social conditions in general. Jones (2006), describes in great detail the historical social and structural roots of health disparities among Native communities in the U.S., and the current persistence of these disparities.

In reporting some of these disparities, American Indian and Alaska Native (AI/AN) is a general demographic category used by many government and other agencies. However, it inappropriately lumps together disparate groups of people who experience different lifestyles, cultures, and health outcomes. Still, most health statistics do not separate these two groups, and so I report the aggregate here. The life expectancy of AI/AN people is 2.4 years less than the national average life expectancy for all races, and AI/AN infant mortality rates are 8.5 per 1,000 live births verses 6.8 per 1,000 live births for all U.S. races. In 2003, the AI/AN demographic group suffered from diabetes at a rate 1.7 times higher than the rate for all U.S. populations, (Centers for Disease Control and Prevention 2006).

Alaska Natives, as a general demographic group, exhibit rates of diabetes consistent with this statistic. However, an interesting phenomenon occurs in the YK Delta. While rates of obesity are similar to those in the rest of the United States, the rates of T2D, also known as Non-Insulin-Dependent Diabetes Mellitus (NIDDM), are currently less than 1.5%, and less than half the prevalence of the rest of the United States (Boyer et al. 2007b). While the rates are thought to be increasing in the region, there is reason to inquire as to what has protected this particular

\[\text{2 As in the AI/AN category, the Alaska Native demographic category also inappropriately combines culturally different groups of people who live in different situations and exhibit different health outcomes. However, data about individual ethnic groups are not readily available.}

\[\text{3 This paper cites personal communication with the Alaska Native Tribal Health Consortium (ANTHC) Diabetes Prevention Program (2003) for these data.}\]
population from developing the disease; why diabetes prevalence seems to be increasing more quickly in indigenous populations than in non-indigenous populations, particularly in the YK Delta; and perhaps most importantly, how this knowledge can contribute to future disease prevention.

1.3 Aim of This Study

While there is a concern for reducing health disparities in the U.S., and a movement toward decolonizing the research process through a CBPR approach, few studies have examined the return of research results (particularly genetics) to participants. Thus, for my thesis project, I undertook to address the research question posed earlier: How should CANHR return genetics research progress and results to participating Yup'ik Eskimo communities? First, I studied the theoretical and ethical arguments for doing so, with the Center for Genomics and Healthcare Equality at the University of Washington during the summer of 2007. I then conducted fieldwork during the winter of 2008, during two separate visits to one YK Delta community. Following the first visit, I familiarized myself with the community and recognized that it was premature to examine my original research question. I refocused my project on identifying steps that must be taken before we can begin asking the community regarding what they want to know about genetics research and how they want to learn it. The second visit consisted of my formal data collection: participant observation, interviews and focus group sessions. I completed a qualitative analysis of my data, and have compiled several lessons and recommendations to offer CANHR investigators for future work, specifically how to approach communicating CANHR research results and progress to participating communities.
In the second chapter, I outline the theoretical basis for my project, including a summary of the literature that I reviewed, and ethical considerations for the project. I introduce the community where I carried out my project, and discuss some of the issues in setting parameters of “who is the community” for this type of research. The third chapter resembles a more traditional “methods” section of a scientific paper, including a description of my field site, my actual data collection process and the reasons for making these decisions, and the analytical procedures used. The fourth chapter details the findings of my project and introduces a theoretical framework by which I examine the issue of genetics research dissemination. The fifth and final chapter provides a discussion of these results, suggestions for CANHR, limitations and implications for future work. I offer concrete ways for improving efforts to bring beneficial research information to the communities.
CHAPTER 2 BACKGROUND AND LITERATURE REVIEW

This chapter is intended to provide the background necessary for the reader to contextualize my project. I review the key literature that discusses community-based participatory research (CBPR). Then, I describe the issue of defining the community as one problematic aspect of CBPR. Next, I introduce the community in which I worked, providing a fairly brief sketch so as to maintain the confidentiality of the community and its residents. Finally, I discuss the ethical basis for the dissemination of genetics research to communities, and some of the issues involved.

2.1 Community-Based Participatory Research

2.1.1 Definitions

The tradition of community-based participatory research has existed for generations of researchers, in various forms. It is defined as, “a collaborative approach to research, [CBPR] equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities,” (Minkler and Wallerstein 2003). This is contrasted with the more common investigator-driven model of research, in which all aspects of the study are developed and executed by investigator. While this type of research often provides benefit to the participants, this benefit is generally defined by the investigator, who is under no obligation to ensure an ongoing relationship with or long-term benefit for the participants or community involved.

Similar approaches to research have been practiced under the names “participatory action research, participatory research, action research, mutual inquiry, and feminist participatory research,” (Minkler and Wallerstein 2003). Viswanathan et al. (2004) present a
detailed review of CBPR abstracts to provide a protocol for what is to be considered to be CBPR, methods for evaluation of such projects, suggested ways for projects to increase their community involvement, and a review of how CBPR has previously been implemented and outcomes that have resulted from these projects. They define CBPR as:

Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change. CBPR involves: (1) co-learning and reciprocal transfer of expertise, by all research partners, with particular emphasis on the issues that can be studied with CBPR methods; (2) shared decision making power; and (3) mutual ownership of the processes and products of the research enterprise, (Viswanathan et al. 2004).

In health research, CBPR is a fairly new concept, having been discussed in the literature within only the last couple of decades (Trickett and Espino 2004). Minkler and Wallerstein (2003) suggest, in the introduction to their compilation text on CBPR, that the major characteristic that sets CBPR apart from other similar research orientations is a particular focus on “the centrality of issues of gender, race, class, and culture, as these interlock and influence every aspect of the research enterprise,” especially important in the area of health research. While CBPR is still a relatively uncommon orientation to research, funding agencies such as the National Institutes of Health, the Indian Health Service’s Native American Research Centers for Health, the Lance Armstrong Foundation, and other foundations, in recent years, have been increasing their funding specifically for CBPR projects to encourage the more wide-spread use of this approach (Nancy Schoenberg, University of Kentucky, personal communication, July 18,
Burhansstipanov et al. (2005) have made the claim that many Native communities prefer a CBPR approach, and are reluctant to become involved in research projects that do not, as they often feel that they have been over-researched and yet lack the benefits from research that investigators have promised in the past. The authors also provide their recommendations to ensure that communities are truly and adequately involved in studies that claim to follow CBPR, and caution against projects that apply for CBPR funding while only offering the community a token role in the study.

While there is no single correct way to conduct this type of research, CBPR projects follow a set of principles, or values, that guide actions and decisions throughout the entire process. I will discuss these principles and how they have guided the Center for Alaska Native Health Research (CANHR), highlighting the fact that partnerships necessarily have to define their own terms under which to work that allow all partners to participate and benefit from the process.

2.1.2 CBPR Principles

Many authors have described recommendations for appropriate, participatory approaches to research with Native communities, (Burhansstipanov et al. 2005, Caldwell et al. 2005, Christopher 2005, Davis and Reid 1999, Pinto et al. 2008, Viswanathan et al. 2004, Wallerstein and Duran 2006). Israel et al. (2003) draw from a vast literature that defines the approach, to synthesize the various ideas into 9 distinct but integrated principles. While these principles are ideals for which research partnerships might aim, the authors also recognize that all partnerships will develop their terms to suit their own needs, while adhering to the values presented in the principles.

The first of these principles is, **CBPR recognizes community as a unit of identity**, meaning that all members of the community share some common identity and fate, and are not simply
defined by political boundaries. There is some emotional connection and interaction among members of a community, shared norms and values, and common interests. Secondly, *CBPR builds on strengths and resources within the community.* Strengths may be skills, observations, histories, stories, networks of trust, existing organizations or places of assembly (such as churches, etc.). CBPR works to support these existing community assets to improve the members’ ability to collaborate on improving health in the community. Third, *CBPR facilitates collaborative, equitable partnership in all phases of the research,* including empowerment and power sharing among all partners in all phases of the project. It maintains that previously underrepresented groups should have the opportunity to define their own health priorities and influence all decisions throughout, recognizing the particular expertise that community members can offer about what is needed in their own communities and what might or might not work for them. In reality, reaching true equality is complicated, particularly by the inherent inequities embedded in some of the basic characteristics of the partners involved, such as race, gender, class, and differences in expertise. Chávez et al. (2003) describe the interplay of people of different racial, ethnic, social and cultural backgrounds as a complicated dance, that is often under-recognized. They discuss the differences in privilege afforded to people of different races and positions in research, and the importance of taking this to heart when conducting community-based participatory research. “Giving advisory status without power is tokenism,” offered a community member involved with a CBPR project in Seattle (Sullivan et al. 2003). The partners should talk honestly about these inequities in order to work toward reduction in the power differences that result from these differences and to avoid the trap of tokenism in research.

Israel’s fourth principle states, *CBPR promotes co-learning and capacity building among all partners.* This indicates that researchers should learn from their community partners the local norms and beliefs, while the community members should gain skills for conducting research.
This is meant to result in the long-term increase of capacities of all partners, which should outlast the partnership itself. This does not necessarily mean that all partners are involved in the same roles and ways, as the strength in the partnership stems from the different expertise and skills brought by each partner. But all partners might be interested, and therefore should have the opportunity to, increase their skills in any of the areas outside of their own expertise. It also requires the partnership to work to accommodate the different styles, goals, interests and languages that are inherent in working with people of diverse cultural backgrounds (including people across varied academic disciplines). Starting by acknowledging and expecting that there will be differences among partners may help to improve communication. The fifth principle is, *CBPR integrates and achieves a balance between research and action for the mutual benefit of all partners.* The information that is gained in the research is used to inform social change action, as desired by the partners. The focus should be on the benefit of all partners, ensured by the translation of information for community use. As a group, and preferably early on in the process, the partners should all establish how this will most effectively and appropriately be accomplished, including how to deal with professional dissemination, and where/how to disseminate information locally. Principle number six is, *CBPR emphasizes local relevance of public health problems and ecological perspectives that recognize and attend to the multiple determinants of health and disease.* CBPR takes a broad-scale view, considering multiple determinants of mental, physical, and social health, in order to address public health issues from an ecological, holistic perspective. This should come from the community’s assessment of their own needs. However, it is important to recognize that this approach might not be preferred by communities who are more interested in more immediate change. The project may begin with shorter-term priorities and then work with the community to develop larger, longer-term priorities for change.
The seventh principle states, **CBPR involves systems development through a cyclical and iterative process.** The entire research process is to be conducted iteratively, from the development of the partnership, assessment of needs and problem definition, to the data collection and interpretation, and finally the long-term sustainability of the project. The eighth principle covers the focus of my thesis, **CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process.** This dissemination should be relevant, respectfully presented, and understandable to all partners, so that the information may be used for social action (principle #4). This is an ongoing process, and communication occurs in all directions. In terms of public or professional dissemination, all partners ideally, should be included in authorship, reviewing publications, and presenting at professional meetings. The ninth principle is **CBPR involves a long-term process and commitment.** This final principle extends from the preceding eight principles, in that it is only truly possible to adhere to the others within the context of a long-term relationship, and true commitment by all partners. As the goals of the CBPR approach include avoiding harm and negative research experiences for the communities, as well as providing true benefit in the form of change to reduce health disparities, this type of study cannot be successful unless it is intended to continue for a long period of time, as agreed upon by the partners. In forging this partnership, those involved should establish methods for ensuring adherence to CBPR principles. As the partnership develops and progresses, there ought to be measures that evaluate the extent to which these CBPR principles are followed on an on-going basis.

What does it mean to transfer all of these principles into real-life research? The answer is consistently changing, as new partnerships develop and new studies are carried out. Different studies provide different models of CBPR, and just as any interpersonal relationship has its own unique characteristics, there is no one-size-fits-all definition of what this research must look like.
After struggling for some time with the question of what counts as CBPR, I examined the CANHR partnership to understand where the Center fits within the range of possibilities for CBPR. In the following paragraphs, I address each of the nine principles presented by Israel et al. (2003) and comment on CANHR’s application of each. A detailed account of the development of the Center can be found in Boyer et al. (2005).

### 2.2 CANHR as a CBPR Center

As a CBPR center, CANHR values the active participation of both the community as well as the university researchers in each step of the research process from defining study priorities to the dissemination of research results. In order to invite this type of interaction, a level of trust must be attained over time and maintained among all partners throughout the long-term collaboration; active co-learning and communication are paramount to this endeavor. These principles rest on the belief that communities participating in research should benefit from the research and that this is accomplished through their active participation, while acknowledging the inadequacy of strictly outside “expert” opinions in community health research (Minkler and Wallerstein 2003).

I will address CANHR’s consideration of the CBPR principles and the steps that the Center has taken toward realizing how the CBPR approach has taken shape within its partnership. The first principle, the community recognized as a unit of identity, is central to the CANHR project. As identifying who is included in the community is a complicated topic, I will take this

---

4 I will explain what is meant by the term “community” later in this chapter.
issue up in the next section of this chapter, and devote to it an entire discussion. This is a fundamental piece to the CBPR puzzle, yet it is a question that is seldom addressed directly in project reporting.

The CANHR investigators and staff have established the Center in partnership with the YKHC Board and Traditional Council members in the various participating communities. They have made a long-term commitment to each other, after a period of negotiations early in the Center’s development, to continue the studies on an on-going basis, to ensure that the trust built over the years continues to grow in order to address pertinent health issues. The research process is relatively slow, as proposals must be reviewed by the health corporation board prior to initiation of the study. After obtaining approval for the overall project, the investigators present the study to individual communities’ governing councils, who represent the community members’ interests. Sharing power in this way means that all partners have opportunities to choose whether or not the project is acceptable, and if not, individual communities have the power to opt out of a particular project.\(^5\)

CANHR works with the local community members to integrate the research information into the community in a way that is meaningful to the residents. Investigators have solicited and listened to Council members’ input regarding how to present research information; they employ local research assistants to translate for them in the community, to make announcements, to consult on questions of cultural relevance, and to present information to their fellow community members. Investigators train local research assistants in research protocols such as obtaining

\(^5\) However, this does not fully address the concern of group harm on the regional level. The regional health corporation approves the research on behalf of the region, yet individual communities who choose not to participate in the research are still considered part of the region that the research affects.
informed consent, filling out demographic and pedigree questionnaires, and conducting food frequency questionnaires (FFQ). The Center also takes specific, short-term community health concerns as suggestions for inquiry on a more immediate basis than the longer-term studies. For example, in one participating community, local residents were concerned about the recent appearance of sores found on a species of fish on which they rely as food source. Although this particular issue was not a specific aim of the CANHR project, residents asked investigators during a visit to this community to test the fish to see what the cause of the sores might be, and whether the fish were safe for human consumption. The CANHR investigators present at the time contacted the Center’s wildlife toxicologist to ask him to evaluate the fish when one with a sore was caught.

As a multidisciplinary center, CANHR aims to understand selected health issues from many different angles, including the physiological, genetic, nutritional, cultural, behavioral and social determinants of health. This approach may enable the team to develop more ecologically focused health suggestions, benefiting from a broad, comprehensive perspective to see the bigger picture. At the same time that the research is underway, the participants directly benefit from the overall project. Although each individual project might not be able to provide immediate, individual results from the entire research study to each participant, as a larger center they are able to provide immediate results of their blood lipids and glucose tests, percent body fat, BMI and blood pressure. Thus, investigators provide participants with a direct benefit from their participation in the research, namely a profile of their current health status and an interpretation of what those figures mean, as well as referrals to their primary health care provider as necessary. These tests are conducted free of charge, in participants’ own communities, with immediate results, unlike other opportunities that community members which require air travel to the regional hospital to receive the same health screenings, and a period of time to wait for the
results. Additionally, participants receive a modest monetary gift to compensate them for the time that they devote to the study. They may also benefit from learning about the research to which they contribute, placing their own results in the context of the aggregate results that are presented to the community, and from the satisfaction of contributing to the improvement of their community’s health in the long run.

An additional benefit that the communities enjoy is the economic boost provided by bringing several researchers into the community who must pay for their own lodging, food, and other supplies, and the employment of local research assistants and translators. The local schools benefit from guest lectures provided to classes by members of the research team, regarding nutrition, health careers, genetics, and other topics of their interest. At the same time, the investigators benefit not only from conducting research of their interest, but also from immersion in a culture different from their own, including participating in community activities such as potlatches, Eskimo dances, berry-picking, and steam bathing. This interaction enhances the level of trust and understanding of each other as research partners get to know each other more personally, and have opportunities to communicate and learn from each other in multiple settings. This additional interaction is where a lot of communication occurs that is relevant to the research process. While anthropologists are accustomed to joining the communities they study in order to conduct their ethnographic research, biologists and other health researchers are less accustomed to doing so, and thus the importance placed on participant-researcher interaction is unique to CBPR projects in biology.

Throughout the past five years, CANHR investigators have made efforts to return research results to the communities in which they work. These efforts have included mailing out an annual newsletter to those participants who have signed up for the mailing list (which is
offered during the consenting process), as well as community-wide presentations at meetings held during a follow-up visit to the community. At this time, the aggregate results of the data are presented to anyone who is willing and able to attend. CANHR investigators advertise the meetings through all of the commonly utilized avenues in the community, and offer a door prize raffle to attendees, as community members have suggested. Additionally, these presentations have been modified from the original scientific format to include more culturally relevant symbols and images, upon recommendation of the community leaders who were the first audience for the early research presentations. For instance, when it was clear that a standard scientific bar graph depiction of the results of overweight and obesity rates in the community was incomprehensible to the Council audience, they suggested that CANHR revise the figure with more culturally relevant symbols. With input from the CANHR cultural consultant, member of the CANHR team created figures with shapes that are commonly found on the cuspuaq, a traditional shirt worn in the region. These more familiar visual symbols helped to communicate the information that was in the original graph in such a way that the Council found to be clear. This and additional examples are described in Boyer et al. (2007a). After these attempts to provide information, most of the onus is then placed on the community members themselves to assimilate that information and benefit from the integration of this with their own prior knowledge.

In order to ensure that the community benefits from the research that CANHR is conducting, the capacities of both partners to conduct the research must be enhanced and the two-way communication that would influence the transfer of knowledge between community members and researchers must be improved. This would increase the community’s ability to understand the research and would increase the researcher’s ability to understand the community’s views and beliefs about the research. Sharing a common understanding of the
multiple worldviews within the partnership thus builds the capacity of the community members and university investigators to conduct research in these communities. CANHR is interested in looking for ways to engage a broader range of community members in the process, to expand the benefits of the partnership in the communities. With increased research familiarity, experience, and trust with the research process and the research team, community members might begin to take a more active role in influencing the research directions.

These substantial achievements notwithstanding, there are several ways in which CANHR’s development has not been purely CBPR in its approach. Initially, the research question was not originally generated by the community members themselves. CANHR investigators noted a public health issue of their interest in the region, found a funding opportunity, and presented the project to the regional health corporation and potential participant communities to see if these were questions of interest to them as well. As mentioned in Chapter 1, CANHR hosted a Genetics Education for Native Americans (GENA) workshop, provided by Dr. Linda Burhansstipanov, for 40 community leaders from communities throughout the region, to help them gain the background information necessary to make an informed decision as to whether a genetics project would be relevant and beneficial to their communities. While the question did not originate directly from the communities, representatives confirmed after gaining some education on the issues, that the CANHR project was one that addressed several of their concerns.

Additionally, CANHR is working to increase community member participation in data collection and interpretation, as well as in presentations within and outside of the communities. For example, several representatives from various participating communities recently traveled to Fairbanks to become trained in collecting FFQ data in their home communities as part of a new
phase of the project. Their assistance in the data collection will both increase the number of participants that the team can include in the study, especially those who speak primarily Yup’ik, and also broaden researcher perspectives on this piece of the data collection.

The above description of the CANHR project highlights the reality that, in practice, all CBPR endeavors will necessarily look different from one another. There is no one-size-fits-all model. The specific research partnership determines which principles are to be weighted more heavily, and how they are realized in practice to suit the partnership’s own goals and unique strengths and needs. Community leaders should not necessarily be expected to become geneticists, and nutritionists shouldn’t necessarily be expected to become completely competent in the nuances of cultural norms and beliefs. The Centers for Disease Control and Prevention’s Partnership Toolkit states, “One purpose of partnerships is to bring together groups and organizations with complementary resources so that, collectively, they can accomplish a determined goal;” “One goal of partnering is to expand the expertise available to develop a solution for the problem at hand,” (Olson 2006). Each should be given the opportunity to build these skills if they are interested, but having separate sets of skills and expertise is what makes the collaboration so successful.

Just as in any inter-personal relationship, the nature of the partnership should be expected to change over time as well. Community members are, at the outset, not always experienced with research, and thus might not know they have the ability to influence the research that goes on in their communities. They might be accustomed to a more conventional model of research, and therefore won’t necessarily be inclined to bring their own research questions to investigators, as they might not know how or to whom to ask. The investigators will experience a steep learning curve in understanding the community’s needs, expectations, beliefs and strengths. But over
time, as a result of capacity-building efforts by all partners, these various skills should develop, enabling all partners to share the various aspects of the research more equitably. Davis and Reid (1999) recommended that partners participate in workshops to increase their own capacities and skills, particularly when the research question does not originate with the community. With some effort, over time, the partners will have an increased ability to take on tasks and become involved in additional aspects of the research. This is certainly the case with the development of the partnership involved in the CANHR project.

2.3 What is Meant by “Community”?  

In the CBPR literature reviewed above, authors write about the “community” and “community partners” as an integral part of the CBPR process. As an abstract concept, this sounds like a fairly simple one to grasp: one cannot conduct community-based participatory research without working directly with a particular community. However, in practice, one must define who is included in the list of “community partners,” and what scale within a given community is meant to collaborate in order for this to work. This is not always clear from the outset. In the case of a politically defined “community,” is it comprised of people who live there? If so, should they have been living there for any particular length of time? How does a researcher or partnership determine this? Does simply residing within certain boundaries imply that those people have a common stake in the research? How many members of the community are necessary to include in order to call the project CBPR, and is it practical to do so? How do these questions change for a case of a community that is not defined by physical boundaries such as the “homosexual community” or the “Red Sox Nation”? Then, is it prudent to assume that any given community would reach consensus on what their priorities are?
Defining the community that a CBPR project intends to reach is fundamental to the practicality of the study. Moreover, defining how this community can be legitimately represented by a smaller group of members is also essential for a successful research endeavor. This leads to questions not only of who represents whom, but how is this decided? How might a researcher’s allegiances impact the quality of their work, enhancing or inhibiting the participation of other members of the defined community? Sullivan et al. (2003) describe their struggles with defining community, multiple ways of defining their community, and the related (sometimes erroneous) assumptions that were made regarding each definition. In their project, they also ran into issues of overlap among partners who could be identified as members of various communities. For example, in a CBPR partnership between a community of color and a university research team called Seattle Partners for Healthy Communities, a university researcher of color could be seen as part of the university partner, or the community partner, depending on the situation and who makes the interpretation. Their solution to these discrepancies was to operationalize their definition of community, with stated involvement or affiliation required in order to be identified as one or the other partner (Sullivan et al. 2003).

In the case of the CANHR project, the community is defined at multiple levels and for multiple purposes (Figure 2.1). Most broadly, CANHR works with the community at the regional level, though because this level includes the smallest number of members, it is depicted at the top of the triangle in Figure 2.1. This level is represented by the Yukon-Kuskokwim Health Corporation (YKHC), which is responsible for overseeing medical care of area residents, as well as medical research within the region. Their Human Studies Committee (HSC) is responsible for reviewing all research proposals, presentations and publications of results prior to implementation or public dissemination. The YKHC Board of Directors makes the final approval based on the HSC review. The HSC is comprised of YKHC members, and representatives from the region’s
communities. The local governing Councils, who are considered some of the leaders in the individual cities, are the next level of “community” that partners with CANHR. Individuals elected to the Council deal with local issues such as city ordinances (curfews, dog policies, etc). CANHR investigators present their proposals, once approved by the YKHC HSC and Board of Directors, to the local Council during one of their meetings for their review and support. The Council members have the opportunity to ask questions, provide their input on the projects, the presentation style and relevance to their communities; they then may decide to invite CANHR to conduct the research in their city community. The next level of “community,” is referred to as the “community members,” or “public,” or “residents.” These are the residents of the individual city communities in general.

---

6 The word “cities” is used here to refer to the incorporated communities, over which the Councils have jurisdiction, though it should be noted that these cities are frequently comprised of far fewer than 1000 people.
Initially, about seven years ago, when the CANHR investigators were developing the Center, if the Council approved the study the investigators then presented their projects to the community members in a public meeting, after which the community decided as a whole, whether or not to take part in the study. As CANHR is now in its second phase, investigators now consult the council members for approval, before initiating the research project, though they do not expressly seek approval from the public for each new phase or aspect of the study.
On the community member level, CANHR employs local residents as research assistants, to help with translation, interviews, focus groups, and obtaining informed consent with Yup’ik speakers, as well as to help with various aspects of the project, including relevance, appropriateness and presentation for their communities. Investigators also welcome feedback and input from community members through formal evaluation questionnaires and informal discussions that are used by CANHR investigators in the on-going development of their projects. Community members, of course, also comprise the participant samples. Using the term “community” throughout the project is complicated because CANHR investigators use the term to refer to different groups in the region. The individual tribal cities are called “participating communities,” but the term “community” is also used in reference to the various levels of community in the partnership discussed above, and sometimes to the community partners as a whole, meaning all partners except the university investigators. In the absence of a more appropriate term for these multiple meanings of “community,” I will attempt to clarify the specific meaning of the term when I use it.

The first two levels of “community” are clearly defined, with unambiguous selection methods, and distinct roles. However, on the community member (or public) level, it is less obvious how those members are chosen and roles defined. In such a small, isolated location, the “community members” are defined by their residence within the city limits. By virtue of their environment and shared circumstances that define many of the options available to them, there is more homogeneity of lifestyle than one might find in, for instance, a large American city on the densely populated Northeast coast. Still, it would be erroneous to assume that because of these circumstances, people share the same concerns and interests. In my conversations with various residents of the community in which I worked, I frequently heard people claim their statements and observations were only valid from their personal experiences and beliefs, insisting that they
cannot speak for anyone else or speculate about salient concerns in the community at large. For my project, I identify themes that emerged in my conversations while also mentioning the breadth of responses that were given. I do not intend to generalize my findings to the community as a whole or to the larger region.

A research project might only gain participation from relatively few community members who are self-selected. Indeed, CANHR investigators are advised time and again to offer door prizes in order to draw a crowd at their public meetings; and though they offer substantial door prizes, average meeting attendance only amounts to about 5-10% of the total community membership. Yet, investigators have no choice but to rely on these attendees to represent the interests of people in the community. The “community” that is represented by the attendees who demonstrate an interest in the project, does not necessarily represent the community as a whole, but instead represents a particular group of concerned citizens with various reasons for participation. However, the percentage of the community members who thus far have participated in the study (about 30% of the eligible population), is larger than the group that has attended the meetings, and participation increases with every return visit. In Dr. Boyer’s longitudinal study, past participants bring their previously non-participating friends and family members to join the study, which suggests to CANHR that participants have had good experiences with the project and trust the investigators enough to want to repeat their participation and include others.

2.4 The Community of Quyana

As part of the arrangement that CANHR has set up with the YKHC and participating communities in the Yukon-Kuskokwim (YK) Delta, CANHR investigators never identify the
individual communities nor participants by name and maintain confidentiality of all involved. Thus, when reporting about projects, investigators omit any details that might identify the communities or people. Therefore, I will use the pseudonym Quyana (the Yup’ik term for “thank you”) to refer to the individual community in which I conducted my research.

Quyana is a community of less than 1,000 mainly Yup’ik Eskimo residents, located in southwestern Alaska. A rural community off the road system, it is accessed most often by small airplane, boat, snowmachine or four-wheeler if traveling from nearby communities. The community members depend largely on subsistence activities for their food and livelihood, although there are a few stores and a small cash economy, which provide a portion of their diet. Subsistence foods are hunted and gathered from the surrounding wilderness. The men fish and hunt, and the women process and butcher the catches and provide the gathered foods. There are well-defined, yet flexible roles (that they are in transition somewhat) for women and men in the region (Hensel 1996).

Like all YK Delta communities, Quyana is a dry community, which means that the importation, possession or consumption of alcohol is officially forbidden. Favorite pastimes, beyond subsistence activities, include active basketball leagues for kids and adults, Eskimo dancing, crafts and bingo. The major sources of income include commercial fishing, the local school, the Council membership, city administration, stores, gas station and health clinic employment, as well as dividends and transfer payments. Subsistence activities comprise a large portion of supplemental income and provide much of the diet.

A characteristic that further distinguishes Quyana and other YK Delta communities from many other Native communities in Alaska is that most residents are bilingual in their traditional language, Central Yup’ik, and English. Students are taught exclusively in Yup’ik generally by
Yup’ik teachers in the schools through 3rd grade, after which they transition to instruction in English (most often by non-Yup’ik teachers who move to the community from outside either temporarily or permanently). Students continue to take daily Yup’ik culture classes throughout high school. Quyana was settled around the middle of the 20th century, populated mostly by people from neighboring communities. Therefore, only people born after the middle of the century have been born and raised there. Many elders were born elsewhere and moved their young families to Quyana, or were, themselves, moved by their families when they were young adults.

Religion plays a large role in people’s lives in Quyana. The dominant religion is Roman Catholic, and there is only one church in the community. The services are given mainly in Yup’ik, with some English mixed in throughout. A choir sings hymns in Yup’ik. Homes are frequently decorated with religious statues, paintings, and other symbols. In my conversations with various community members, their faith in God was mentioned in many contexts, including health and illness.

The community gathers for various occasions, including celebrations to welcome home military service men and women after deployment, funerals, entertainment (e.g. bingo, Eskimo dancing, and watching the high school basketball team play their championship game via television at the school) and to discuss issues of concern. It is during the community meetings that research projects and results dissemination are sometimes discussed. These events are advertised by bulletins posted at the stores, school and post office; announcements over the VHF radio; and by word of mouth. Advice and prayers are broadcast over the VHF radio by elders, who impart wisdom to the public who have VHF radios in their homes (most of the population). Written health information is distributed by mail or at the clinic, and public service
announcement-type posters are displayed in public spaces, warning people of the dangers of such things as alcohol and tobacco.

Communities in the YK Delta region are considered to be culturally intact, especially in comparison with Native communities in other parts of the United States (Mohatt et al. 2007). A traditional lifestyle integrates aspects of a Western way of life, yet people maintain wide use of the Central Yup’ik language, subsistence activities, dance, crafts, and other aspects of their traditional culture (Hensel 1996, Kawagley 2006). Based on my observations, there are distinct differences among the generations, as is found in western cultures as well. This will be discussed in more detail in Chapter 5.

2.5 Ethics of Dissemination

2.5.1 Introduction

In this section, I switch gears to consider an ethical argument for disseminating aggregate genetics research results to communities who participate in such studies, despite a precedent of specifically not disseminating genetics research to participants under conventional research practices. I discuss reasons why researchers have an obligation to return their research results to participating communities, even if these results are complicated, multifactorial genetic results that do not provide any immediate benefit to the community’s health outcomes. Throughout the remainder of this chapter I present issues raised by the dissemination of genetics results to communities, new guidelines that are needed in order to address these issues, and how this relates to CANHR’s work.
In the past, genetics research projects involving Native Americans have resulted in
distrust of the researchers based on negative interactions and unethical treatment of participants’
samples. In indigenous communities around the world, the word research is laden with negative
connotations, born out of a history of harmful experiences (Arbour and Cook 2006, Ball and
Janyst 2008, Harry et al. 2000, Smith 2005). For example, the Havasupai people are engaged in
on-going litigation against a group of researchers who allegedly violated the terms of research in
which they had agreed to participate (Dalton 2004). While the standard has been to conduct
secondary analyses on de-identified blood samples, the Havasupai community who donated their
samples had only consented to be part of studies on diabetes. When their samples were used in
studies on mental health and migration theories, studies to which they object, they felt that their
rights had been violated, although the researchers had not meant any harm and believed that they
were acting in accordance with good research practices. In Barrow, Alaska, studies of alcohol
use painted a very negative picture of the community, with a problem-focused perspective. The
reports ignored the healthy, positive attributes of the community that have enabled them to thrive
and adapt to changes for centuries; instead they had the effect of contributing significantly to the
slandering and stigmatization of Alaska Natives as “alcoholics” and also led to a decrease in the
bond rating for the town (Manson 1989, Mohatt et al. 2004a). The Navajo Nation currently has a
complete moratorium on all genetics research in their communities, and has developed their own
institutional review board (IRB) through which all studies involving their people must be
approved prior to conducting the research; this stems from the Navajos’ history of being over-
researched and stigmatized (Brugge and Missaghian 2006, Tallbear 2000, U.S. Department of
Energy 2003). Several accounts have detailed the historical context surrounding the negative
experiences of various Native communities, providing explanation for the common reluctance of

In addition, there are unresolved issues of group harm and extrapolating individual research outcomes to the community level in such small, identifiable populations (Boyer et al. 2007a). In CBPR, participating communities are involved with each step of the research process, from developing the questions to be investigated to interpreting and disseminating the results (Boyer et al. 2007a). This approach to human genetics research has allowed CANHR to continue to conduct studies while avoiding situations such as that of the Havasupai tribe in Arizona.

2.5.2 The CBPR Approach

As discussed above, CBPR values reject the practice of conducting research simply for the sake of advancing science. A key aspect of community-university partnerships is the ethical, culturally appropriate, relevant dissemination of all research results back to the participating communities to ensure that all partners benefit from the project (Israel et al. 2003). Because there is, by design, considerable cross-over among participants and active co-researchers involved in the partnership, the traditional approach to disseminating genetics research results to participants (which is in place to avoid harming research participants, as will be discussed below) does not apply in a CBPR approach. Further, in addition to simply disseminating research information, the researcher has an obligation to the partnership to contribute to improving health outcomes as a result of their study. Thus, the dissemination effort should aim not only toward providing research information, but also the appropriate education and context for people to understand and benefit from knowing the results.
2.5.3 Guidelines for the Return of Genetics Research Results

2.5.3.1 Individual Results, in Short

Genetics research claims particular ambiguity in terms of ethical practices in the return of results, because it involves results that are not necessarily clinically actionable. The National Bioethics Advisory Commission (NBAC) was a federally appointed committee established in the mid-1990s to provide guidance and recommendations on a wide range of medical and scientific issues. Prior to the NBAC’s establishment, the United States was notable for being one of the only developed countries to rely on a wide variety of state-level and academic organizations for advice on bioethical public policy, instead of a centralized public body (Charo 1998). The NBAC was established by executive order under the Clinton Administration to provide such a body (Clinton 1995). In their Research Involving Human Biological Materials: Ethical Issues and Policy Guidance Executive Summary (Shapiro et al. 1999), the NBAC addresses the issue of reporting research results to participants. This document summarizes the generally accepted idea that research results should only be disclosed to subjects when “they are scientifically valid and confirmed, have significant implications for the subject’s health concerns, and a course of action to ameliorate or treat these concerns is readily available.” They assign the responsibility of determining exactly how this works in practice to the IRB at individual institutions. These guidelines limit what information is disclosed to individuals, and do not give participants the right to receive their own results from the research, with the intention of protecting individuals from harm related to uncertain, unreliable results, with ambiguous relevance or implications.

Their case is reasonably made that without the fulfillment of these guidelines, participants won’t benefit from having the knowledge of their individual genotype, and might in
fact be harmed instead (Shapiro et al. 1999). However, under the CBPR model, the research results must be disclosed to all partners in the research, both in the interest of transparency in the research process, and also as part of an on-going relationship with the participating community. Some of the research partners involved in the interpretation of overall results are also bound to be individual participants. While this does not mean that each individual who provided a blood sample has equal status as principal investigators on the project, they should expect culturally appropriate feedback that informs them of their contribution to the study and any benefits that might be derived. The complexity of genetics research and the diseases with which we are concerned presents a major roadblock to the question of dissemination. The questions that are posed here are: Which genetics research information should be disseminated to the participants? and Does CBPR necessarily mean that both individual and aggregate results should be returned?

The National Heart, Lung and Blood Institute (NHLBI) has more recently published a set of guidelines that include the return of individual research results to participants. Generally, the NHLBI suggests that only community aggregate data should be returned to participants, not individual results in the absence of clinical utility. However, it suggests that researchers should make individual data available to those who ask for it (Bookman et al. 2006). According to some, this disclosure should follow current genetic counseling standards (Shalowitz and Miller 2005).

The Belmont Report principle of respect for persons indicates an obligation to provide results to participants. It has been argued that this includes individual genetic results, in

---

7 The Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979. "The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research." Edited by the National Institutes of Health, pp. 1-8: US Government Printing Office) is a United States Government publication, which provides ethical guidelines for human subjects research. It was developed in response to a history of abuses in research with humans, such as the Nuremberg War Crime Trials during World War II. The three principles on which the Belmont Report
compliance with the idea of self-determination (Fernandez 2007, Shalowitz and Miller 2005). Yet, in doing so, it is necessary that the researcher emphasizes the many possible limitations to the results, including the scenario in which the results are not replicated, the analysis was not conducted in a Clinical Laboratory Improvement Amendments (CLIA)-compliant laboratory (thus analytic validity cannot be ensured), and that the results might only be preliminary (Shalowitz and Miller 2005).

2.5.3.2 Community-wide Results

The principle of Respect for Persons is traditionally operationalized through the practice of obtaining informed consent. However, the reality of conducting genetics research in small, identifiable populations (with high degrees of relatedness) is that there is the potential for group harm, as individual findings could have implications extending to the greater community network (Fong et al. 2006); these complexities are examined in Underkuffler (2007). Although individuals might consent to the use of their genetic data in a study, the fact that families share genetic information indicates that, indirectly, the family members’ genetic data are also being

focuses include the principles of Respect for Persons, Beneficence and Justice toward human research participants. The principle of Respect is rooted in “at least two ethical convictions: first, that individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection. The principle of respect for persons thus divides into two separate moral requirements: the requirement to acknowledge autonomy and the requirement to protect those with diminished autonomy.” The principle of Beneficence refers to the “two general rules [that] have been formulated as complementary expressions of beneficent actions…: (1) do not harm and (2) maximize possible benefits and minimize possible harms.” The principle of Justice refers to “‘fairness in distribution’ or ‘what is deserved.’ An injustice occurs when some benefit to which a person is entitled is denied without good reason or when some burden is imposed unduly.” Institutional Review Boards (IRBs) have the responsibility of reviewing all research that is carried out with human subjects through their institution, to ensure adequate adherence to the principles.
used in a study, to which they may or may not have consented to participate. Likewise, when results are disseminated from genetic studies, there is a possibility of stigma associated with certain genetic risk factors or other genetic information that might adversely affect the community as a whole (Jones 2006).

While the three Belmont Report principles are certainly indispensable for ensuring protections for individuals who volunteer to participate in studies, they do not take into account rights of communities in research (Weijer et al. 1999). In fact, Weijer and colleagues point out that the word “community” is not found anywhere in the Belmont Report. Emanuel and Weijer (2005) propose an additional consideration, Respect for Communities, to protect identifiable communities who participate in research. They suggest adding this principle to the Belmont Report, as this document is the basis for how the research system in the United States judges research acceptability. Communities, they argue, have their own interests beyond the concerns of each individual. The NBAC also recommends the acknowledgement of community consent in research (Shapiro et al. 1999), as do Chadwick and Berg (2001), in their examination of the ethics of DNA banking. CANHR, in partnership with the YKHC, has instituted a process to ensure results are not disseminated without prior community-level approval. The process attempts to address the concern over community consent by using a CBPR approach, gaining the approval of each community’s governing body, (the overall health corporation in the region), and notifying the public before proceeding with any study.

---

8 An additional issue that is worth noting, but will not be fully addressed in this paper, is the debate over Genome Wide Association Studies (GWAS) and the return of results to participants, as well as databases that make GWAS results available worldwide. There is scientific progress in compiling GWAS data in a database that may be accessed by researchers for studies beyond the original study for which the sample was taken. Having access to an increasingly large sample enables higher statistical power and comparisons across different demographic groups. However, this would complicate data ownership and control issues, return of individual results, and ethics of conducting genetics research.
In addition to the argument regarding group harm and respect for communities, the argument based on “respect for persons” is also about the researchers’ obligation to fulfill our implicit research promise that our work will benefit the participants. This is true both on an individual level, and on a community level. Individuals and communities alike are more apt to be in a position to take quicker action toward benefit when dissemination is directed to them. For example, at the YKHC level, health care providers may act on information regarding diet pattern shifts among various age groups in the region; On the individual level, participants may be able to change their behavior based on nutritional information received directly. Such responses would not be possible if communities or individuals waited for a scientific publication to influence policy and practices, from which any benefit would not necessarily be timely or guaranteed.

2.5.4 Paternalism and Concepts of Risk

While a paternalistic approach to medical care was once a standard given the differences in education and skill between doctors and patients, this approach is increasingly considered to be depriving patients of their right to self-determination and autonomy in decision-making about their own health (Kittay 2007). The assumption that the provider knows all factors that the patient would take into account when considering their treatment options is fallacious, and has been replaced by notions that the patient should be educated with the information needed to make his or her own decisions. When working with communities of a different culture (broadly defined) than one’s own, including people of different economic or social class, race, gender, education, geographic residence, and so on, scientists ought to acknowledge that ideas about what constitutes risk are specific to people of different cultures, and simply, to people of different
perspectives. Because the concept of risk is based on what a person values, it would be erroneous to assume that one can impose one’s own concept of risk on another.

One example of disparate concepts of risk between healthcare providers and community members took place in an Inuit community in northeastern Canada. In this case, a new law required women to leave their home in rural communities to give birth in a city hospital (Kaufert and O'Neil 1993). According to the doctors’ perceptions, the biggest risk to consider was the physical health of the baby and mother during the birth, to the exclusion of some other considerations; and they believed in good conscience that the best way to protect the patients was by mandating hospital births. However, the women and their families’ concepts of risk included loss of traditional knowledge and sense of community that was fostered by birthing babies near home, with the support of their communities and their own midwives. This loss was a greater risk than the possibility of severe complications in childbirth, many of which they had traditional means for addressing.

In the case of CBPR, the researcher has an additional obligation to share research information with community partners. Much of the research information is indeed difficult to communicate and understand if one is not a geneticist. There are nuances, huge uncertainties (some of which are possibly just noise in the data), and potentially harmful information that might be seen as best kept from the participants. So, there is an ethical obligation to provide the education necessary for the non-geneticists to understand these issues. Once there are results to share, the decision about what information is shared with the community at large must be made collaboratively among research partners. The university researchers must be transparent in their assumptions surrounding their information and recommendations, such that the decision-making power that traditionally rests with the researchers is transferred to the community partners.
2.5.5 Positive Examples of Genetics Research with Communities

Next, as there are not yet examples of disseminating genetics research in CBPR projects in the literature, I mention a couple of examples of CBPR research projects that make special considerations to include protections for communities. In the first example, the research partnership placed ownership over the DNA samples with the community members, thus ensuring more equitable power-sharing within the partnership (Arbour and Cook 2006). While this example is about data ownership and control, and does not address dissemination directly, it is a model for taking steps toward equitable partnering in genetics research. In the second example, I review Minore and colleagues’ experience (Minore et al. 2004) with community-based education for building research capacity within the partnership, enabling collaborative interpretation of the data. While there is a dearth of literature detailing the return of genetics research results, there are examples from the CBPR literature from which genetics research projects might draw regarding individual and community aggregate results of health studies.

Arbour and Cook provide an example in which the research partnership considers the participating communities to be the owners of their DNA, and the researchers who use it do so under the terms of a loan (Arbour and Cook 2006). The terms of their partnership place the responsibility and right to own and control the data with the community alone, thus upending the tradition in which the researchers have had primary power over the data they collect. By negotiating community ownership of the data and by placing the responsibility of stewardship over the data with the researchers, the embedded expectation is that the community interests and benefit are of primary importance. The samples will be treated in accordance with the community’s wishes, and any results will be provided in partnership with the provider for their own use and the partnership’s use. This “DNA-on-loan” arrangement ensures that the default is
equitable power sharing, in contrast with other research arrangements in which power sharing is more of an uphill battle.

A second example is detailed in a paper from the Center for Rural and Northern Health Research (Ontario, Canada), showing how its research results were disseminated. In summary, the research team collected their results (generally chart review, meetings and interview data) regarding the “delivery of oncology, diabetes and mental health care, specifically, as well as systems issues such as recruitment and retention of health human resources and financial costs” in aboriginal Canadian populations, with a community-based research approach (Minore et al. 2004). As part of their agreed-upon research design, a two-day workshop gave 20 community members and community healthcare providers an opportunity to interpret the research findings with the university researchers. The first day was a discussion of the findings, while the second day was dedicated to devising a list of recommendations for Health Canada and tribal leaders’ activities aimed at returning results to positively impact health outcomes. The foremost obligation of the researchers was to ensure that the work benefited the community, and doing so meant involving the community at every step of the process, including interpreting and disseminating the results for their use. While theirs was not a genetics research project, their process might provide a model for collaborative genetics research dissemination.

2.5.6 Time for Collaboration

Many indigenous communities around the world have developed policies regarding research in recent years. Many of these have consisted of the CBPR principles, including the requirement that the community be involved with the interpretation and dissemination of all research results, in which any report of results must be approved first through the communities
before going to broader publication. Again, the Navajo Nation has created its own IRB, outlining terms by which research may be conducted with their community members (Brugge and Missaghian 2006). The Canadian Institutes of Health Research (CIHR 2007) has also published guidelines for conducting research with indigenous populations in Canada. The time has come for collaborative research partnerships between university investigators and identifiable communities. Genetic research partnerships especially, require education, capacity-building, and true dedication to mutual respect and power sharing.

2.5.7 The Next Questions: *What? and How?*

The partners must ask themselves what type and amount of information is appropriate to deliver to the participants, which will minimize their risk for harm and community stigma, while respecting their right to be informed throughout the process. This must take into account the various levels of utility that the results can offer: from being directly clinically relevant to the care of individuals, to the results that would be relevant to the health care delivery system as a whole, to results that appear to only have relevance for continued research, honing in on the genetic markers that might eventually offer clinical applications in the future. Then, once that is determined, the next step is to learn how to accomplish this in a respectful, relevant, comprehensible manner that fosters two-way learning on the part of the researchers and the community.
2.5.7.1 What

Depending on the terms of the individual partnership, it is often the responsibility of the researchers to conduct the analysis and initial scientific interpretation. They present the findings to the community partners, then discuss further interpretation of the results and determine what will be relayed to the community. The community may have specific rules, written or unwritten, about what information should or should not be discussed publicly, for example, cultural taboos, or information that will harm the community in ways unknown to the university researchers. For example, in the community of Quyana, as I discuss in Chapter 4, I learned from my research that traditionally, predicting a disease or discussing a person’s susceptibility for disease was akin to inviting the disease. So, it was understood that people should not predict diseases. However, one aim of genetics research is to identify individual risk levels for diseases, thus enabling people to predict disease, to some extent. While participants have the right to know information that researchers learn, they also have the right not to know any undesirable information. Presumably, the community partners possess the particular expertise to be in the best position to determine this distinction.

The nature of genetics research is such that often results are not actionable in the short term. Yet, it is the responsibility of the partnership to maintain on-going contact and transferring of knowledge between the community and the university researchers, and it is an aim in CBPR to build research capacity among all partners. Therefore, it may be more tenable to provide progress reports, rather than individual results, or definitive results. This leads to issues regarding the uncertainty, reproducibility and clinical validity inherent in any results of genetics research. Researchers might not know now, or they might never know, the relevance of any particular result. In order to provide progress reports, they must understand how the community members view uncertainty of information, and what interest they might have in either learning or not
learning this information. In some cases, people might want to know even uncertain information, as they might choose a conservative course of action. For example, if a woman learns that she has a genetic variant that may be associated with insulin sensitivity (though the association is not confirmed), and it is modified by certain nutrients in one’s diet, that woman might be more likely to prioritize her behavior changes in favor preventing the disease for which she might be at higher risk. However, if she learned that she has this variant, but it is unknown what she might be able to do to prevent the disease, will she still want to know the result? For some people this knowledge might cause unnecessary stress, and so might be considered best left unsaid.

Necessary to a complex dissemination effort is an educational effort. That is, the investigators in the research must share with the community enough background information to understand the results as well as possible without attempting to turn them into geneticists. The same is true for the community representatives in the partnership, whose expertise lies in their local knowledge, and who should not be expected to necessarily want to learn as much about genetics as the investigators. Indeed, this is the strength of the partnership concept, with each partner bringing his or her own expertise to the project. However, in order to understand the issues and nuances involved in the results, and in order to broker this information between the investigators and the rest of the community, co-learning must take place, in which the investigators also become educated by the community experts. With this level of collaboration, a process for managing alternative interpretations of the same data must be in place. What should the partners do if the community sees something that the researchers do not, and vice versa? Whose interpretation takes precedence? This decision-making process is on-going and includes education about the issues that are embedded in the complexity of genetics research. The partners communicate the potential genetics information that might be available, and what available
information the community partners conclude would be desirable or beneficial for wider dissemination.

2.5.7.2 How

Once it is determined what kind of information the community wants to learn, it is necessary to figure out how to provide this information in a way that will be relevant and helpful to them. These two steps, “what” and “how” are not necessarily separate and sequential as I treat them here, but integrated and iterative, as is the case in all CBPR work.

Once the content of dissemination and the accompanying education have been determined, the approach and format of the product must be developed. The community leaders or a representative group will be instrumental in developing the appropriate means for presenting the findings they have agreed to share. For example, if results eventually point to action, and show that people with certain genetic variants particularly should not eat excess sugar, but the partners want to avoid this stigma or potentially culturally unfeasible avoidance of candy, would it work to instead focus the intervention on positive recommendations? Instead of saying, “don’t eat candy,” can we say, “do eat (culturally appropriate alternative) to improve health”? Or, how can we fill the cultural role that candy might play in the community, while focusing on solutions, on what works, not what we’re trying to get away from? The specific format and avenue through which the information will be disseminated must be established, again in collaboration with the community representative body, keeping in mind the many different ways in which people learn and have access to information (which I will discuss in Chapter 4). Then the product might be vetted through focus group sessions, much like in market research before resolving a final version to pilot with the community residents.
2.6 Conclusion

This chapter has provided many pieces of background information that will assist the reader in understanding the context for the rest of this thesis. With a preparation in the basics of the CBPR theory and how it applies in the CANHR project, the community in which I conducted my research, and some of the ethical considerations surrounding this work, the reader should be able to navigate through the remaining text, to challenge and question my work, and to gain an enriched understanding of community-based research practice through the CANHR case study.
CHAPTER 3 METHODS

3.1 Qualitative Research, in Short

As I anticipate that my audience is more familiar with quantitative research than qualitative research, I begin this chapter with a short primer on some of the major concepts that will be necessary for the reader to understand in order to evaluate my work. Throughout the report of my methods in this chapter, I continue to highlight some qualitative research concepts, in particular the “grounded theory” approach (the process of developing theoretical constructs that are rooted in textual data), as they arise, as I make the case for adopting this methodology in my research.

In an informative volume by Auerbach and Silverstein (2003), the authors explain that grounded theory analysis is most appropriate for a hypothesis-generating research design, rather than a hypothesis-testing research design. Through qualitative research, an investigator is able to generate hypotheses about a particular research concern (note that this is not the same as an explicit research question), that is grounded in actual data from participants’ own words; and thus it is more concerned with “questioning rather than measuring” the data. In this section, I summarize some of their thoughts about qualitative research.

Given that qualitative inquiry examines participants’ subjective experiences, beliefs and attitudes, it is inappropriate to try to impose “objective” measures, such as numerical scales, onto these experiences. Without knowing some of these subjective realities, it is impossible to know

---

9 For example, a research question might be “What are the factors that impact a Yup’ik community member’s understanding of health research?” while a research concern is a more general idea of what the investigator wants to learn, “How do we improve our dissemination efforts?” The research question develops out of the research concern throughout the research process.
how to appropriately ask questions that can be measured quantitatively. By conducting qualitative research, we can better understand which variables would be relevant to our research concerns. Again, as this research is intended to understand subjective experiences (about which the participant is the expert), it is important to gain contextual information and to remain open to listening to participants’ complex, detailed thoughts, while recognizing that many concepts are interconnected. Prematurely reducing experiences down to a simple, quantitative scale risks losing the richer details and nuances, and thus the deeper meaning of the data. Further, the textual data that are sought by qualitative researchers cannot be obtained in numerical form.

When working with humans in studies about beliefs and experiences, the assumption that one makes is that it is more likely that people’s experiences, behaviors, and beliefs are diverse rather than homogeneous. Thus, in qualitative research, one does not aim to generalize the human experience, but to highlight the variety of experiences, including differences among and within defined groups of people.  

Qualitative research allows for subjectivity in data collection, given that subjectivity and values are endemic to human interactions. It is impossible to eliminate our own values and perspectives as researchers, as in Bourdieu’s concept of *habitus* (Bourdieu 1990), so it is preferable to acknowledge them and examine our positions specifically as they relate to our research. This practice is known as *reflexivity*, and writing about it transparently is an important aspect of qualitative research, as it enables us to identify our personal biases, and others to evaluate our research more effectively. Throughout the remainder of this chapter, I describe the

10 Quantitative research in the social sciences possesses other strengths, including statistical power and significance of findings, and collecting data among a large, random sample of the population of interest, which allows for generalization of the findings to the whole population. However, designing this type of study requires knowledge *a priori* about the population and research interest, which qualitative research can inform.
process of my study, from entering the community to conducting my analysis, based on the concepts described above. I include additional conceptual descriptions as necessary throughout the text.

3.2 From Entry to Analysis

During one week in March 2008, I visited one of the Center for Alaska Native Health Research’s (CANHR) participating communities, which I call Quyana for the purpose of maintaining our confidentiality agreement with Yukon-Kuskokwim Health Corporation (YKHC) and the community. I spent six days living as part of the population, sleeping in a small room at the only school, and cooking meals in the teachers’ lounge kitchen. This lodging afforded me the flexibility to conduct participant observation, coming and going as I pleased, and to spend time with many different community members in the midst of one of the central meeting places for the community. Being stationed in a public space, I was also available to potential participants who simply stopped by to talk with me, which was particularly advantageous, as I did not have a phone by which residents could contact me. In my conversations, including formal interviews, focus groups and participant observation, I attempted to gauge the status of the community, in terms of their current understandings of health, research, the CANHR partnership, where they would like to see it heading, and which aspects of the research they want to learn more about.

After I gained University of Alaska Fairbanks (UAF) Institutional Review Board (IRB) approval, I sought and obtained approval of the YKHC Human Studies Committee (HSC) and Board of Directors to conduct my study. Next, I traveled to the community of Quyana and
presented my proposal to the Traditional Council to gain their support, as well as informally to
the city mayor to gain his support on behalf of the City Council.\footnote{The project was initially introduced to the Council by Dr. Boyer and Ms. Hopkins during a prior visit, as the project is an extension of Dr. Boyer’s work.} It was only after this lengthy approval process was complete that formal data collection could begin. I presented my project to the public at a community meeting, during which I also recruited participants. I conducted interviews with fifteen participants (eight in English, and seven in Yup’ik through a translator), and held two focus groups with a total of eleven additional participants. I also relied on participant observation to gather additional contextual information during the week that I spent in the community. With a grounded theory approach, I analyzed the data for themes both by hand and then also with the Atlas.ti (version 5.2) software program.

In this chapter, I will describe, in a step-by-step fashion, methods I used to conduct this study. As I discuss each step, I will lay out the reasons for my methodological choices, made based on the realities and constraints of my situation. I will explain what might have happened in a best case scenario, and the challenges and constraints that I encountered, which made it difficult for me to adhere to these ideals.

3.3 Getting Set-up

3.3.1 Gaining Entry

Once approval was secured from both the UAF IRB and the YKHC Board of Directors, I began making plans for travel to the community for fieldwork. Working closely with Ms. Scarlett Hopkins, R.N., M.A., the field research coordinator for CANHR, we obtained a place on
the Traditional Council’s agenda for that month’s meeting. Ms. Hopkins’ extensive field experience and connections with various leaders and members of the community, as well as CANHR’s 5-year history of work and trust in the community, enabled me to gain entry fairly easily. In addition, having visited the previous fall, several community members and I were already familiar with each other, which also seemed to help my recognition in the community.

A major advantage that CANHR can offer to a student researcher is infrastructure and familiarity in the communities. Entering as an extension of Dr. Boyer’s project provided a starting point for me in the community, a reference when justifying my position there, and gave me a foothold without having to start from scratch to gain legitimacy. The trust that has been built over seven years of CANHR development provided a platform for my introduction. At the same time, because of the groundwork that has been laid by the Center, however, it was particularly crucial that I act cautiously, spend more of my time listening rather than talking, and observe local norms and behaviors. I wanted to be sure to show my genuine respect for the community and culture, as I represented myself, research and perhaps most importantly, the Center. I wanted to be exceptionally mindful to extend the relationships built by CANHR, rather than to compromise any of this trust.

Paramount in this process was Ms. Hopkins’ knowledge of the regional culture and norms. Having limited experience in this community, I found myself relying on Ms. Hopkins’ knowledge and intuition, which is something that cannot be taught outside of the rural community setting. One might only learn how to function in the community, when to press an issue and when to back off, whom to consult about a particular issue, and how you might offend people, 

\[\text{12 Dr. Boyer’s project is an NIH-funded study aimed at identifying genetic risk factors for obesity and how they are modified by environmental factors such as diet and physical activity.}\]
through extended periods spent in the area. Developing intuition about situations comes from direct experience, and hence anthropologists have traditionally spent at least a year in the field during ethnographic studies. As this amount of fieldwork was not part of my program, having Ms. Hopkins by my side for the first part of the week was invaluable. Once I began to feel more familiarized and made some connections of my own, I felt comfortable staying for the remainder of the week after she returned to Fairbanks.

To recap, the process of gaining entry into the small, rural Yup’ik Eskimo community in the YK Delta region was facilitated by the connections and previous experience that CANHR has in these villages, in addition to my previous visit to the community prior to designing my study. However, one potential disadvantage should be mentioned: being connected with an existing institution was the risk that the community might already have preconceived ideas about a new person entering, and they might not all be positive. This was not obviously at play in my work, but I cannot exclude the possibility that some people might have avoided me because of my affiliation with a center that they might not approve of outright, or harbor some suspicions about, and thus I would not be able to engage these people in my project. Another disadvantage to having already met and talked with some community and Council members was that some seemed reluctant to talk with me in a more formal setting, this time on the record. One participant expressed that talking formally and on tape provides an added level of stress and requires extra care with the words that one chooses; consequently he thought that some people might not be as willing to speak formally as they did informally. Although I tried to schedule an interview with one City Council member with whom I had had a lengthy and interesting conversation during my first visit, many factors prevented us from meeting again for a formal interview; and this precluded my gathering usable data from him. Although these initial
discussions very strongly guided my project development, I cannot include them in the data that I collected.

3.3.2 Traveling

As travel is a significant aspect of conducting research in remote Alaska communities, I should briefly report the process and experience of travel that I encountered during the course of my fieldwork. Ms. Hopkins initially phoned the Traditional Council administrator to request a place on the agenda for their upcoming meeting at least a month before we had HSC approval to conduct my research. Originally, he agreed to put us on the schedule, (provided we successfully gained HSC approval) to present our proposed project for their support, as required through CANHR’s arrangement within the partnership; but he informed us that we should not plan to begin data collection during the same visit, as Council support was not guaranteed. We would stay in the community for a few days to present to the Council, and then we would have to return to Fairbanks for as long as it took for the Council to consider our proposal and to arrange another trip for data collection. However, once we had gained HSC approval and Ms. Hopkins called to confirm our place on the agenda, the administrator informed us that we would, in fact, be allowed to begin data collection during the same visit, provided the Council agreed after hearing the proposal. This meant that I suddenly had less than two weeks to prepare (logistically and mentally) for collecting all of my data.

It is worth mentioning at this point that an additional, significant factor in traveling to rural Alaskan communities is the high cost. In addition to the nearly $1000 price tag for air travel (which is unavoidable), it costs $50 per person per night to stay at the school (there are no hotels in the small communities); and all other expenses in the communities, including food, fuel and gifts that we provide our participants, are roughly double those costs in the state’s urban areas. If
the weather is unsuitable for travel in the small bush planes (as is often the case during winter travel), then the cost of the trip includes additional nights in the school or at a more expensive hotel if grounded in Bethel, the hub community in the region (Figure 3.1). The more we are able to decrease the number of trips that are made, the more cost effective the project will be, and the more money that will be available to put toward other aspects of improving the overall study. Thus, it was particularly important that I was prepared to collect my data during the approval visit.

Figure 3.1 Map of Alaska. The Yukon-Kuskokwim Delta region (with cities on the route for commercial air travel from UAF to the YK) are shown.
The travel coordinator for CANHR scheduled our flights, and Ms. Hopkins contacted the school administrative assistant to reserve overnight space at the school for both of us for the duration of our stay, as is customary. She also ordered a box of fruit for snacks that we would offer to our participants, which we would pick up from the grocer in Bethel during our brief scheduled layover. Ms. Hopkins and I flew from Fairbanks to Bethel, via a stopover in Anchorage on a commercial airline. From there, we planned to take a small bush plane to the community. Upon our arrival in Bethel, we learned that most of the bush flights had been cancelled due to stormy weather, again as is common during the winter months. To our delight, we boarded a six-seater plane and started the hour-long flight to our final destination. About 30 minutes after take-off, however, the pilot regretfully informed us that we would have to turn around due to a shift to poor visibility on the receiving runway. We spent that first night in a Bethel hotel, after making a trip to the local grocery store to pick up supplies for our meetings (including the pre-ordered box of fruit), in order to save shipping costs to the community. In the morning, we took an early taxi to the tiny airport, boarded the plane which was packed full with store orders, supplies, and the community’s mail; and we headed out through beautiful, clear blue skies.

On the ground, we were greeted by a local agent, who agreed to transport us and our gear to the school by snowmachine, as the only truck-friendly road between the airstrip and the center of the community (and one of only a few roads) was buried under several feet of snow. We checked into the school, amidst approximately 200 students (kindergarten through high school) and teachers, going about their usual daily routines, friendly and unfazed by our presence. We settled into an extra office on the upper level of the school, which we were fortunate to have, as it provided us with a secure room in which to sleep and store our gear. Our week’s worth of food that we had brought from home was to be kept in the refrigerator in the teacher’s break room. We
were also lucky to have access to the school showers when the kids were not present. In this setting, we enjoyed the use of a full kitchen with refrigeration, water, electricity, and bathrooms. When visiting the rural communities, however, these amenities are never a guarantee, so it’s always wise to plan accordingly.

### 3.3.3 Traditional Council Approval

Once we were settled, the first appointment was with CANHR’s local translator and life-long resident of Quyana, Darla,\(^\text{13}\) to discuss the PowerPoint presentation that she would give in Yup’ik later that evening at the Traditional Council meeting. Darla joined us in our school office, where I explained each slide and clarified my project plan with her, so that she would understand what I wanted to convey and so she could advise me on the style, comprehensibility, and wording of my presentation and interview plan.

That evening, we all met once again in the multipurpose building, where eight male Traditional Council members gathered to begin their meeting promptly at 7pm. We set up our computer and projector so that we could show my PowerPoint presentation that I had judiciously crafted for this meeting. After the opening prayer, Rules of Order governed the discussion, which was conducted mostly in Yup’ik. Darla presented my slides, translating each line into Yup’ik. I realized that for as much as I tried to decrease the number of words on the slides, the presentation was still too verbose. If I had been presenting, I would have naturally paraphrased what was on the screen, rather than read it word-for-word, as was the only option for a translator who did not write the presentation. The Council previously had expressed a preference for having a local interpreter present in Yup’ik, instead of having an English-speaking university researcher present.

\(^{13}\) Names of all community members and communities have been changed to protect confidentiality, in accordance with an agreement between CANHR and the YKHC.
and then having the interpreter translate throughout. Complying with their request afforded me the opportunity while listening to the Yup’ik translations of my slides, to watch the faces of the Council, and to realize which slides were probably superfluous for my audience.\textsuperscript{14}

At the conclusion of the presentation, the Council members held a brief discussion in Yup’ik, asked Darla a clarifying question, and finally replied that they would support the project. They signed a letter of support for us, which they found gratuitously formal, as they’d already shown support for CANHR projects. My final request for Darla that evening was to propose a focus group with the Council members for the following day, as was mentioned on my “proposed methods” slide that she had presented. Their reaction was laughter and some comments in Yup’ik, after which Darla left the building without conveying to me their reply.\textsuperscript{15}

3.3.4 The City Mayor Approval and Space Reservations

Often, the two governing councils in the community gather in a joint meeting, enabling CANHR researchers to present to all members at the same time. Since this month’s meeting was not a joint meeting, we did not have the opportunity to gain the full City Council’s support.

\textsuperscript{14}For example, I’d received advice from another university investigator who worked in the communities to include some personal information to introduce oneself and one’s interest in working in the community. Although no one said anything to me about the presentation, I felt that they didn’t take to my talking about myself quite as well as the community did in the other investigator’s experience. Specifically, my intuition said that giving background about myself, my interests and my connection to the research topic (diabetes) was probably unnecessary.

\textsuperscript{15}Upon following up with Darla about this situation, she said that they were laughing, unrelated to my request, because of a joke between Darla and one of the Council members, who is her “teasing cousin.” The relationship between teasing cousins is one of public joking and light-hearted teasing of one another. More has been written on this familial relationship in Dr. Phyllis Morrow’s work (Morrow, P. 1987. Making the Best of Two Worlds: An Anthropological Approach to the Development of Bilingual Education Materials in Southwestern Alaska, Cornell University.). The Council members were too busy during my visit to take part in the study.
Instead, we sought the project endorsement from the city mayor, representing the City Council. We visited the city offices the morning after our Traditional Council presentation, and met with the mayor, a friendly man in his early 50s. After describing my project to him informally (and as the City Council had already been introduced to the project by Dr. Boyer and Ms. Hopkins at a previous visit), he agreed to support the project and sign our letter.

While visiting the city offices, we also reserved the city’s community hall to use for our focus groups the following day, including the use of the Council’s coffee maker (a must for any community gathering). Earlier that day, we had talked with the school administrators to tentatively reserve the large common room at the high school in the event that our project would be approved and we would be allowed to present to the community that evening.

3.4 Data Collection

All data were collected according to the agreement between the partners in CANHR, the YKHC, and the people of Quyana. The Community-Based Participatory Research (CBPR) approach that guides this partnership is explained in Chapter 2.

3.4.1 Overview

The data were collected between March 3 and March 10, 2008 in the community of Quyana. Interviews were conducted in English or Yup’ik through a local translator, and audio recorded and later transcribed. Yup’ik interviews were translated into English by Ms. Eliza Orr, at the University of Alaska Fairbanks. A codebook was developed, adapted from the method outlined by MacQueen et al. (1998). A grounded theory approach was used to develop
theoretical constructs from the textual data (Strauss and Corbin 1994). The theoretical constructs were then integrated into a theoretical narrative to address my research question.

3.4.2 Participant Recruitment

With the support of the Traditional Council and the mayor, we began advertising our community meeting using the standard means that CANHR researchers (and local residents) generally use: VHF announcements and posters. We asked Darla to make announcements in Yup’ik on the VHF radio that would be transmitted to nearly all homes, once in the morning, once around lunchtime and once just before the meeting time, which would coincide with dinnertime. We posted IRB-approved flyers at the stores, post office and school (the three most commonly visited public spaces), as well as in the city office building, to invite people to the meeting and to participate in the study.

I presented at the community meeting in English, as Darla confirmed that all of the approximately 30 audience members present were comfortable hearing presentations in English. As it is a small community, she was familiar with everyone who attended and their comfort level with English. She also felt that the audience would appreciate hearing me present. After I gave my PowerPoint presentation to the community members, (about which I felt comfortable, knowing that I was able to paraphrase and adjust my explanations of the slides on the fly, and to use body language to express complexity of ideas) I offered a sign-up sheet for both the focus group meetings and the individual interviews. In addition, some community members who attended the meeting later stopped by my office at the school to volunteer to participate. The elders who were interviewed were recruited by local residents who learned about the study and suggested that they participate.
3.4.3 Sampling Methods

A nonprobabilistic sample was sought for this study, as is common in qualitative research. I used convenience (recruiting whomever the researcher has access to that suits the sample criteria) and purposive (recruiting participants with particular characteristics of importance to the study) sampling methods to acquire my list of participants (Bernard 1995b). My recruitment criteria simply stipulated that participants must be current, full-time residents of the community, age 18 or older, as well as, unofficially, they must be available to speak with me during my stay. I was interested in hearing what the general public had to say about the research, since we are concerned with reaching out and disseminating the research information to the community at large. I only wanted to enroll adults, as enrolling minors in research adds several steps and layers of protections that I did not have the time or ability to work with. In an ideal scenario, I would have held discussions with local youth, as teens as young as 14 years old are included in the CANHR study population overall, and could provide additional, informative perspectives. However, given the time constraints and scope of my project, I elected to restrict my sample to adults only. Gaining input from youth would be an interesting next step in the research process, both to include in a comparison of themes across age groups, and to gain their perspectives on the role of youth involvement in research dissemination.

The size of a sample population in a qualitative study depends on the concept of theoretical saturation (Glaser and Strauss 1967, Guest et al. 2006). Because it is based on subjective experiences of unforeseen variation, the sample size cannot be determined in advance, as is feasible in quantitative research. There is no functional equivalent to a power analysis in qualitative research. As a researcher interviews new participants, new concepts are added to the data set. Grounded theory methodology suggests that the researcher continue interviewing participants until, on examination, no new concepts are being added to the data set. So, the
sampling stops once new participants are not contributing any new information. The frequency of particular responses is not of concern, but the diversity of answers is. The sampling that is associated with seeking theoretical saturation is done to “discover categories and their properties,” for development into theory (Glaser and Strauss 1967). Adequacy in this type of sampling is judged based on “how widely and diversely the analyst chose his groups for saturating categories according to the type of theory he wished to develop.” The skill required for this type of sampling requires flexibility, time and practice to develop. In the following paragraphs, I explain the merits of the sampling methods that I have used, for my theoretical purposes, in contrast with quantitative methods.

The convenience and purposive methods were sound sampling methods for my purposes for the following reasons. First, my purpose was not, as is the case in the biological sciences, to collect a randomized sample and provide a generalizable set of data that I could use to extrapolate to the rest of the region or beyond. Instead, I intended to learn about various ideas and stories from interested community members. Given the short amount of time I had available to do my work, I did not have the time to spend with uninterested or uninformed participants who would have likely resulted from a random sample. In addition, given my time constraints, I could only interview people who were available to speak with me during that visit. A random sample would have required me to spend much more time in the community, to allow for people who were hunting or traveling to return home, and to allow for the time necessary to interview a larger number of participants, in order to reach a sample size that would be expected in a quantitative study, dictated by a power analysis. Second, purposive sampling, in particular, enabled me to speak with elders who wouldn’t necessarily have sought out participation. However, they were willing to speak with me when directly approached, perhaps because their participation was suggested by someone they knew and trusted. As I did not find many elder participants through
my open-call (convenience sampling) for participants, I relied on a local informant’s insight and connections to select elder participants to fill out the age distribution that reflects CANHR’s adult population range. Doing so in a purposive manner ensured a wide spread of ages represented in my overall sample, enhancing the breadth of age-groups represented, as has been identified elsewhere as important categories of stratification in the community (Mohatt et al. 2004b).

Originally, I had intended to sign up a focus group of elders/community leaders, a group of younger people/non-community-leaders, and a group of mixed ages and positions. This was because I wanted to know how people who had attended the Genetics Education for Native Americans (GENA) workshop (described in Chapter 1) might have understood the project differently than those who did not. Additionally, in Yup’ik culture, the younger people often do not speak readily in the presence of elders, and so I felt that breaking up the groups by age would be the best option (Kawagley 2006). However, because the Council (comprised predominantly of older adults) had not shown an interest in taking part in a focus group, I quickly had to change my plan. Instead, I opened the groups to any adult resident who was interested, and assembled groups with mostly women signing up for the morning session and only men signing up for the afternoon session. Because in Yup’ik culture, the men and women have distinctly different roles, I felt that was also a prudent way to separate the participants into groups. I asked the one man who signed up for the morning to participate in the afternoon instead, but his schedule did not permit him to do so. Because my study was so limited for time and the opportunities that participants would have to join group sessions, I allowed him to participate in the morning session, rather than turn him away, which might have been perceived as offensive (Mohatt et al. 2004a). I did not detect any significant affect on the discussion by his presence.
In the best-case scenario, I would have gathered separate groups of men-only and women-only, of various age groups: 18-30, 30-55, and 56+, totaling at least six separate groups. I noticed during the groups that I held, that the dynamics of the group and the willingness or reluctance of various participants to speak reflected the ages present in the group. Of course, there were individual differences among participants, accounting for some of the willingness that I found; but, in general, the youngest people, those under 30, were most reluctant to speak up in a group, even when addressed directly. In the interview setting, the younger participants spoke more readily. Thus, if I’d had more time, I would have liked to target, in a purposive manner, people in the younger age range, in more interviews and in a small group setting. There, I might have gained a better understanding of their particular concerns and ideas, and observed the dynamics of younger people talking in a group setting, without the social constraints of observing proper speaking order. Also, there was only one participant in the focus groups who was over the age of 56, so I would have preferred to hold groups with only elders, broken up by gender as well, to gain these particular perspectives in the group setting. Again, time and budget constraints did not allow for conducting six focus groups, and so I had to gain as much data as I could from the two focus groups that I conducted, split by gender, and of mixed ages.

Additionally, deep snow and strong winds during my visit might have prevented some people from participating, given the need for them to trek to the community hall or school. This was my own impression, as I observed few people outside in blustery, snowy weather, and those who were out were generally on a snowmachine or four-wheeler; conversely there were many people talking in a group setting, without the social constraints of observing proper speaking order. Also, there was only one participant in the focus groups who was over the age of 56, so I would have preferred to hold groups with only elders, broken up by gender as well, to gain these particular perspectives in the group setting. Again, time and budget constraints did not allow for conducting six focus groups, and so I had to gain as much data as I could from the two focus groups that I conducted, split by gender, and of mixed ages.

---

16 As mentioned previously, these designations are taken from the People Awakening Project, (Mohatt, G. V., S. M. Rasmus, L. Thomas, J. Allen, K. Hazel, and C. Hensel. 2004b. "Tied together like a woven hat:" Protective pathways to Alaska native sobriety. Harm Reduction Journal 1:12.)
people walking around and playing outside during the clear, calm weather. There is a trade-off when conducting research in the communities during the winter months. On the one hand, as requested by the Councils, we travel during the winter months because people are more likely to be physically present in the community and more free, because fewer subsistence activities are conducted during the winter that take residents out of the community. On the other hand, storms, blustery wind and cold weather could prevent people from moving around the community, as all transportation is by foot, snowmachine or four-wheeler without protection from the elements. This idea was confirmed by several participants who agreed that people might be less willing to go out in bad weather unless they have a particularly compelling reason.

### 3.4.4 Sample Population

The final population that I recruited is outlined in Table 3.1. The overall age range of males was 19 years to 83 years of age, with a median of 39. The overall female age range was 19 to 77 years, with a median of 40. There were a total of 8 participants under age 30, 10 participants age 30-55, and 8 participants over 55. All but one of the participants over 55 years of age were actually between 70 and 83 years of age. Four men and seven women participated in focus group sessions. All but one of the focus group participants spoke English comfortably. One focus group participant (a female) required concurrent translation from our local translator, Darla, during the session. The youngest participants in the focus groups (under 30 years of age) appeared to be much more reluctant to speak in the group than the older participants, even when addressed directly, and thus their opinions may not be as well-represented as those over the age of 30. This finding is consistent with many of my participants’ explanations about the differences between younger people and older people (to be discussed further in Chapters 4 and 5).
All participants were long-time residents of the community, though given that the community was settled relatively recently, none of the participants who were in their late forties or older was born there. A few of the younger people were also not born there. All of the interview participants who were not born there were born in a nearby community and moved to Quyana as a child or young adult. All but two of the interview participants (one English speaker and one Yup’ik speaker) reported prior exposure to the CANHR project.

Table 3.1 Characteristics of sample population

<table>
<thead>
<tr>
<th></th>
<th>All participants</th>
<th>All females</th>
<th>All males</th>
<th>Females &lt;56 years</th>
<th>Males &lt;56 years</th>
<th>Females &gt;55 years</th>
<th>Males &gt;55 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total N=</td>
<td>26</td>
<td>15</td>
<td>11</td>
<td>4</td>
<td>4</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Age range</td>
<td>19-83</td>
<td>19-77</td>
<td>19-83</td>
<td>19-45</td>
<td>19-43</td>
<td>61-77</td>
<td>78-83</td>
</tr>
<tr>
<td>Raised in Quyana</td>
<td>N= 14</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>7</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Adult residents since community establishment</td>
<td>N=8</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Yup’ik-only (or limited English)</td>
<td>N=8</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Primary language English or both</td>
<td>N=5</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Primary language Yup’ik</td>
<td>N=21</td>
<td>13</td>
<td>8</td>
<td>8</td>
<td>5</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>No formal education</td>
<td>N=8</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Some high school</td>
<td>N=4</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>High school grad/GED</td>
<td>N=6</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Some college</td>
<td>N=8</td>
<td>5</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>
3.4.5 Participant Observation

An important part of any ethnographic fieldwork, and much qualitative fieldwork, is simply being present in the community where the study is taking place. Formally, the method for this type of data collection is participant observation (Bernard 1995a, Emerson et al. 1995, Spradley 1980). Included in this designation are informal interviews (casual conversations with community members); participating in local activities; interacting with local people; taking copious notes about one’s surroundings, impressions, questions, and experiences; and reflecting on how one’s presence is being interpreted by oneself and others (i.e., the reflexivity practice mentioned earlier). The information that is gained in this way provides a context within which to situate and interpret the findings gained in the more formal interviews, focus groups, and any other qualitative or quantitative methods used in the study.

During my six-day stay in the community, I kept lengthy, detailed notes of my experiences and impressions. At multiple points throughout the day and at length at the end of the day, I described my surroundings, interactions, and observations from the day. I attempted to remain open to noting everything, with the goal of documenting the experience as comprehensively as possible (Becker 1998, Emerson et al. 1995, Spradley 1980). Of course, being human with a particular identity and perspective, I selectively noted the things that I observed, with my own interpretation, and with my own specific aims for the project. Ideally, an ethnographer would spend at least a year in the field in order to gain a fuller understanding of the community and context within which to situate her/his research question; but given the limitations of my project timeline and budget, I was afforded only a total of three weeks, and only

17 That is, I was a married, 27-year-old female kass’aq (non-native person), a graduate student, and a visitor with a particular academic purpose.
two weeks to make official observations under IRB approval. Therefore, I do not consider my work to be properly ethnographic, but a brief qualitative study that draws on some of my own experiences as well as those of others, both in written scholarly accounts, and in conversation with others who have spent time in the communities.

3.4.6 Focus Groups

3.4.6.1 Overview

The purpose of conducting focus groups is to obtain a wide variety of opinions, ideas and stories in a short period of time. While this format does not provide for an in-depth understanding of any particular participant’s views, it enables the researcher to access many ideas (Krueger and Casey 2000, Schensul 1999). In addition, group discussions can be advantageous for a project because they allow for the observation of group dynamics, and provide a forum for various people to actively discuss and debate different topics. In some cases, the group setting can help encourage participants to share information because it provides a more lively, trusting scenario than a one-participant-to-one-researcher interview might provide (Krueger and Casey 2000). Observing different group dynamics can be helpful to understanding how the community is structured and how members of the community might communicate with each other. Allowing people to discuss and debate a topic, in theory, allows for greater depth and breadth in the various topics of discussion, because the debate that might take place would provide a more complete picture of the topic, and a sense for how different people relate their own experiences or ideas on the topic. In some cases, when a group of people discuss a topic together, they are able to conjure up a greater number of ideas than would be suggested by the same number of interview participants. This is because group participants are able to jog each other’s memories, build on
each other’s observations, and make suggestions that one-on-one interview participants are not able to produce alone (Krueger and Casey 2000). The following segments of this chapter describe my process of conducting focus groups during my visit.

3.4.6.2 Logistics

Both focus groups were conducted at the community hall, centrally located in the community. These sessions were co-moderated by Ms. Hopkins and myself. The morning session consisted of seven women and one man, and all but one who were fluent English speakers. Darla, the local interpreter, was employed to translate for the single Yup’ik speaker, though others in the group also chimed in with their interpretations, shared words, and helped to explicate different concepts for both the exclusively Yup’ik-speaker as well as each other when the English words for certain ideas were in question. The afternoon session consisted of three men, all of whom agreed to conduct the discussion in English. The group was seated around a large table, and the three microphones connecting to two different audio recorders were spread out along the table, so as to pick up all participants’ voices as they spoke. Each participant was provided a pen and a blank piece of paper to record their own thoughts or comments throughout the session. These notes were not collected from participants, but meant to provide a place for them to note their thoughts while waiting to speak, if they chose to do so. Some participants made notes, others drew doodles, and others chose not to use them. We offered coffee and healthy snacks to participants throughout each session. Participants received a monetary honorarium of $30.00 at the conclusion of the focus group for their time. The morning focus group lasted for 1.5 hours after the consenting process, and the afternoon session lasted for 2 hours after the consenting process.
Challenges at this location included a loud heating system, which switched on automatically from time to time, making some of the audio recordings difficult to understand later on. Some participants brought young children, who played somewhat noisily throughout, not only distracting some participants from the discussion, but also creating extra difficulty in hearing the audio recordings. We were grateful, however, to have free access to the space, and accepted these challenges as part of the reality of working in a field situation. In addition, it is ideal for focus group participants to be unknown to each other, as sometimes participants who know each other well might be reluctant to speak openly about certain topics. However, given the situation in the small communities, it is virtually impossible to assemble a group of people from one community who would not know each other. Although we emphasize the importance of confidentiality of responses, we cannot ensure anonymity of participants.

3.4.6.3 Obtaining Informed Consent

Before conducting each session, I reviewed the consent form with all present participants and gave them a copy to take home, while keeping a signed copy on file. I explained the purpose, procedure, risks, benefits, and other details of the study, as required by the partnership and IRB regulations. I also informed them that their participation was entirely voluntary and that they may withdraw their participation at any time, as the document outlined. All participants signed the form, then I co-signed as the investigator obtaining informed consent. The local translator described the consent form to the one Yup’ik speaker and obtained her written and verbal consent to participate.
3.4.6.4 Note-Taking, Audio Recording, Transcription and Translation

With participants’ permission, I audio recorded each session. I noted each participant’s name and position around the table, and kept a tally of how often each participant spoke in order to encourage quieter participants to contribute. Ms. Hopkins took live notes on the discussion throughout each session on a laptop computer at the next table, while I led the questioning. Upon our return to Fairbanks, Ms. Eliza Orr and I transcribed the sessions, and Ms. Orr translated into English the responses that were contributed in Yup’ik. Analysis of the data will be addressed later in this chapter.

3.4.7 Interviews

3.4.7.1 Overview

Semi-structured, open-ended interviews provide a formal setting for discussing topics of interest to the researcher, while allowing for the full range of ideas that might come from the suggestion of the topic question, not limited by a set of pre-determined responses. Each interview session is an opportunity for the participant to respond to open-ended questions however he/she interprets them, without the pressure or hindrance of another community member’s presence, allowing a level of confidentiality not possible in a group discussion. The one-on-one setting also enables the researcher to probe the interviewee’s responses, to check for deeper understanding, and to follow certain ideas for more complexity than would be possible in a group setting (Fontana and Frey 1994).

As mentioned in my description of participant observation, my identity as a non-native outsider, female, young adult, English speaker, university student, and outsider unknown to the
interviewees, may have affected my data collection. On the one hand, participants might have been reluctant to tell me their true opinions and ideas about the topics that we discussed, or these characteristics might have influenced participants’ interpretations of my questions. On the other hand, my status in the community might have enabled a more open discussion than would have been possible with a member of the community as interviewer. Similarly, the Yup’ik interviews were conducted with one of two local translators, whose positions in the community might have also affected the interview process. These ideas will be discussed in greater detail in Chapter 5.

3.4.7.2 Logistics

I conducted 15 semi-structured, open-ended interviews, eleven of which were one-on-one, and six of which were conducted in pairs in accordance with the participants’ preference. The average length of each interview was approximately 45 minutes. All participants received a monetary honorarium at the conclusion of the interview, of equal value to those received by focus group participants, $30.00. Participants were recruited during the community meeting, via VHF announcements throughout the day, on flyers around town and by other participants’ suggestions. Interviews were scheduled in person, over the phone, or conducted on the spot, and all were conducted face-to-face. All of the English interviews were conducted at the school, either in an empty classroom after school hours, or in the office where Ms. Hopkins and I stayed. Generally, this provided a level of privacy and quiet needed for audio recording interviews and for maintaining confidentiality. In some cases, events taking place at the school (such as basketball games and Eskimo dance practice) created background noise that interfered with the audio recordings, but generally not significantly enough as to obscure participants’ responses. In one
case, a participant brought a small child who was present throughout and required attention from
time to time.

The Yup’ik interviews were all conducted in the homes of participants, surrounded by
family members, televisions, video games, and activities such as food preparation. All of these
were conducted through one of two local translators, with whom I had discussed the purpose of
the questions so as to aid their interpretation of each one. Six of seven of these interviews were
conducted in pairs, as per the preference of the participants. Each participant within the pair was
asked to answer each question in turn, providing their own perspective on the question. Because I
was unable to understand the details of what each person was explaining due to the language
barrier, I could not effectively probe each person’s Yup’ik responses, and relied on the
translators’ discretion and follow-up questioning during a return visit, months after the initial data
collection. I will further discuss the challenges of the language barrier in Chapter 5.

3.4.7.3 Obtaining Informed Consent of Participants

As in the focus groups, before conducting each interview, I reviewed my consent form
with each participant, giving them a copy to keep, and asking them to sign the copy that I kept on
file. I explained the purpose, procedure, risks, benefits, and other details of the study. It also
informed them that their participation was entirely voluntary and that they could withdraw their
participation at any time, as required by the partnership and IRB regulations, and as outlined in
the consent document. All participants signed the form, then I signed their forms as the
investigator obtaining informed consent. The translator present at each interview described the
consent form to the Yup’ik speakers, obtained their consent to participate, and signed
accordingly.
3.4.7.4 Gathering Basic Personal Information

At the start of each interview, I took note of several demographic characteristics, such as age, gender, place of birth, and place of residence. I also asked participants to identify the types of activities or organizations in which they were involved in the community. This was intended to provide a better sense of the participants, some of their backgrounds and how they are connected with other organizations or groups in the community; it also gave them an opportunity to tell me about themselves, before I asked what might be perceived as more difficult questions.

3.4.7.5 Note-Taking, Audio Recording, Transcription and Translation

With participants’ permission, I audio recorded each interview. Later, I transcribed each English interview, and Ms. Orr transcribed and translated the Yup’ik interviews into English. During the interviews, I took general notes about the setting, such as background noise and distractions, time that the interview started and finished, and some detailed observations about the participants and the place of interview if it was not the school.

3.4.8 The Interview Guide

The interview and focus group guide consisted of seven domains of semi-structured, open-ended questioning. These areas of questioning were presented in a variable order, depending on the flow of the discussion with the interviewee or group. I presented each question and probed responses as I was able, to gain a fuller understanding of each topic. The seven areas of inquiry include:
• **General questions about community structure**: What are the leadership bases in the community? How are they chosen? Whom do these groups serve? What kinds of advice do they give? How do people of different ages think or learn about things differently?

• **Information sharing**: In what ways does information get around in this community? Are there any groups of people left out by these means of communication? How could CANHR share our research findings with different people in the community? What do you think about training youth health educators based in the school to bring CANHR research to the community?

• **General health research priorities**: What do you consider to be current health concerns in the community? If you could ask researchers to study any health problem in your community, what would it be?

• **Familiarity and knowledge about CANHR**: What is your familiarity with CANHR? Why do you think the community is involved with CANHR? What do you want to learn through participating? Do you feel that you learned this, or were there things that you wanted to know more about but didn’t learn? Did participating make you do anything differently (diet, activity, etc.)? Is there anything you’d like to see CANHR do that it is not doing now? Do you have any questions about CANHR or genetics research?

• **General genetics understanding**: What is your familiarity with the topic of genetics (family heredity) or genetics research? Do you ever hear people talking about the things that are passed in families through the blood? If so, how?

• **Genetics research**: Given the project’s focus on obesity and diabetes, do you think that heredity is an important aspect of the project? Would you be interested in learning more about family heredity? How so? What might the community’s interest be, if at all, in learning more about genetics research in general and how genetics can influence a person’s health if they knew it was an important part of preventing diseases? Since this kind of research takes such a long time to do and current residents probably won’t benefit (but people in the future might), is this a project that you support?

• **Other information**: How is this community like or unlike other communities in the area? Is there anything else you would like to share about the community, or that you think is important to discuss right now?
3.5 Analysis

3.5.1 Data Preparation

As noted, I transcribed the MP3 files of my digitally recorded English interviews and focus groups. Ms. Orr transcribed and translated the Yup’ik interviews and one of the focus groups and sent them to me as a text document. Audio files and transcripts are kept with only numbers, age and gender as identifiers, and separately from the consent forms, in a locked file in the CANHR Biostatistics lab. The digital audio files and transcripts are stored in a password-protected file on the CANHR share drive, allowing only the research team access to the files.

3.5.2 Analytical Approach

I used a grounded theory approach to my qualitative analysis (Eaves 2001, Mohatt et al. 2004b, Strauss and Corbin 1994). That is, I analyzed my data according to a set of questions on which I was focused, but I allowed the theory to emerge from the data; I didn’t test a set of pre-conceived ideas or theories. First, I read each transcript several times to become familiar with the texts. I wrote preliminary memos, to keep track of overall impressions and issues that seemed to emerge from the data. Second, I open-coded all transcripts by hand, keeping my codes very close to the data by using participants’ actual words as initial codes. Using these initial codes, I grouped similar codes according to similar, repeated ideas, until all initial codes were included within a set of emergent codes.\(^\text{18}\)

\(^{18}\) One way to evaluate the reliability of the analysis in team-based research is using a kappa statistic to determine the frequency of agreement and disagreement between coders for the various codes, taking into account the possibility that some of this agreement and disagreement can be explained by chance (Cohen, J. 1960. A Coefficient of Agreement for Nominal Scales. \textit{Educational and Psychological Measurement})
I developed a codebook including the emergent codes, each defined, with inclusion examples and exclusion examples (MacQueen et al. 1998). I coded each transcript again, using the codebook and Atlas.ti (version 5.2.20), to organize the codes and quotes in order to more effectively develop my themes. I refined the codebook in an iterative fashion throughout this process, and discarded codes what were no longer useful. Throughout this process, I began to learn more about and to refine the details of my research question. I then selectively coded the text in order to draw on the information that pertained directly to the question that emerged from the early coding process. I grouped emergent codes into families, called “Social Location,” “Communication Pathways,” and “Health Beliefs.” I detected patterns in each of these categories, and developed a network of codes and themes to visually depict the shape that my theory was taking. I assigned relationships among codes and families in order to ensure that my theory was grounded in the textual data.

Once I began to develop the theory, I brainstormed various metaphors that might be used to tell the story, or the theoretical narrative that I wanted to present to the community and in my written work (Auerbach and Silverstein 2003). I wanted to use an example from nature that would be familiar to the community, but also one that would be clear to a broad audience. The metaphor that I selected linked all of my findings to different aspects of a river. This will be discussed in Chapter 4.


19 It is at this point that I defined my research question as “identifying factors that impact rural Yup’ik community residents’ understanding of health research, especially genetics” under the guidance of Dr. Jim Allen.
3.5.3 Validity and Reliability

Ideally, qualitative analysis is done in teams, and ideally with approximately four members (Auerbach and Silverstein 2003). The team would meet frequently during every step of the analysis, to discuss the process and come to a consensus on the meaning of the data, the appropriate wording for codes, themes and theoretical constructs. Kappa statistics would be calculated throughout the coding process to maintain reliability and consistency among the team (Cohen 1960). However, given the study’s status as a thesis project, most of the work had to be done independently and not in collaboration with a team. Instead, I utilized several methods to ensure the highest quality results that I could, including memoing, triangulation, and cultural auditing. Though I consulted with advisors, another graduate student coder, community members, and researchers with experience in the community, I take responsibility for the theoretical constructs that I have developed out of my data.

3.5.3.1 Memoing Process

Throughout the coding process, I wrote memos expressing patterns that appeared to emerge, queries that I wanted to pursue or my participants upon follow up, and any other reactions that I had to the text. In some cases, this involved enriching the textual data with information that I gathered through participant observation, or that I otherwise know about the participant that would help to clarify or contextualize his or her responses. These memos guided the development of my working theory and recommendations to be discussed in the remaining chapters.
3.5.3.2 Triangulation

One way to ensure that the findings from a qualitative research project accurately represent the population of interest is by collecting information from multiple sources. This is one reason why qualitative researchers conduct both participant observation and formal interviews. In addition, consulting prior accounts written about the region, and seeking counsel from other outsiders who have experience in the region with the population, help to improve the accuracy of one’s interpretations. Having consulted works by Fienup-Riordan (1983, 1996), Hensel (1996), Kawagley (2006), and Morrow (1987), I was able to ask specific questions about the culture and modern perspectives and beliefs (as the region has undergone rapid cultural change throughout the past century or more). As I was interested in how people understand health research and information, starting with beliefs about health, it was important to know which areas to address specifically and to determine whether beliefs and conventions held in the past are still applicable to today’s population. Conflicting findings provide a basis for re-examining the data and revisiting the population, seeking better understanding of the phenomenon. Also, these sources helped to round out my interpretations of the data, filling in gaps and highlighting the different assumptions that people of the YK Delta and I might make.

3.5.3.3 Cultural Auditing

During a return visit to the community of Quyana in November 2008, I spent 9 days following up with my participants, asking clarifying questions and checking my interpretations, as well as continuing participant observation. This “cultural auditing” (Mohatt et al. 2004b) took two different forms. First, I bound copies of each interviewee’s transcript and included a page summarizing their major points, as I interpreted them. I also included some key quotations that I
found particularly interesting in their interview. I offered the printed materials as a gift to each participant, and met with them briefly to check in and ask any additional questions that I might have had. I also invited them to review the materials and make comments or corrections. (I did not receive any feedback from this process). I did not give the focus group participants copies of their group transcript, as it would have violated confidentiality agreements. (I couldn’t be sure that each person would agree to having the transcript at large in the community). Instead, I checked in with individuals as I was able, in person or over the phone, and collected the few additional demographic questions that I had later ascertained would be helpful, and as I had received approval as a modification to my IRB protocol.

I was able to meet with all but three of my English-speaking participants in person, and I reached two of the three by phone (one had moved out of the community, and the other was traveling). I was unable to follow up with the third participant, who had passed away during the 6 months between my two visits. The Yup’ik interviewees were more complicated. Because I didn’t have Yup’ik transcripts for them, I had brought their transcripts in English. However, when I consulted my local translator about providing them with the English transcripts, he advised against it. So I simply visited with as many of them as I was able, in their homes, accompanied by my translator, or during community events. There was a festival out of town which many elders attended, and so I did not see all of these participants.

Although this piece of the cultural auditing process did not yield much useful feedback for the study, I felt that it was an important part of closing the research loop with participants. By contacting them individually, and providing the interviewees with transcripts, I hoped to convey my sense of respect for their time and responses, to reinforce the idea that I was there to return information to the community.
The second form of cultural auditing involved more formal follow-up interviews with certain members of the two focus groups and with one of my translators who helped with the Yup’ik interviews. The second translator, Darla, had moved out of the community, and although she was visiting for a few of the days that I was also visiting, I was unable to schedule an interview with her. Her mother had just passed away, and as part of the grieving process, the family of the deceased avoids certain activities for five days following the funeral. Since she and other family who were in town for the funeral were only there for the five days following, I did not think it was appropriate to ask her to take part in an interview. I did, however, ask her a quick follow-up question (that only she would be able to answer) while I visited with the family for dinner while she was in town. Originally, I had intended to ask the focus group participants to select their representative, but during the group sessions I sensed that this would not be effective and that I would not be able to conduct the follow-up interviews during the first data collection trip. Therefore, I selected these follow-up interviewees based on their engagement during the focus group session, and their positions of leadership within the community. From the first focus group, I invited two middle-adult women who both have positions working for the city government. From the second focus group, I invited one middle-adult male who is an elected leader in the community.

The three follow-up focus group interviews were conducted in the participants’ place of work. The translator’s follow-up interview was conducted in his home. All were conducted in English. As with my original set of interviews, I obtained informed consent, recorded the conversations with participants’ permission, transcribed, and provided each participant with a $30.00 honorarium. Each interview lasted approximately 1 hour. I asked participants to explain certain ideas voiced in their focus group, or patterns of responses from all participants that I didn’t completely understand. I also presented some of my findings and asked for feedback on
the accuracy of my interpretations and appropriateness of my conclusions. Their responses guided my final results and recommendations.²⁰

I had intended to conduct the interview with the two women in a pair, to allow for some discussion surrounding my follow-up questions. While the interview began as a pair, after 30 minutes, we were interrupted and had to complete the interviews separately due to scheduling conflicts.²¹ One participant stated after the first half of the interview that when she was talking with the other woman present, she had to answer carefully, so as not to offend the other woman with her answers if they differed. This admission was informative for me, confirming my suspicions surrounding speaking in a research setting with other members of the community; that is, some people will be more likely to guard their statements and speak less freely with others than if they speak alone.

3.6 Reporting Back

In addition to the follow-up and cultural auditing process, one of my main goals for the return visit was to present my findings to the Traditional Council. After rescheduling the meeting multiple times due to the national election day (the local polling place is in the room that the council uses for their meetings) the festival, which drew people out of town, and other scheduling

²⁰ During this follow-up visit, I developed a bronchial infection and lost my voice almost entirely for a few days. Because of my limited time in the community, this limitation demanded particular patience on the part of my interviewees, and resulted in asking several of my questions by writing them on a piece of paper for the interviewee to read.

²¹ This session was interrupted by a family member of one participant who arrived, as he often did, to have lunch with her. As I recognized that taking that time for lunch with the family is important in the community, I asked if she would like to take a break. While she originally said that she did not need to stop, I assured her that it was not a problem for us to continue later, and so she agreed that she would prefer to discontinue the interview at that time.
conflicts, I extended my stay and presented to the council before flying home the next morning. Due to various circumstances, none of our usual CANHR-employed translators were available to translate for the council meeting, so Ms. Hopkins asked the president of the Council to translate. However, once the Council was assembled around the table and our projector was set up, he informed me that I could present in English and those present would understand well enough.

We were first on their lengthy agenda, so we attempted to stay within a limited time block. Ms. Hopkins provided a brief update on CANHR’s progress since their last visit and then introduced me to the Council.

Using PowerPoint, I presented my findings after a brief reminder of the project’s purpose and goals. I used a photograph of a river as a visual representation of my metaphor (to be described in Chapter 4), to which I could refer throughout the explanation of my findings. I briefly described the methods I used, the questions I asked and the themes of my conversations, illustrated with direct quotes. I explained that the information from the study will be written up as my thesis, but all papers would be submitted to YKHC for their approval first, and that we would use this information to inform future CANHR work. I encouraged their feedback and ongoing communication between the community members and researchers.

The Council members listened attentively to my presentation. After I finished, I opened the floor for questions and comments. The president of the Council spoke first, stating that he found the presentation to be helpful to them, and that he appreciated hearing back from us, while our research project was in its finishing stages. His comments confirmed for me the importance of closing the research loop and providing results to the community, as it is not only important for the researchers to report back, but it is also appreciated by community members as well.
One other member offered his comments, talking at length in Yup’ik. The president of the Council translated for us, explaining that the Yup’ik speaker had related his own experiences growing up in the region, for 68 years, seeing the significant changes that have come to the people and environment there. He mentioned the impact on climate change, allowing for new species of plants and animals to live in the area, and the drastically changed diets of the people in the area (both due to the new species available, and to the introduction of the stores). He noted that there has been an increase in diseases coinciding with the changes in diet. His comments indicated that although he speaks Yup’ik, he understood most of my presentation given in English, and also that these health issues are of concern to him, given his observations regarding the changing environment and society’s impacts on the health of his community.

3.7 Conclusion

The process of conducting fieldwork is always unpredictable. While there are ideals in research project design, the best-laid plans and protocols must allow for adequate flexibility, and the fieldworker should be prepared to improvise. When conducting research in small, rural communities, it is important to remember that the researcher is a guest. Though I cannot speak for other communities, I can say that when working in Quyana the most effective way to complete one’s work is by allowing it to happen on its own schedule, and by integrating into the community. Thus, a compromise must be reached between following a rigorous protocol (in accordance with IRB and other regulations) and accommodating participants’ individual needs. And while many university researchers might interpret “downtime” in the community as wasted, there are critical lessons to be learned by just sitting around with people. I found some of the most informative conversations or experiences I had occurred while “nothing” was happening. It
was during these hours that community members and I became well acquainted, thus developing trust between us. By sharing stories, I learned much about their way of life, perspectives, and means of communication, including differences in the meanings of English words that we both used. By participating in community activities to the extent possible (such as dancing at traditional Eskimo dance practice, and attending church services) it is my belief that I demonstrated my genuine interest in and respect for the culture, and the people in the community.
CHAPTER 4 FINDINGS

4.1 Overview

I began this study with a general research concern that I intended to address: *How can the Center for Alaska Native Health Research (CANHR) improve the dissemination of health and genetics research results to their participating communities?* The specific research question that I endeavored to answer developed out of the analytical process described in Chapter 3. Through the open coding process, my question was refined to state, *What are the factors that impact rural Yup’ik community residents’ understanding of health research, in particular, genetics?* The goal was to provide recommendations to CANHR investigators about how to improve dissemination of the genetics and other health research information, by better understanding how information might be received by community members. In my research, I have identified the following three major factors that might affect how people in one Yup’ik Eskimo community perceive health research information:

- Communication pathways: The channels through which communication is transmitted within the community;
- Health beliefs: Existing beliefs and understandings about health;
- Social location: A person’s status and role in the community.

In this chapter, I will discuss each of these factors in detail. First, I present a metaphor, “the river” to summarize how the three factors are interconnected. I developed this metaphor with the help of several people, including a faculty member at the University of Alaska Fairbanks (UAF), Dr. Jim Allen, and also a leader of the Quyana community. I consulted this community participant during my return visit and enlisted his help in refining the metaphor so that it is simple, familiar and relevant to the other community members and leaders, in order to present it
to the Traditional Council during my findings report presentation, and later to the community during a public meeting that other CANHR investigators will host. I end this chapter by focusing on a case examination of these factors, regarding genetics research results, addressing how these factors might provide for different community understandings of genetics research information.

While I take responsibility for my interpretations and theory that I developed as a result of my fieldwork, I would like to acknowledge the extensive guidance and advice I have received from my community informants, as well as from the many university scholars who have donated so much of their time and expertise to help make this work a reality. Any statements and interpretations contained in this thesis are my own, and I recognize that while I draw from the words of my participants and informants, I cannot speak for them.

4.2 The River

In Quyana, the communication pathways are like water flowing through a river (Figure 4.1). First, there is an original source of a river water, which could be a glacier or spring. That water then flows downstream, and is filtered through different features in the river. It changes and swirls over rocks, sweepers, floating logs, and so on, as it responds to its environment. Over time, tributaries bring in new water from other sources that mix with the existing water already traveling in the river. The river splits into braids through which different parts of the water flow. Where a person stands in the river influences the water that they receive.

This is much like how information flows through a community. The source of original information is the traditional knowledge that is transferred down the generations. This information is changed and filtered as it passes through different minds of people at different
points in time and in different positions in the community, as well as in response to changes in their environment and society. Each time the information flows over another person or group, it changes form. The tributaries bring in information from new sources, such as television, school, health care providers and research presentations. As this new information mixes in with the existing knowledge in the river, it is blended and may take on new qualities, just as the water does when a silty, glacial tributary enters a clear, spring-fed river. The water mixes and becomes a blend of the two water sources. A person’s role in the community and in time directly affects the information that he or she can access and receive. An elder located upstream in the river (such as point A on Figure 4.1) will have greater access to the traditional sources of information, which provide a basis for understanding the world. A younger person who enters the river at a later point (such as point B on Figure 4.1) just after the confluence of the river with a new tributary will gain information that is more of a blend of the different sources. Likewise, if a person is in one braid of the river, he or she will receive somewhat different information than the person who is in another braid.

In this chapter, I present my findings as illustrated in the above river example, with quotations from participating community members to further explain the factors that influence how a person learns and understands health information. In the following chapter, I apply these findings to recommendations for genetics research scientists interested in disseminating the research progress and results to the community residents.
Figure 4.1 The River: A metaphor for understanding the assimilation of knowledge in one Yup’ik Eskimo community.

4.3 Communication Pathways

The first of the major themes that I found in my data is that the way information is transmitted in the community influences how people receive and understand information. In this section, I present how people learn about events in the community (including CANHR visits), the importance of recognizing the complexities of language in the community, and the various ways people take in information. Throughout this section, I also provide support for the finding that a
person’s role or status in the community influences how they receive information and integrate details about communication pathways.

4.3.1 Learning About Community Events

When participants were asked how they first learned about the presence of the CANHR project, the most common answer was VHF radio. CANHR field research assistants announce their community meetings, and invite new participants to the study over the VHF, in Yup’ik and sometimes also in English. In general, people reported learning about events in the community by VHF radio, posters at the store and post office, school newsletters, community gatherings such as town meetings, bingo games, church, and Eskimo dance practices.

Also commonly cited was word of mouth: hearing from family and friends, and sometimes from the researchers themselves, about meetings or encouraging participation. Some indicated they learned from others talking about their experiences with the project, comparing their results from the screening with their friends’ results. One woman added that she encouraged her family and friends to participate, telling them that it’s an opportunity to get these health tests done for free, thus citing direct benefit through learning about one’s health.

Word of mouth was emphasized as a means of communication throughout the community, but often it was described in the context of gossip or rumors that go around. Several people reported mixed feelings about this method of communication, as it was highlighted as both

---

22 Most houses and other community facilities have VHF radios through which community announcements are made. These announcements include events notices, elders’ teachings, morning and evening prayers, paging community members, and other announcements of community interest, as well as various incidents of children playing with the radio, making noise.
an asset of a small community and “highly sociable people”, as well as a hazard of living in a small community: information of interest travels quickly. Words that participants used to describe this concept include *gossip, rumors, grapevine, spread like wildfire, co-workers mention, through people who are getting ready, word of mouth, friend-to-friend, people call them*. In some cases, participants referred to this as a way to account for people who don’t have radios or read posters receiving information. Others expressed disdain for the propagation of misinformation, particularly of false rumors about themselves or others they know.

4.3.2 Language Complexity: Three Age Groups

Interpersonal communication is complex in Quyana. The community is officially bilingual, with Yup’ik and English being spoken widely, across all ages. After my various conversations with community members, I deduced that there are three major language groups in the community, based loosely on age.23 In general, the elders speak Yup’ik and very little if any English, and may or may not know how to read and write in Yup’ik (which until recently, was an oral language only). Children and teens learn to read, write and speak Yup’ik in school, which was described to me as a more modern form of the language. The local school district mandates that children are taught in Yup’ik in kindergarten through third grade, then a year called 3T, is spent transitioning kids into English. They are taught in English from 4th through 12th grade, with one course per year in Yup’ik language and culture. Although many households include three generations of family members, and largely speak Yup’ik, young children also learn some English through watching television. The middle adults are a major source of communication in

---

23 As mentioned in the Preface, these age categories are defined for research purposes only.
the community because they can translate, and know how to broker understanding among the various versions of Yup’ik spoken by younger and older people. Participants of this middle generation self-identified as the translators within the community. Being bilingual is seen as an advantage, as are reading and writing, because one who has these skills can then communicate with more people.

While most members of the non-elder generations in the community are bilingual to some extent, several bilingual speakers expressed a lack of confidence in their own ability to translate for others. One participant who had studied as a teenager to become fluent in reading, writing and speaking Yup’ik, explained being fluently bilingual, reading and writing were “magic in your hands.” Yet, he was reluctant to work as a translator, for fear of being responsible for any potential misinterpretation and the resulting conveyance of incorrect information. Another participant and elected leader in the community was also reluctant to translate for the CANHR project. Although he reported speaking primarily Yup’ik at home, and was comfortable conducting the interview in English, he insisted that he wasn’t competent enough with the language to translate during diet recall interviews conducted during a previous CANHR visit.

4.3.2.1 The Fourth Language Group

When the CANHR researchers are visiting the community, they bring in an additional language group: the researchers themselves. Not only are the researchers accustomed to using scientific language in their work, but they also speak a dialect of English that is subtly different than the dialect that is spoken in the community. An English word spoken by an English-speaking Yup’ik person sometimes has a different meaning than that word spoken by a non-Yup’ik interviewer. One example of this is a phrase I commonly heard both in formal and
informal discussions with people. When the Yup’ik person with whom I was speaking said the word “even” often this actually meant “also,” as in, “my mom, grandmother, even my aunties told me what to do.” The sense in which this participant used the word “even” was simply to express three sources advice, all with equal emphasis, as would be expressed by using the word, “also” in place of “even.” If I didn’t know that the word was being used in this sense, I would read the sentence to mean that the aunties were perhaps a particularly unlikely source of the advice, and so the fact that they provided it was to be noted as an unusual or special case. This is one example, which highlights the subtle differences that can be effected by using a single word in a slightly different sense than is commonly used in another culture. This particular misunderstanding is minor, but this type of misunderstanding is common (an impression that was confirmed by several consultant participants) and could have greater implications when the misunderstanding is over words or phrases with more consequence.

The same type of misunderstanding is possible for native Yup’ik speakers using Yup’ik terms differently. As explained earlier, younger people learn Yup’ik in school, which is a different version of the language than the elders know. Also, different dialects are spoken in different communities within the same region, so a translator from one community may not accurately interpret the words spoken in another community. Without careful examination of the language, and diligent checks for meaning, words in either language can be easily used in different ways, with both members of the dialogue unaware that there is a miscommunication.

4.3.2.2 Found in Translation

The English words “healthy”, “disease” and “genetics” are examples of terms that the CANHR researchers often use that do not translate directly into the Yup’ik language. I learned
hints about how people conceptualize these terms from the back-translations of my interview questions that had been translated in Yup’ik. The left column of Table 4.1 shows the English terms that I used, and the right side of the table shows the corresponding description that the translator provided, or in some cases that were direct English responses to my questions about health. When translating from English to Yup’ik during the actual interviews, the translator made necessary changes and interpretations in order to be clear to the Yup’ik speaking interviewees, though to some extent, answering my question in part. The inclusion of this information is intended to help researchers learn how to increase the comprehensibility of their presentations to the community, and to call attention to the continued need to seek understandings of these and other commonly used terms in research.
Table 4.1 Found in translation: Yup’ik phrases to describe English terms

<table>
<thead>
<tr>
<th>English Term</th>
<th>Yup’ik Translations</th>
</tr>
</thead>
<tbody>
<tr>
<td>To be healthy</td>
<td>To have a strong mind, strong body, blood, no illness [“toward our body”];</td>
</tr>
<tr>
<td>Diseases</td>
<td>To have a good life, follow the right path, live righteously, stay out of trouble</td>
</tr>
<tr>
<td>Genetics</td>
<td>Something that would ruin our bodies;</td>
</tr>
<tr>
<td></td>
<td>Something that gets into their system</td>
</tr>
<tr>
<td></td>
<td>Some diseases that are passed down through our blood from generation to generation;</td>
</tr>
<tr>
<td></td>
<td>You know how people who are related get diseases (like cancer) that are similar</td>
</tr>
</tbody>
</table>

4.3.3 People Learn Differently

Participants described many ways of learning different types of information. In past generations, children learned how to conduct subsistence and related activities by observing their parents and elders doing these things. Children emulated their elders, and it would have been considered embarrassing for a child to ask their parent how to do something. Along similar lines, it was explained to me by several participants that elders often communicate largely through body language, that elders pay close attention to someone’s body language to know what that person’s
attitudes are and if they are really listening to their words. Several elders expressed the idea that “Some people learn just by observing, others require lots of instructions, and some never learn.”

Nowadays, some information is learned by watching television programs, reading magazines and through the internet. Although only one participant mentioned these routes of communication, I observed them to be more common than reported to me. Many houses had satellite dishes, and every home that I was invited into had a television on, even if no one was directly watching it. In addition, I observed the use of computers and internet by high school students and in private homes. Several homes had internet connections, and I observed people looking up news information, making online purchases, and occasionally communicating with others via email. The high school students have access to both a computer lab and laptop computers that connect to the wireless internet at the school. Although I do not know what the kids actually watch on TV or which webpages they frequent, it is apparent that these serve important roles in the community, among younger people in particular.

Health information, in the western sense, is learned in western ways: in school, the kids learn nutrition information in Health class, and genetics information in Science class; young children are taught basic hygiene through the local Head Start Program. One young female participant who previously worked as a dental assistant explained that she taught nutrition, oral health, and how to brush one’s teeth as a guest teacher at Head Start. The elders explained that they learn information about their own specific health condition from the booklets and written information that their health care providers give them. They then rely on their family members to translate this material for them, thus “learning through their ears.” One elder female explained that she and her fellow elders won’t learn anything without people telling them, so she supported the idea of community meetings to convey health information to the community. Some elder
women also spoke about learning as children from their elders about healthy eating and medicines harvested from the environment around them. This is clearly still the case to an extent, at least in some households, as I observed the use of boiled willow bark as cough medicine (among other uses) in one elder couple’s home. The couple explained that their grandchildren now use the medicine when they have coughs, without the grandparents telling the kids to use it: they learned about using traditional medicine by observing their elders.

Participants of a range of ages expressed having learned the validity of traditional teachings through their own experiences. For example, one elder male described the teachings he learned from his elders about ignoring pain, continuing to work through any pain or sickness, and to hit sore spots on one’s body to relieve the pain. He explained that he wouldn’t tell others about it if he hadn’t experienced it himself. A middle adult male explained that his parents taught him while growing up not to believe everything he hears, only to believe what he sees for himself. He related a story about a case when he experienced the importance of that directly, after not believing a rumor that he’d heard about someone committing suicide, which he later learned was not true when he saw the subject of the rumor alive. Likewise, a young female adult described the advice that she’d learned from her mother, grandmother and aunts about how to behave during pregnancy. For example, a pregnant woman should not procrastinate in her daily chores, or her baby will procrastinate during the birth. She didn’t heed their warnings during her first pregnancy, and suffered the consequences of her choices; chastened, she complied during her second pregnancy. Some people will take a long time to understand a saying that they hear, and it will only make sense later in life, when the advice becomes relevant to that person’s experience.

For those who have not experienced a situation in their own lives, they can understand what they haven’t experienced by applying their own knowledge that they have gained from
experience to a story they hear. One interviewee explained that although women in general, do not hunt, they can understand the challenges that the hunters face by feeling the cold hands and catches of their husbands who return from a hunt, and hearing their stories about what they experienced during the hunt. The woman can then apply the information that she gathers from the stories and by feeling the cold hands to her own experiences of being cold in the wilderness, and similar situations she might have experienced herself to relate to her husband’s experience.

4.4 Health Beliefs: The Water in the River

In this section, I present some of the ideas that participants shared with me regarding their understandings about health. In sum, when researchers talk about “health,” in English, many community members interpret this to mean physical health, that is, lack of disease, interpreting more of a western biomedical concept of health rather than a more holistic Yup’ik concept of being a healthy person that came out in my Yup’ik interviews. That is about a “Yup’ik way of life,” that combines all aspects of a person’s wellbeing. Secondly, people bring together information from different sources to make sense of these concepts of health.

4.4.1 Synthesis of Health Information

People’s beliefs about health are drawn from two categories of sources, brought together to create their complex understandings about health. For one, they learn the teachings that are

---

24 This is not a story, but actually a direct sensation that evokes an understanding of another person’s experience.
passed down through the generations from their ancestors, which are the “source of the river” from the river metaphor described earlier in this chapter. The elders teach their children and grandchildren because they want the younger generations of people to “live a good life.”

Traditional knowledge is rooted in information developed prior to the introduction of new information by visitors, missionaries, and other non-Native groups who worked to suppress Yup’ik culture in favor of their own ways of life. However, inherent in traditional knowledge is continual change, as the knowledge that is passed down is shaped to suit current needs and in response to changes in the environment and contemporary experiences. The participant with whom I consulted on the river metaphor explained that traditional knowledge is water that picks up silt, carries it along, entrained in the current, until such a time as it is laid down again in the river bed, not longer needed or relevant. Likewise, novel information is learned from newer sources and then becomes passed down through the generations, also eventually becoming traditional knowledge.25

The second category of information sources is what has been learned after contact with the kass’aqs, which includes new public health information from the hospital, clinic, health corporation, school, and researchers who have worked with the community members, as well as media sources such as television and magazines. From these sources, people reported specific health activities such as deliberate exercise (such as walking and jogging for the sake of getting exercise, not necessarily for practical purposes), and eating fruits, vegetables and vitamins.

25 An example of this concept at work is the how Christianity has become ingrained in the culture as a traditional value. The Christian concept of God is like a tributary to the river of information that becomes assimilated into the traditional knowledge and part of the local canon that is passed through the generations. The missionaries established a presence in the YK Delta in the middle of the 19th century and have had a significant influence on the culture in the region. This information that was originally from a source outside of the community has become included in the teachings that elders pass on to their children (Burch, E. S. 1994. The Inupiat and the Christianization of Arctic Alaska. *Etudes/Inuit/Studies* 18:81-108).
4.4.1.1 The Yup’ik Way of Life

In Yup’ik culture, “health” is treated as a holistic “way of life,” encompassing aspects of a person’s physical, mental, spiritual health, relationships, and choices. The elders shared information given to them by their elders, defining a healthy life under the ideal of “living a righteous life,” and “following instructions.” This includes a list of characteristics, many of which are listed in Table 4.2. There is the belief that if a person follows the teachings of their elders and family then they will prevent sickness, and some would say that God would reward that person with a long life (indicative of a life in good health).

This is distinct from the notion of health in western biomedicine, which treats the aspects of a person’s identity and wellbeing as discrete specialties or fields of study for different health care providers. In western biomedicine, we tend to seek medical advice from specialists according to particular ailments and symptoms, visiting a physician for physical ailments, a psychiatrist for mental ailments, and a priest, rabbi or other religious leader for spiritual advice. In the Yup’ik view, disease prevention and treatment are inextricably linked to all aspects of a person’s wellbeing.
Table 4.2 Characteristics of someone who lives a good life.

<table>
<thead>
<tr>
<th>Follows Directions</th>
<th>Lives Peacefully</th>
<th>Compassion for Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Listens to their parents/ancestors and remembers what they’re told, believes in the sayings</td>
<td>• Not causing any trouble, not fighting</td>
<td>• Has compassion for family members</td>
</tr>
<tr>
<td>• Understands family values, passes on traditional values so they don’t disappear, follows moral laws.</td>
<td>• Better not to say something if it will be hurtful.</td>
<td>• Recognized as someone who ignores others when they’re talking about him; pretends not to know about someone who offended him</td>
</tr>
<tr>
<td>• Is aware of his/her surroundings, is humble, pays attention to gain knowledge and strength.</td>
<td>• Thinks before he/she speaks, doesn’t talk back and listens to others without commenting.</td>
<td>• Forgives a person who offends, without confrontation and lets it go.</td>
</tr>
<tr>
<td>• Doesn’t do whatever he/she wants to do.</td>
<td>• No unnecessary stress</td>
<td>• Treats strangers well, make sure they’re not hungry.</td>
</tr>
<tr>
<td>• OPPOSITE: “some of them it’s like they never heard anything. Those, our ancestors said, were the ones who will not listen.”</td>
<td>• In a home: a couple doesn’t argue so that their children don’t see a bad situation and they are not raised in a bad way.</td>
<td></td>
</tr>
</tbody>
</table>

4.4.1.2 A Blended Understanding

Several times throughout the interviews and focus groups, participants reported a blended view of what makes a person healthy. The views expressed varied based on the person’s age. The elders spoke often about “living a good life,” or “following a good path” to maintain physical strength or health, including many specific means for doing so (see Table 4.2). In several instances, they compared western doctors (seen at the hospital and clinic) to their ancestors by stating that doctors tell people what to do to prevent or recover from sickness, and become frustrated by people who are hard to work with, who don’t follow their instructions. Their elders
too told people what to do to prevent and heal sicknesses and became frustrated by people who
don’t listen. Younger people tended to report health activities in terms of the kinds of health
activities that one might learn from a western public health nurse, doctor, or public service
announcement or poster. That is, they mentioned exercise, eating healthy foods, among other
activities. When asked about what kinds of exercise people do to stay healthy, answers often
combined walking, jogging (extremely rare in rural communities) and playing basketball, with
traditional chores and activities such as shoveling snow, fishing, and Eskimo dancing. Health
foods were categorized as “Native or Yup’ik” foods and “Store-bought or kass’aq” foods. It was
widely understood that the Yup’ik foods were healthy foods and the kass’aq foods were
unhealthy. However, further explanation often revealed that fresh produce, fruits and vegetables,
were also considered healthy foods, but were difficult to obtain in the community. This
conflation of the different categories of healthy vs. unhealthy foods demonstrates the complexity
of these categories that might not appear obvious to an outsider upon first glance.

The single English word, “health” was often described in physical terms when translated
for the Yup’ik speakers: “to have a strong body,” or “what the Yupiit say is strong” (see Table
4.2). In conversations with both English and Yup’ik interviewees, there was a sense that a
person’s health is related to being physically able to work, fish, hunt, etc. To some degree,
sickness was discussed in severe terms, linked with death. One elder man explained that “I
haven’t been sick enough that I couldn’t work, but maybe when I’m about to die I might be sick.”
Indications offered by participants of the younger and middle generations that a person is healthy
include people who are not sick, including those without migraines, injuries, diabetes, or skin
conditions (boils or paleness); those who are in shape, those who have all of their teeth and no
cavities (an indication of a person’s diet being low in sugar), and those who don’t get suddenly
weak but are strong.
Evidence of living a good life equals living a healthy life, which results in living a long life. As several participants (both elder and middle-adults) noted, “those people who follow the instructions and prohibitions are rewarded with a long life.” In order to live a long life, one must be physically healthy or strong, and without serious illness. The following paragraphs describe various aspects of maintaining health from the perspectives of the Yup’ik participants in my study.

4.4.1.3 Different Minds

New technologies in the community are received by people with mixed skepticism and support. One elder expressed gratitude for the new technologies in the rural communities, such as electricity, running water, improved clinic facilities and airstrips, schools, and so on. He welcomed these new improvements as helping to make life easier for the people in the community. However, his wife expressed some hesitancy in welcoming all of those things without question; she was concerned that the schools were teaching their children about the kass’aq way of life, not the Yup’ik way of life, which she expressed, has led to a decline in the respect and good way of living. Other elders claimed the (relatively) new ways of hunting and fishing, using motorized boats and snowmachines instead of qayaqs and dog teams were changing the way people viewed the world, so that younger and older people have “different minds.” At the same time, there seems to be some recognition that these things can be helpful to the community and that people appreciate what is gained from technology.

______________________________________________________________

26 Implicitly, this suggests some responsibility on the part of the person who becomes ill for their illness.
4.4.2 What is Healthy?

The following paragraphs provide examples of responses to the questions regarding what it means to be healthy, and what healthy people do to become or stay healthy. The three main areas about which participants provided health information include values, healthy foods, and activity. In this section, I have listed the general health concepts, then detailed the responses given by elder, middle and younger adults regarding each concept.

4.4.2.1 Values

4.4.2.1.1 “How you live is up to you”

The importance of personal choice in determining how a person lives was mentioned on several occasions. It was explained that elders provide younger people with information learned from experience and sayings that they were taught by their elders, but that it’s up to the individual to listen and remember those teachings in order to stay safe and healthy. As one middle adult male put it, “elders believe that each individual is responsible for their own actions; therefore they suffer the consequences if they’ve done something wrong.” It was also repeated many times by participants of all ages that people perceive things differently, or "people have different minds," based on their individual experiences. While other people might provide an individual with advice, no one else can be held accountable for that individual’s decisions.

4.4.2.1.2 “When you are sick, be happy”

Every elder who responded to the question about how to be healthy mentioned the importance of “raising oneself up” mentally, maintaining a positive mental attitude. When ill,
continuing one’s usual activities; not thinking too much about one’s ailment; going outside, to
church and other activities; and acting normal and happy helps one become well. Making these
choices also shows others that the person who is ill is trying to recover and fight the disease.
Several participants advised that if you have pain, a headache, or other mild to moderate
affliction, just ignore it and it will go away: The illness will know that the person whom it has
infected is strong and so it will leave the person. Fathers taught their sons not to “welcome pain,”
and if they had a sore part of their body, they should punch it to make the pain go away, without
taking medicine. Likewise, strong people don’t show their pain or depression even if they have
just experienced a tragedy in the family. One elder woman disparaged the increase in disease
nowadays, citing that “people get what they anticipate. Belief depends on the mind. If he
believes in it, it’ll happen to him, but if he doesn’t believe in it, then it won’t happen.” Another
ever woman explained, “a person who lives will have sadness or will have happiness; we all go
through those as we live,” but it is best not to dwell on sad emotions.

Younger and middle adults expressed several things that a person can do to “make their
mind healthier.” For example, a person can refrain from confronting someone who hurt or
offended him or her, as “it’s about pretending to not know, forgive that person and let it
go…that’s unnecessary stress. If you do that, it makes your mind healthier and you see that life is
precious.” For one young woman, going out to pick greens and berries with her family members
helps “take her mind off of something” that might be troubling her. For one young man, listening
to the morning and evening prayers and psalms over the VHF helps to “ease the mind.” Another
middle adult man expressed that he feels good about himself when he has been productive, and
put in a good day’s work.
4.4.2.1.3 “Fighting it”

All of the elders I interviewed mentioned ways that a person could actively fight or prevent disease. One common traditional prescription for how to prevent disease is to listen to one’s ancestors, parents, grandparents, to their sayings, and to believe in them. One elder explained, “if they listen to what they heard from their ancestors and pray about not getting the disease, it’s like taking medicine.”

One of the women was following her doctor’s orders by changing her diet given her high blood pressure diagnosis, and explained, “I’m trying to help myself, and if it helps me I plan to tell others.” This statement also demonstrates an idea that might be of interest to researchers, particularly those studying such individualized medicine as genetic testing. Her concept of “if it helps me, I’ll tell others” demonstrates a collective view of human health, that what is good and helpful for one person will be good and helpful for another person (though this idea isn’t necessarily unique to the Yup’ik participants). However, in genetics research and western medicine, the focus is on individualized health care, and treatments that are tailored to a specific person’s needs. Doctors make recommendations and prescribe particular drugs to individuals who have the specific indications for the recommendations and drugs. This assessment doesn’t assume that what is good for one person is good for all. Of course, there is a distinct difference between different people eating the same foods and different people taking potent drugs without a prescription, but the concept of what is good for one is good for all is one that should be kept in mind.

They also described uses of medicine to help fight or prevent ailments. One couple described their uses of different medicines that they made from commonly available items, such as using Wesson oil to cure earaches, and boiling the bark of willows (and sometimes wormwood), to make a very strong solution that cures coughs, skin rashes and cuts, and helps to keep them strong if taken everyday before bed. In another instance, a story was told of a woman who makes a fireweed tea for her husband three times a day, and he takes it to decrease the cancer in his body.
the minds of researchers when disseminating health information. The assumptions about medicine might be different in the community than in the lab.

Additional behaviors that younger participants expressed that actively help keep a person healthy include abstaining from smoking cigarettes, limiting/abstaining from alcohol use (as being hung-over prevents a person from wanting to be active), taking care of oneself by getting enough sleep on a regular schedule and eating on a regular schedule.

4.4.2.1.4 Social Bonds

Again and again, the importance of family and encouragement from others was stressed as important factors in a person’s health and overall community well being. There was a concern that family bonds are no longer as strong as they once were, due to people leaving the community to pursue education or employment, and activities such as gambling, alcohol and drug use breaking families apart, and keeping some parents apart from their children.28 Grown children leave home and “do whatever they want to do,” to their parents’ dismay, which is a concern because the next generation of children grow up without knowing who their relatives are, and because these grown children are not available to help the rest of the family. Likewise, members of the elder generation recognize that a person who leaves the community will not have the help support of their family in the community in times of need, and the network is broken down.

28 Gambling in the community refers to card games that are played in people’s homes for money. While bingo, “rippies” and “pull tabs” are also frequent activities for adults of all ages in the community, they do not have the same connotations as the private gambling. Proceeds from bingo, rippets and pull tabs go to support the city administration, and are conducted openly as a community event. Children under the age of 18 are not allowed in the room during these activities.
Several middle adult women explained that what made the elders “back then,” in a prior era, healthy was their mental support from family members who were all close to each other. “If a person needed correcting, they would let them know, mainly the parents, uncles, aunts, grandparents.” Beyond behavioral correcting, people provided encouragement for each other to help them fight diseases. This support helps people gather the strength to take care of themselves when sick. When a person learns about being diagnosed with an illness, they often become weak and then their health will deteriorate, but having family to help them deal with the diagnosis improves their ability to fight the disease. For example, an elder woman expressed that she became weak when she learned about her illness, but then she decided to learn about it in order to fight it; she let her family translate the doctor’s informational booklet for her, working together as a family to help her get well.

According to one young female participant, being healthy includes spending “time with family to stay out of trouble…makes the family stick together, just bring them closer together…because other families, there’s so much commotion going on, drama.” A middle adult male participant agreed that families are not as close as they used to be, and attributes this to an increase in the use of negative words toward others and a general loss of respect. He explained that this is, in part, because programs that people watch on television make people think that violent behavior is acceptable, and in part because parents distance themselves from their kids through gambling, all leading to community strife. This negativity has also led to a decline in the encouragement that people have given each other in the past, encouragement that helps people stay healthy.

In marriage, an elder asserted, a couple who live life without arguing and who try “not to hurt each other through what they say” would live a peaceful life, and would bring children up in
a good home. An unmarried middle adult man cited a good marriage as part of the key to happiness and health, but later provided a negative case for the benefits of getting married, possibly reflecting a change in attitudes of younger generations. He said, “I don’t know about getting married- I look at it as a problem…I see my peers, and they say ‘I wish I didn’t have to get married, I can’t do what I want to do.’ I’m glad I didn’t (get married).”

Finally, some middle adult males reported that having poor skin condition, being pale, or having sores or boils indicate to other people that one is sick or doesn’t go outside much. If people perceive a person in this way, then they will be less likely to invite him/her to go out. This suggestion seems to indicate an importance of appearing healthy, or at least actively taking care of oneself in order to keep the acceptance of others, but might somewhat contradict the other participants’ statements about other people providing encouragement and support for being healthy.

4.4.2.1.5 “God is watching me”

Several of the elders spoke of God’s role in people’s health at different stages of life. First, God preplans each individual’s life, so this explains why some people do not get diseases that their parents might have. Second, if a person tries to help others who are in need, if she/he follows and believes in his instructions, God will reward her/him with a long life. Third, when sick, it is okay to continue working through the illness because the belief is that God is watching over and protecting each person. And finally, whatever a person endures is what God intended for that person, so if he lived his life properly, when his life ends, it is seen as God’s
determination that that person was ready to go.\textsuperscript{29} I asked some middle-adult participants during a follow-up trip about leaving the role of God out of presentations that draw from scientific research about health, and how this would be received by people in the community. They responded that although religious beliefs appear to be strong in the population, the younger generations hold an understanding of this separation, and of the fact that science does not attempt to explain religion, but is limited to what researchers can test about the physical world.

\textbf{4.4.2.2 Healthy Foods}

There are several common themes that are widely understood among my participant sample: 1. Yup’ik food is healthy, 2. Store-bought or \textit{kass’aq} food is unhealthy, 3. Fresh fruits and vegetables are healthy, but hard to come by in the rural communities. An interesting point here is that people know that Yup’ik food is healthy and store-bought food is unhealthy, yet fruits and vegetables that are (mostly) bought in the stores are considered healthy.\textsuperscript{30} When I inquired about the confusion that I saw in calling store-bought foods unhealthy, but calling produce (which can only be bought in the stores) healthy, interviewees explained that the foods that are referred to as “\textit{kass’aq}” or “store-bought” are generally considered to be the more processed foods, such as chips, candy, pop, frozen pizza, pre-packaged snacks. They put produce in a separate category, acknowledging that is it both healthy and store-bought. Participants draw similarities between vegetables found on the tundra and vegetables found in the stores, which might account

\textsuperscript{29} This might be an example of a way in which religion is used to comfort those who are grieving, perhaps more so than an explicit health belief.

\textsuperscript{30} There are Yup’ik fruits and vegetables that grow in the wild, but most of the examples that people offered when talking about healthy foods were produce that are not grown in southwest Alaska, such as oranges, bananas, apples and avocados.
for this unspoken category of health foods. Researchers need a clear definition of what is interpreted by the community as healthy food, and the types of items that are captured by that designation in order to provide useful health information.

Some of the attributes of healthy foods that participants reported include foods that are natural, without preservatives, low in sugar, have vitamins, and are fresh. Seal oil was a commonly mentioned example. The perception is that Native food generally has more of these characteristics than store-bought food. Native food is known to help keep one’s teeth healthy, and one young woman boasted about having lost 20 pounds after giving birth by eating native foods. She related a fact that she heard, that Native food “keeps your weight much lower if you eat a lot.” Store-bought food, also known in the community as “fast food,” is perceived as unhealthy and having more calories, but it is also known to the younger and middle adult participants as tasting better, and more easily accessible because one doesn’t have to travel out and hunt for it. Store-bought foods are known to lead to heart disease and other ailments, yet the convenience and appealing taste make them more attractive to some people. Some elders also believe that foods such as tundra vegetables are good for one’s health and in particular, one’s heart. Their elders taught them which foods were healthful for them in the wilderness when they were growing up. The elders also stressed that one should have respect for the animal that one is taking for food, that one should not “make a mess of your catch”, that one should take care of it “keeping in mind that it gives strength to the body.”

4.4.2.2.6 “What you are raised with is what you like.”

Several participants expressed the opinion that what people are exposed to as children influence what they will choose to eat as teens and adults. Grown adults will prefer what they
were fed when they were young. One young female provided a story of her dad who prefers plainly boiled salmon without rice, which is what he was often fed during his youth. A middle adult male told about an older man who prefers seal oil to mayonnaise, in contrast to younger people he knows who were raised with mayonnaise. Another middle adult mother also expressed regret that giving her kids pop and candy at too early an age has made them into “sugar addicts”. She believes that parents should not give their children foods that are high in sugar when they are young, to prevent them from needing to eat it all the time as older children and into adulthood. This pattern observed by participants is an indication that one area of intervention that might be appropriate is supporting parents in an effort to help them teach their young children about nutrition choices and developing healthy habits.

4.4.2.3 Activity

4.4.2.3.7 “It’s about being strong, not sitting around too much.”

Participants of all ages brought up the importance of being physically and mentally active in order to be healthy. Many talked about their ancestors’ way of living as exemplary, highlighting their physically demanding lifestyle and getting foods from the land and ocean as factors that kept them healthier than people are today. The men “back then” are described as “going hunting all the time,” “always working, never idle,” and “never tiring.” However, the elders explained, one could only do this if they did not over exert the body and if they didn’t do strenuous work when they were young and growing so as to ruin the body. Back then, people

31 There were many instances in which people of all ages stated that people today are not as healthy as people were back then.
had to use their bodies as weapons and tools, used their arms to row qayags, and depended on
their legs or dog teams instead of snowmachines to travel into the tundra.

Today, men still hunt for food, though new technologies have changed the way people
hunt. They still do other chores as well, (e.g., shoveling snow, splitting and hauling wood,
packing freshwater, and fishing). One young woman explained that the men “keep healthy by
fishing, building their muscles.” Another young woman explained that for both males and
females, fishing provides a way to stay out of trouble by spending time with one’s family, which
helps to make a person healthy. One middle adult male described his picture of health as having
all of one’s body parts, which enables a person to go hunting. He mentioned the healthy person
having working body parts, but the point he was making appeared actually to be about the
importance of being physically able to hunt. The ability to hunt and carry out subsistence
activities embodies a set of values that extend beyond just maintaining physical activity to the
greater good of the community.\(^{32}\)

Nearly everyone with whom I spoke cited the use of snowmachines and 4-wheelers to get
around in the small community as an unhealthy change. Now that there are motorized vehicles
available for people to use, it is a challenge for many people not to use them, even to go relatively
short distances, much like in the more urban parts of Alaska. One young man explained that he
started refusing snowmachine and four-wheeler rides during the past couple of years, and as a
result, he has lost a lot of weight, for which he was proud. Yet many other younger and middle

\(^{32}\) Note that being a hunter also means that the person provides Native foods for the family, which are
considered healthy foods, contributing to the family’s health. A middle adult female also described picking
berries for an elder woman in the community and then continuing to provide her family with berries for one
season after her passing. Being physically able to conduct subsistence activities contributes to the
community’s overall physical and social health.
adults admitted that they take rides, despite knowing that it would be healthier for them to walk, as their ancestors did.

4.4.2.3.8 “This is a basketball town!”

Many younger and middle adult participants specifically mentioned exercise as a way to keep healthy. Basketball, Eskimo dancing, walking, and doing chores such as shoveling snow and fishing, were named as the most common ways people exercise. There was a large difference between the reported males’ and females’ levels of exercise. Several participants pointed out that although the women (particularly older women) stay busy, they tend not to be as physically active as the men. Although they Eskimo dance in the winter and fish in the summer, most of their activities are less physically demanding than those of the men. The men tend to do the more physically active chores, as mentioned in the above section; and more men than women tend to play basketball. Several mothers expressed being stuck between knowing they should exercise more and not having the time and energy to do so, after working (some in office jobs or school) all day and cooking and cleaning for the family. There is a weight room at the school that may be used by school employees, and jogging was mentioned as means for exercise, though the rare jogger (usually an outsider) in a rural community is met with confusion by others.\(^33\) The desire to find alternative ways to exercise was mentioned many times, especially by the women who do not play basketball. Many expressed an interest in a public gym to set up treadmills, stairclimbers

\(^{33}\) Though I have never seen anyone jogging in a rural community, a non-Native teacher at the school who has been living in the community for just over two years, explained that people have questioned what he is doing when he is seen jogging near town.
and a weight room that is open to people who do not have access to the school exercise equipment.

4.4.3 Health Concerns

I now turn to concerns mentioned by community members when asked which things were major health concerns in the community. The most commonly cited health concerns for the community were cancer and its speculated causes, diabetes; the changing diet of many people in the community; and the changing social milieu. Other health concerns mentioned by individuals reflected their own personal health issues, or those that afflict their family members.

4.4.3.1 Cancer

Often, the first disease that participants mentioned was cancer. When asked to be more specific, responses included breast cancer and brain tumors; middle adults reported observing kidney, liver, colon, stomach cancers in the older generation; they noted cancers of the neck, brain, lungs, and heart, characterized as cancers located higher up in body in the younger generations. Particular interest surrounding cancer includes what the causes of cancer might be, as several participants reported that they have heard that shampoo, various products sold in stores, environmental factors, contaminated oceans from oil spilled in the water, air pollution, and dried smoked salmon all cause cancer. These causes were qualified with a statement indicating that the information was “a rumor,” or otherwise unsubstantiated, and no one stated these causes as known fact. There is also a common concern that when the kass’ags came and shipped outside foods into the communities and the residents’ diets changed in the early to middle 20th century,
this might have caused the increase in cancer rates that seems to have occurred.\textsuperscript{34} For some of the elders, their concern regarding cancer, also described as “the one that is incurable,” is that people who are diagnosed with such a disease suddenly become weak and begin to deteriorate quickly as a result of knowing their diagnosis.

4.4.3.2 Diabetes and Diet

Diabetes was also frequently named as a health concern, and though its prevalence was only mentioned by one participant, the risk of developing Type 2 diabetes was reportedly disconcerting. Several people mentioned little kids, parents, siblings and others drinking too much pop and eating candy or “fatty foods” as risk factors for diabetes and related diseases.\textsuperscript{35} Similarly, the elders were particularly concerned about the fate of the younger generations who eat mostly store-bought foods, when the stores and technologies that they rely on disappear or become unavailable, as they warn will happen. An additional dietary concern for some is that the meat that is consumed locally might come from sick or contaminated animals, including locally

\textsuperscript{34} There are no data that show the cancer rates from dates earlier than this. It is unclear whether any recorded increase that might have occurred would be due to an actual increase in prevalence or an increase in testing and diagnosis. Previously, cases of cancer could have gone unrecognized and cause of death would have been attributed to old age or a generic sickness. However, there are reports that infectious diseases were a more wide-spread cause of mortality in previous generations, and that generally people might not have lived long enough to develop cancer.

\textsuperscript{35} It is relevant here to point out that most of the participants in my study had prior experience with CANHR’s work in the community. Given CANHR’s focus on diabetes, it is possible that this response might have been influenced by an association with talking with CANHR investigators. This seems probable, as most of the concerns mentioned were accompanied by an explanation that there is a perceived high or increasing incidence of that health issue in the community. As diabetes incidence rates are still less than 1.5% in the region, this does not account for the reported importance of the issue. The apparent importance of diabetes as a health concern might be over-represented in the population that has been involved with CANHR projects on more than one occasion as compared with the general population.
hunted and store-bought meat. One example of this was a commonly consumed specifies of fish that recently had been caught, with unusual lesions of unknown significance.\(^{36}\)

### 4.4.3.3 Social Ills

There is some concern that tobacco use (especially in young kids), alcohol, drugs, gambling, and bingo are weakening people’s bodies and minds, and breaking families apart. The increase in negativity and decrease in people providing each other with encouragement and support, which many people have stated are an integral part of being healthy, is seen by some as degrading the culture and way of life. One middle adult man remarked, “the health concern, I think, has spread around because of that negativity towards each other. Like, not being supportive or not giving encouragement to another, I think is the main source that’s making us fall apart, (inaudible) our culture, our way of life.” These negative changes lead to weakness, which makes for unhealthiness in the community as a whole.

### 4.4.3.4 Honorable Mentions

Other mentions of health concerns include the recent respiratory syncytial virus (RSV) breakout, migraines, physical injuries, allergies to local foods (red salmon, tomcod and other fish), and high blood pressure. These were issues experienced by the participants themselves, observed by the participants in their family members or in the clinic, or seen and heard about in

\(^{36}\) CANHR has offered to help the community determine the source of this fish concern, upon receipt of an affected tissue sample. As a multi-disciplinary center, CANHR has the expertise to address a variety of community concerns.
community members in general. Though I asked about general community health concerns, most people described illnesses identified from their own experience.

4.4.3.5 Participants’ suggestions for future research

When asked about research interests, individuals’ responses did not necessarily mimic the responses they gave when I asked about a person’s community health concerns, though the aggregate interests remained largely the same. This seemed to be a more difficult question for many people to answer than other questions, and I can only speculate that this is because of most people’s limited familiarity with research. One young male participant directly stated his perceived lack of influence in the research process when I asked him what he’d like to see CANHR researching: “I have no idea. It’s your research, your own creation of what you made.” Others provided the following few suggestions for research: animal diseases, such as those of the cow, fish, and birds that the local residents eat; environmental pollution and contamination, such as air pollution that damages lungs; oil spills in the oceans that contaminate subsistence food sources and local water supplies; and causes and prevention of various types of cancer, as they have seen, “too many young ones died of cancer.”

4.5 Social Location: Where a Person Enters the River

As in any community, different people occupy different roles in Quyana. The groups that were highlighted in my conversations with participants can be delineated in multiple overlapping directions. A person’s age, whether that person occupies male or female roles, a leadership or non-leadership position (which is also associated with age), and languages spoken (Yup’ik,
English or both), all impact that person’s understanding of health information. A person has multiple different roles within the community, and, undoubtedly, there are other roles not mentioned during my study. A person might be a female Yup’ik speaker, who is an elder in the community and whose advice is respected by others. Or a person might be a middle-adult male, elected to a Council, who speaks both languages. In this section, I explain the dichotomous roles as individual pairs, as I do not have sufficient data to determine how much each of these different roles influences an individual, and which roles should be weighted more heavily.

4.5.1 Gender Responsibilities

Although girls and boys are no longer taught in the traditional settings of men teaching sons in the *qasgiq* and women teaching daughters in the smaller homes, women and men continue in general to fill traditional gender roles. Men are generally the hunters, providing food from the tundra and water for the family and community members. They repair boats and other motorized vehicles, pack freshwater and shovel snow. Women tend to take a larger role in caring for the children, gathering berries and tundra greens, and the house-based chores. These separate but shifting roles are also described in Hensel (1996). Not everyone is completely satisfied with his or her assigned responsibilities. One day after a snowstorm, I was walking by a young teenage girl digging a snowmachine out from under a deep snowdrift. We greeted each other, and

---

37 The *qasgiq* was a large sod room, with a fire in the center and smoke hole above, whose walls were lined with benches. This is where the men spent most of their free time, sharing stories, teaching younger men and boys over the age of five how to survive in the wilderness, hunt, built *qayaqs*, etc. They slept and took meals in this house as well (Fienup-Riordan, A. 1996. *Agayuliyararput (Our Way of Making Prayer): The Living Tradition of Yup’ik Masks*. Seattle: University of Washington Press). Elder men still talk of growing up in the *qasgiq*, but report that such a structure has not been built or used in over half a century.
I asked her about what she was doing. She admitted that the snowmachine wasn’t even hers or for her own use, but shoveling the snow was “better than doing girl things.”

Many of the men’s chores and responsibilities require physical activity. Men also tend to play basketball (the only organized sport in the community) much more often than the women play. All of these activities require leaving the house to complete. One perception that was mentioned several times in my discussions with community members was the notion that the men are more active than the women, especially in wintertime. They are responsible for more of the physically demanding chores, which, in one female participant’s words, meant that “men are more healthy here (than women).”

Women complained about not having enough time to do the things they want to do or think they should do for their own health. Several expressed an interest in exercising more but not having time to do so. The three main reasons for not having time included having to do house chores such as cooking and cleaning, preparing teas and “putting away” food such as seals, caring for children and grandchildren, and not having babysitters or anyone to help with these responsibilities. One young mother begrudged having to quit her job at the clinic in order to take care of her children, as she had no babysitter. An additional reason for not having time is that

---

38 By at least one measure of health, this claim is supported by CANHR’s data. The prevalence of metabolic syndrome is higher in women (19.8% of the study cohort) than the men (8.6% of the study cohort), with the most common risk factor being large waist circumference, (Boyer, B. B., G. V. Mohatt, R. Plaetke, J. Herron, K. L. Stanhope, C. Stephensen, and P. J. Havel. 2007b. Metabolic Syndrome in Yup’ik Eskimos: The Center for Alaska Native Health Research (CANHR) Study. Obesity 15:2535-2540).

39 While the men go out and hunt seals, it is the task of women to butcher the catch. This includes cutting the seal down the abdomen, cleaning out the internal organs, and harvesting the blubber, fur and meat. Depending on the size of the seal, the skill and number of workers, this can occupy a significant part of an afternoon. One young female community member reported having put away seven seals in one long day. This chore keeps the woman sitting or bent over, while working. The actual energy expended during this activity is one subject of interest in the next phase of Dr. Boyer’s physiology project.
some of the women hold jobs outside the home as well as care for the children and maintain their roles as caretakers in the home. Some women gather wild greens and berries for subsistence, a task which takes them out of the home and into the hills surrounding the community. Although walking out to the berry picking locations is physically demanding, most of the responsibilities delegated to the women require less physical activity than those of the men.

4.5.2 Leaders vs. Non-Leaders

There are two categories of leaders identified in the community: those who are elected to official seats in the Councils (not necessarily elders) and those elders who have gained the respect from the community for having knowledge and experience in life, to whom others look for advice, though they are not members of a formal Council. For my purposes here, two attributes distinguish the leaders of both types from the rest of the community: they sometimes have additional opportunities to learn information that others do not, and they are generally considered to have more knowledge and experience, which means they might have a broader base for applying new knowledge to their existing knowledge than would non-leaders.

4.5.2.1 Elders vs. Youth

Many people identified elders as a type of leader in the community, because they have gained knowledge through their life experience, in a community where survival and life skills and a relationship with the natural environment are highly revered. For my purposes, I assume that the elders are the carriers of the traditional knowledge, as they might have the least amount of outside information (from newer tributaries) due to the language barrier, which acts as a type of
filter, preventing them from accessing much of the information that flows into the river. If information enters into the river of knowledge in a community and is applied to individuals’ existing bases of knowledge, then people who have lived a long life would have gathered more knowledge. Thus, they would be mixing the new information with a broader base of knowledge from an older source, which would influence the shape that the aggregate information takes on. I was told that it is beneficial to have elders in meetings because they’re willing to speak up and voice concerns about an impending decision that, in their opinion cultivated through life experience, will have negative consequences. In contrast, young people are reluctant to speak up in a group of people who are older than they are, as one middle adult explained it, “because they’re afraid people won’t listen to them.” Elders speak about traditional values at dances and at the school, to pass on these values to help the younger generations live a good life. Elder men might share their concerns with the community (often over the VHF radio) about weather conditions for the hunters, and if people listen to and heed those concerns, then that shows that the elder is an effective, respected leader. Female elders talk more to the women, about respecting everything around them and the right way of living, passing on values to children (but not about hunting), how to act toward their husband, and about chores, or spiritual advice. Elders in the past taught the current elders (in their youth) what foods from the tundra were healthy for them (which vegetables were good for the heart is one example that I heard). They use shaming as a way to teach people when they are doing something wrong, or acting against the Yup’ik way of life.

40 There are some elders who also hold elected leadership positions, which afford them more outside opportunities for learning information.

41 There is also an accepted public speaking order, which gives first priority to the eldest people and last priority to the youngest people.
However, several of people over 55 years of age expressed concerns about an absence of “true elders” in the community now, those older adults to whom people looked for advice and whose role in the community was particularly highly valued. A big reason for this lack is apparently strained communication between younger and older people nowadays. A male and a female elder both mentioned wanting to give advice about “how to live a good life” to younger generations but feeling unable to articulate the instructions in a way that younger people understand. This non-communication was attributed, by several participants, to changes in younger people’s attitudes, influenced by television and the media, and outside ideas that degrade the respect that community members once had for their elders. It may be the case that, having failed after several attempts to pass on the traditional values to younger people, elders find it not to be worth the effort when their words fall on seemingly deaf ears. This also may result from information that was lost after the missionaries and others asserted influence over the culture and prevented much of this information from being orally transferred, as it traditionally would have been shared. A further reason named for perceived lack of inter-generational communication is the language barrier that exists in the community between the young people who learn modern Yup’ik in school, and the elders whose Yup’ik is of an older era.

In contrast, the youth in the community have access to western education and informational technologies that older people do not. One reason is that no school system existed when the elders were growing up, and even as late as twenty years ago, students had to leave the community for their formal secondary education. Young adults and children nowadays are able to attend K-12 school in their home community.\textsuperscript{42} As part of their education, students have

\textsuperscript{42} Though some highly motivated students also leave the community to study at boarding schools in other parts of the state.
access to laptop computers and the internet, which they use both for academics and for recreation. Being raised with both Yup’ik and English, and learning to read, they can access a broader range of written and oral sources of information than the elders who speak only Yup’ik or limited English. However, several adults, middle aged and elder, emphasized that this school education is important but not an adequate substitute for life experience and education “out on the tundra.”

4.5.2.2 Elected Officials vs. the General Public

The elected officials have a somewhat privileged position in the community in terms of learning new information from outside of the community. These are the members who tend to travel for meetings in Bethel, Anchorage or elsewhere, representing their community’s interests and taking information back to the community. In some cases, it was reported, when leaders return home from meetings, they hold community meetings or make announcements regarding the new information in various venues, including church, and the bingo hall.

It was the Council leaders who were invited to participate in the Genetics Education for Native Americans (GENA) workshop, led by Linda Burhansstipanov, that CANHR sponsored early on in the development of the project and partnership. This 2-day event provided leaders from communities in the Yukon-Kuskokwim (YK) Delta with some basic knowledge about genetics, and genetics research, enabling them to make better informed decisions about whether or not they would support having CANHR work in their own communities.

Seniors in high school are issued a computer for the academic year, and other students can sign one out for shorter periods. One teacher informed me that access to their laptops provide an effective motivator to students whose grades are not satisfactory.
The above-mentioned opportunities are not available to non-leaders, and thus information that is transmitted from those meetings is necessarily filtered through these leaders before reaching the other community members, if at all. It seems clear, based on my conversations with non-leaders, that the information from the GENA workshop was either not passed on to residents, or the retention of this information was very low.\textsuperscript{44}

4.6 Genetics: A Case Study of a New Tributary

Genetics research represents a new tributary to the river of knowledge about health. There have been other tributaries over time that have introduced concepts of genetics at different stages, such as through the formal school system (health and science classes), healthcare providers, the media (television, magazines, newsletters and the internet), outside presentations (such as CANHR’s and other researchers’ visits) and previous trainings and workshops (such as the GENA workshop and medical training that community health aides receive). Related traditional knowledge exists in the river, here assumed to be the responses that elders provided in response to my questioning about knowledge of heredity, or “things that are passed down in the blood through families,” a phrase used throughout the CANHR project. A person’s location in the river, or social role, influences which of these various tributaries he or she can access, and what he or she reports on the topic of genetics. I will address these two aspects of the river metaphor in the following paragraphs.

\textsuperscript{44} Perhaps this would be true for obvious reasons: the material was complicated and required two days to convey, the leaders were new to this type of information, and it may not be of particular interest to individuals in general. Additionally, the workshop was held in the Fall of 2002, nearly six years before my data collection visit.
4.6.1 Current Beliefs: The Water

There are several main themes running through participants’ responses when asked about genetics and heredity. Most people gained any familiarity that they have with genetics from school, the media, and their elders. The question that was posed to the Yup’ik speakers asked them to explain “the things that are passed in families through the blood.” The following paragraphs summarize the beliefs that people reported when asked about what they have heard or understand about genetics. To illustrate the concept of social location, I provide the current belief responses, divided by the age groups, elder adults and younger/middle adults. In one case, I provide a response from an elder who is also a recognized leader in the community.

4.6.1.1 Elders’ Ideas: The Carriers of Traditional Knowledge

When the elder participants were asked about how they understood the diseases that are passed on through families, many responded that they did know about this. It was one of their ancestors’ teachings that some of the children of a couple would get the disease that the parents have, and children of parents without disease wouldn’t get the diseases, because diseases are passed through the blood in families. One man explained that he doesn’t quite know why but if a parent has a disease, their child will definitely have it too, and offered that it might be because the child ate from the mother’s body and has her blood. A pair of sisters agreed on several ideas, and the younger explained to me, “She always mentions what I’ve been thinking, cause we’re blood,” referring to their propensity to have similar thoughts due to their familial relationship. Another notion that was offered was that while diseases go through generations, they fade and weaken from generation to generation, as the blood changes down the generations. So when the children get the parents’ disease, it won’t be as severe. And one woman explained why some children get
their parents’ diseases and others don’t. This is because “God has given us our life, that is already preplanned...some people even if his parents had it, won’t have it...but what their parents had will show up more often with their children. Because we all have different lives set for us, it doesn’t happen all the time.” One man pointed out that because heredity is not well understood, it would be unwise to use family patterns of disease to predict future disease, as predicting disease (according to many people) might then welcome the disease.

One woman explained that heredity is like a landslide that travels in one direction, from ancestors to descendents, and includes not only what is in the blood, but also other aspects of life such as values, teachings about the way of life, and so on. When she was growing up, this landslide (the way they were living and learning) was smooth and even, but nowadays, the landslide of the younger people is rough and takes a different course. Life is harder for the younger generation because they have strayed from and disrupted the landslide that their grandparents were on. This image of the landslide reflects the holistic idea of health that is endemic in the Yup’ik way of life: she used this image to explain all aspects of a person’s life that are transmitted through the generations.

One male elder and prominent leader in the community explained a piece of information that he received from the *kass’aqs*. He stated (translated from the Yup’ik), “We don’t all have the same blood. Since the couple’s children have the same blood, they can inherit their parents’ disease, through the blood.” This response might reflect a mixing of knowledge in the river. In this case, the elder reports what he has learned from an outside source, which may become part of

45 This participant was a leader in the community who had attended the Genetics Education for Native Americans workshop that CANHR organized in 2002. He was invited to this workshop based on his status as a community leader.
the knowledge that is passed on through the river, incorporated as commonly held beliefs.

4.6.1.2 Middle and Younger Generations’ Ideas

I report both of the younger age groups together in the following paragraphs, as I found commonalities in their responses distinct from those of the elder participants. Many of the younger and middle adults stated that they either didn’t know about genetics, or that they had some understanding that diseases and other personal traits are passed from grandparents and parents to children, but that these things are not necessarily passed to all of a couple’s children. Examples of genetic conditions that they mentioned include cancer, asthma, dwarfism, and having twins. One middle adult participant explained that when he learned about genetics in school, the concepts didn’t sink in for him, but he understood better as an adult when his aunt (also a participant) explained it as a “landslide,” mentioned above, encompassing more than just genes, but also values.

Many of the middle adults explained that there are appropriate and inappropriate ways to talk about genetic traits. First, genetic observations are used in an explanatory, not predictive manner. Parents’ traits are not used to predict what their children will have, but if the child has a disease that one of his/her parents has, they’ll know that it is because the parent had it. Many people believe, as the elders mentioned, that by talking about or “anticipating” a disease, one “welcomes” the disease. However, there were a few participants who expressed an interest in knowing if a disease that they had in their family was genetic, and could be passed to their children. The explanatory-not-predictive use of hereditary traits could have an important impact on bringing genetics information to the community, as it is clinically used in a predictive manner, and to evaluate a person’s risk for a disease.
In addition, it is more acceptable to discuss the parts of the body that are visible on the outside, but less acceptable to discuss the parts of the body that are inside. They talk about the way a person looks, walks, laughs like their family members, or that a man is going bald like his male relatives (the balding spot referred to as an “eagle’s nest”). However, there are instances in which questions about a person looking different than their family members could be taken offensively. As one middle adult female pointed out, “taking the example of why he (the brother) is so tall and why she (the sister) is so short, it might be that they have different fathers…it’s a disrespectful question.” Sometimes, others explained, “our elders get offended by the questions that you want to know, because that wouldn’t be a proper question for me to ask them.” Some people offered that genetic questions might be seen as bringing up sensitive subjects, such as questioning parentage. Some of the questions about observed hereditary traits were met with answers about how a child was raised differently than their siblings, and so would have some different traits. For example, the mother whose son was much taller than his siblings said, “it was probably because of feeding him evaporated milk instead of breast milk.” These environmental factors might have been invoked as a way to avoid discussing other reasons for physical differences among siblings.

4.6.1.3 Infectious Diseases vs. Genetic Diseases

There were a couple of instances in which some important misunderstandings were revealed, simply by explaining genetics as “things that are passed through the blood from parents to children”. One young male offered an example of a disease that is passed from parents to children through their blood. He said, “Like HIV and AIDS…parents who have HIV or AIDS will be passed on to their daughters or sons.” This highlighted that my description of genetic
diseases was inadequate, and that I needed to make clear the difference between infectious diseases and genetic diseases. 46

The second instance was with an elder male who expressed certainty that children will always get what the parents have, and that he heard about people passing diseases such as tuberculosis (TB) to their children and not other people. This disease would perhaps also fit the description of diseases that one passes to one’s children but not to others, if the sick person only comes in contact with their own family members. But like HIV, TB is an infectious disease with a different mode of transmission. This again highlights the importance of making explicit the differences between genetically transmitted diseases and infectious diseases. I make recommendations regarding this concern in Chapter 5.

4.7 Concluding Remarks: “People Have Different Minds”

Finally, I should reiterate a point made earlier, as it was so frequently mentioned throughout my interviews. Each individual person is different, has different opinions and knowledge based on different experiences, so everyone will understand new information at least slightly differently. When I asked participants about their perception of the community, most people declined to offer concrete information. Examples of this idea include, “I don’t know about the younger kids… I guess they’d have to answer that for themselves;” “If they [people in the community] wanted to go, they would show up;” “I’m not speaking for the people, but I would like to know more about it;” “I’m still too young to know [about who has large influence

46 In this case, additional explication would be necessary to explain the ways in which HIV is transmitted as well.
in the community, from a 24-year-old participant],” “You’re going to have to talk to a woman [about the influence of women elders in the community, says a male participant].” “I don’t know, I didn’t ask for that [about why the community agreed to be part of CANHR];” Nearly everyone answered positively about wanting to learn more from CANHR, but they all mentioned that they were only speaking for themselves and not for anyone else or the rest of the community. In the end, people will pay attention if they are interested. Their individual interests and priorities dictate whether they will pay attention to new information and take steps to assimilate the information in their own minds. How each individual chooses to do this is up to him/her. It would benefit the community, and ultimately CANHR, to figure out how to make the health information interesting to a wider segment of the population. As one leader suggested, using multiple avenues is wise, as he thinks the information is good for everyone; and CANHR should attempt to reach as many people as possible. In particular, focusing on the youth seems to be a priority for many people.
CHAPTER 5 DISCUSSION

In this concluding chapter, I suggest a series of recommendations for approaching research and for improving disseminating health research results in a Yup’ik Eskimo community, based on the findings presented in Chapter 4. I offer a review of some of the major limitations to this study, and suggest areas for future research. I end with concluding remarks, situating my discussion within the Community Based Participatory Research (CBPR) literature.

5.1 Recommendations From the River (Figure 4.1)

5.1.1 Knowing the Water

To recap, the water represents the collective knowledge that exists in the community. The source is traditional knowledge from generations ago, having already flowed through centuries of change and adaptation, passed from ancestors to descendants to the current community residents of today. In order for the Center for Alaska Native Health Research (CANHR) to effectively present new health information to the community, it is necessary to understand the water that is already in the river, the existing health-related beliefs in the community. Here, I present some of the reported local knowledge that I believe would be of particular interest to CANHR.

First, a major difference between traditional and western biomedical notions of health is the idea expressed by one elder woman when she said, “if it helps me, I plan to tell others.” While the notion of a communal prescription for health may be common in everyday friendly interactions in many (including western) cultures, it is distinct from the western biomedical view of individualized health prescriptions from physicians, stemming from the disaggregation of the
different aspects of health. As many elder participants in particular described, they hold a holistic view of a person’s wellness, characterized by living a “good life,” or “following a good path.” The instructions for how to do so have been passed down for generations, applying equally to all people in a particular role. There is little differentiation between individuals, when prescriptions for health include such universal rules as treating each other with respect, paying attention to those who have more life experience and heeding their warnings about not hunting when the weather is projected to be too dangerous, and so on. If a person follows these communal instructions, he or she will live a long life, as some would say, rewarded by God.

Some elders’ concepts of food as medicine—again, what is good for one is good for all—provide a contrast to doctors’ orders for a specific individual, which might be good for all (such as general nutrition recommendations), but are often tailored to a particular patient’s particular circumstances (such as extra diligence on the part of people with a higher risk for heart disease, regarding eating healthfully and exercising). Moreover, a doctor’s prescriptions often include medications that are only appropriate for the individual patient, and could actually harm others. This is especially important for CANHR in the case of genetics, as this branch of medicine is expressly individualized. If we provide recommendations that are too far from recipients’ cultural understandings and norms, interventions will not be effective, and could, in fact, be harmful. For instance, with genetic testing, people understand that families have the same blood, so perhaps they might be seen as having the same test outcomes.

As mentioned above, the local understanding of God in a person’s health outcomes is an important additional factor for CANHR to recognize. Although in my follow-up conversations with community members, they confirmed that it is probably not a big issue for everyone, especially younger people in the community, but it’s good to know that this is something that
some people conceptualize. The elders expressed the notion that God preplans our lives, and whatever a person experiences is part of God’s plan for that person. God also rewards people who live a good life by not giving him or her the diseases of his or her parents. I wondered if scientific notions of health choices and outcomes would contradict these religious notions, and offend some community members. The participants that I consulted during my return visit expressed that these different perspectives are probably not necessarily contradictory, and that people understand the difference between scientific knowledge and religiously rooted beliefs. However, given the consistency with which the elders expressed a belief in the role of God in a person’s health, it is important for CANHR investigators to understand that this idea pervades at least the elder generations in the community. While I am not suggesting that scientists should attempt to address religious views in their scientific pursuits, it is necessary to be sensitive to this viewpoint when providing information to the community.

Third, the belief that a person is responsible for choosing their own paths is an important concept in the community, as it came up over and over again throughout conversations with people of all ages. This applies to all aspects of a person’s life, and people recognize that there are consequences associated with the way people choose to live. For example, participants link personal decisions to health outcomes in that some people are “overweight because they ate too much fatty food,” and “kids have ugly teeth from eating too much sugar.” While it is true that there are particular ways in which a person might prevent an undesirable health outcome, and that is why CANHR is interested in helping to provide education to this end, there may be a tendency for some community members to place stigma on individuals who have experienced these health
outcomes. While working in the community, educators and investigators ought to keep in mind that public health interventions might play out differently for people with different roles and status in the community. Some people may have more difficulty (or interest) than others making the “right” choices (as dictated by the outside health educators) and so they shouldn’t have to endure any related stigma for not making these choices. Any educational effort should take care not to play into new complexes for community members, by focusing on making positive changes rather than focusing on avoiding negative behaviors.

Any information that is learned about health is embedded in a larger context of community concerns, understandings, and priorities. CANHR must remain open to how this information might be assimilated in ways that they might not anticipate. This is true for any public health and educational effort; that is, all publicly disseminated information is necessarily going to be integrated into individuals’ current understandings and knowledge about these issues, or to issues that they see as related. These current understandings are dynamic, influenced by a variety of sources coming into the community: the relatively high turnover rate at the school brings in teachers from different backgrounds, providing different information to students; multiple researchers and healthcare providers from outside the community visit frequently, providing different information to the community; the media has some influence on what people understand (although the extent to which this is true is unclear to me, as it seems to impact some

---

47 This is particularly important, as health information is constantly evolving, and new guidelines and recommendations emerge every year or two. As health recommendations are frequently changing, CANHR should be mindful of how shifting recommendations are received in a Yup’ik community. The reality that traditional teachings are tested by time, and thus do not frequently shift could confound community members’ receptivity to health information from outsiders, which has a pattern of changing (Phyllis Morrow, personal communication, December 11, 2008).

48 Another effort might be to help make healthier choices available to all people, by working with the stores to stock healthier foods, and by providing cooking and food preparation information with these different foods.
people very much and others almost not at all, although access to television media appears to be relatively universal).

The nature of the river changes, even if only slightly, between CANHR’s visits, and certainly over the long-term. Even the researchers who are more familiar with the community receiving the information might not have sufficient knowledge of the dynamic social context to anticipate how information might be used. Therefore, it is prudent to expect the unexpected, and to consult with a local collaborator prior to providing health information. A local collaborator can help broker cross-cultural interactions; lessen misunderstandings; dispel myths; and provide on-going support and information to members of the community, and a line of communication between the community and the researchers. Participants suggested that they were interested in having the on-going support of a local person who would be available on a more frequent basis, whose job would be to maintain the momentum of interest in the CANHR project between investigators’ visits.

There are challenges associated with finding a person to fill this role. Many local residents are busy with subsistence activities, which take place on a schedule that is not necessarily compatible with a regular 9-5 work-day. Many people also have family and work obligations beyond subsistence. Finding someone who has the time and dedication to the project might be difficult, though it could benefit the project to have someone who does live a largely subsistence-based lifestyle as a model for the community. Additionally, this person should be old enough to be considered knowledgeable and experienced enough to be trustworthy as a voice of leadership. In the past, CANHR investigators have attempted to leave educational responsibilities in the hands of paid local research assistants with varying degrees of success. Why this has not been more productive in the past would be an area for future evaluation.
Potential progress in this area might be seen with the expanding scope of the CANHR project. Community members’ stated health interests extend beyond those concerns that CANHR has studied in the past. However, CANHR is in the process of developing new projects that address community health concerns such as various types of cancer. There might be greater success with finding and keeping local collaborators who emerge because a health topic is particularly interesting to them. Catering more to local health interests would be both consistent with a CBPR approach, and lead to a greater likelihood of finding someone who is truly invested in the project. Then integrating other health information such as genetics into the effort to report the cancer information might be one way to reach a wider array of goals.

Another possible remedy to the above challenges might be provided by a health educator position based out of Bethel who would work with the local collaborators in the various communities. I would recommend that this position include on-going support for community research assistants who are involved in CANHR studies, or for a potential high school group engaged in a public health project by spending most of their time visiting the individual communities.\(^{49}\) This person could oversee the individual educational efforts in each community, which might enable them to sustain these efforts in a way that is appropriate for each community.

Finally, however successful investigators are in ensuring that their message is culturally appropriate and meaningful (by working with local representatives), one can never be completely certain of how that message will be received or retained by the broader membership of the community. One must anticipate bi-directional misunderstanding, while continually working toward learning about how one’s messages might be understood by the community, and building

\(^{49}\) This school group concept will be explained later in this chapter.
into efforts the flexibility to make changes in content, format or delivery at each stage of the process. An on-going evaluative effort (beyond the use of focus groups/working groups in the dissemination development) might accompany the return of results, so as to continually strive to understand how the information is understood more broadly.

5.1.2 Where a Person Enters the River

Revisiting the next part of the river metaphor, the place in the river where a person enters, or their role in the community, influences how they will learn about and assimilate new health information. As discussed, age, leadership status, and gender are ways in which people might be distinguished in the community, though there are undoubtedly others.

Beginning with age, it was explained to me that people gain more knowledge and life experience as they age, so as elders have a lot of knowledge, they are good sources for advice and teachings about various aspects of life. Their position in the river is upstream from the younger generations, and so they have had more time in the river to gain a broader base of knowledge than younger people. At the same time, however, their picture of new knowledge is limited by the means by which older and younger people learn about new information and events. As most of the elder community members do not speak English fluently, if at all, efforts should be made to present information in Yup’ik, which requires skillful translation of scientific concepts.

Generally, CANHR does well to ensure that their written and oral information is available in both languages, but there are some instances in which information is offered only in English, such as the CANHR newsletter. Additionally, not all elders have learned to read comfortably, as they did not attend school as children. Also, Yup’ik was traditionally an oral language until recent attempts were made to document the language in a written form, and to create an orthography and
dictionary of the language (Morrow 1987). The learning tradition was focused on observation, story-telling, and gaining direct experience. So, elder community members have expressed that they learn by watching, and listening to people telling them things. Dissemination efforts that focus on elder community members must include aural transfer of information, not simply written. Perhaps this effort could be the task of the high school health education group.

Engagement of the students in working with the elders to determine the kinds of health information that the elders would want to learn could become an invitation for greater communication across age groups in general, an expressed interest of many participants.

The advice that I received from participants urged investigators to start kids learning the new information while they’re young or soon after a person enters the river. They reasoned that if educators are able to teach students about the new health information at a young age, they will grow up knowing more about ways to stay healthy, and might then raise families according to these understandings. Researchers might also draw on one participant’s advice to engage young parents to help the community return to eating more healthfully. She described her own experiences as a parent; she fed her very young children candy and pop and regrets that she didn’t know otherwise, now that her older children are sugar “addicts.” However, more than simple education is needed to shift what has become an ingrained cultural norm.

Past experience in educational efforts have demonstrated that behavior changes are more likely sustainable when the ideas for the changes are developed by the community and for the community.\textsuperscript{50} One way that I have conceived present information to the community is by

\footnotesize{\textsuperscript{50}This is also consistent with CBPR principles (Israel et al. 2003).}
integrating directly with the schools. An educator from CANHR could collaborate on a public health project with local high school science, health, or social studies classes regarding cancer rates in the region. The students would learn how to access and think about public health data, including looking at multiple causes, different cancer types and the prevalence of each in their region. This could set the stage for such a program to be the collaborative vehicle for CANHR to communicate new public health data and research results. The students might then host a local health fair, or other community event, in which they could apply their new skills to develop their own projects using the additional information that CANHR would like to disseminate. They would then present to the community through a variety of different media. In discussions with the faculty advisors of the student council, these teachers expressed their students’ interest in gaining more public speaking experience, and this is one way we found to give students such an opportunity in the future.

There would be several benefits to engaging the students. First, we’d be teaching the young people, which is of great concern to the older people in the community. The CANHR educator might also support students who are particularly interested in research and health information, to go on to study at the university, or to pursue health-related training and careers. Elders and parents of children have expressed the value of helping the youth both in learning about issues of concern to life in general, but also for potential economic and educational success, beyond subsistence. They have emphasized the importance of engaging students and starting them at a young age to develop healthy habits and a healthy lifestyle; they also emphasized

---

51 This idea was developed in collaboration with my graduate advisory committee, colleagues at the University of Washington, and with the input of community participants.
supporting people (including researchers such as CANHR investigators) who are interested in helping in this way.

Second, CANHR would be addressing a topic that seems to be at the forefront of many people’s minds (as evidenced by the many times cancer was mentioned in my conversations with various community members), and this would be an obvious place to start building capacity within the community to participate more fully in the research process. While CANHR has not directly addressed cancer in its research so far, paying special attention to this interest would benefit the overall CBPR partnership.

Third, this could build the capacity of the community to start really thinking about public health issues, which can be related back to the topics that CANHR does address directly. At the same time, it would inform the CANHR staff of how the community might (or might not) conceptualize these issues, providing a co-learning experience, and thus building CANHR’s capacity to conduct research in the community. Building research capacity within the partnership is an important aspect of a CBPR approach. The aim is to ensure the sustainability of the community-based program to continue on without the continued intervention of the researchers, with skills and resources shifted to the community members. The community collaborators and leaders might have additional ideas about how to address the needs of the community and the researchers, including improved cross-generational communication, opportunities for youth, improved appropriate dissemination of research progress and results, and a long-term establishment of a community-based program for doing so.

People occupy different places along the river based on whether they are male, female, a leader or a non-leader. Women often complained about being stuck in the home, unable to attend meetings in the community or engage in other activities toward health that would require them to
leave the house, or find a babysitter for their kids. While community meetings were mentioned by many people as effective ways to tell people about health information, many mothers expressed an inability to take part in these events, owing to their obligations in the home and the expectation that they were responsible for taking care of young children. Men who hunt and fish leave the community for periods of time, which could potentially preclude their participation in community meetings and other events that occur once over a period of time.

Leaders in the community often have more opportunities to learn health information than does the general public. They travel outside of the community to attend meetings and training workshops, and they receive presentations of aggregate results from CANHR before the rest of the community receives them. By definition, according to several participants, leaders earn their roles because they have knowledge and experience, so they might have more of a basis than the general public to learn about new information.

The fundamental reality is that people have different priorities, different minds, and different inclinations. Therefore, if CANHR wants to reach a large portion of the population, they must try to get information across in a variety of ways. People in the community are very busy. With many different responsibilities, often holding a paying job in addition to practicing traditional subsistence activities and caring for children and sometimes elders, people have multiple demands on their time.

Traditionally, exercise for the sake of exercise was not part of the way of life in the region, but participants recognized that the traditional way of life was entrenched with built-in physical activity, thus rendering people “healthier” than people are nowadays. With technological changes have come changes in a person’s activity levels, resulting in an increasingly sedentary life for people. Many people acknowledge the need to gain more physical
activity that has been lost with the advent of technologies such as snowmachines, four-wheelers, and motorboats, but there is a lack of realistic and community-appropriate ways to do so. Although many participants described activities such as walking, jogging, and practicing other exercises for the sake of being healthier, these are recommendations that are not necessarily congruent with community circumstances. There is a need for culturally appropriate and relevant exercise advice for community members. This idea confirms the premise of the next phase of Dr. Boyer’s physiology project-- quantifying the physical exertion associated with subsistence activities and other activities in which people already engage, so as to make more effective recommendations for community members looking to increase their physical activity levels.

There is considerable cultural inertia to be overcome in the community, if someone wants to eat differently or exercise more, and this effort is not to be underestimated. For many people, the more immediate daily concerns and activities are more compelling than changing behavior for a perceived longer-term payoff. The balance has yet to be tipped for many people, in favor of effective behavior change. Therefore, research can contribute by asking questions about this cultural inertia that prevents change, and then by experimenting with ways to work with the community members’ toward their goals of increased fitness and health.

5.1.3 It’s About WHO, Not Just HOW the New Tributary Flows Into the River

The questions of how and who should broker information between the community and the researchers are fundamentally linked. As mentioned above, in order to learn the most effective ways to go about bringing research results to a community, it may be critical to have a local collaborator (ideally from the community or else someone who is dedicated to living within the community on a somewhat permanent basis) to provide, interpret and contextualize information
regularly. This agent would also be available to the community to answer their questions and concerns and relate these to CANHR researchers, and it would enhance the sustainability of the health research findings. There are some issues and details that aren’t readily discussed with non-community members and non-Native people; some things are learned by observation only, and if one hasn’t had the opportunity to observe these things, they would not know them.

It is not realistic at this juncture to expect CANHR to fund a full-time position in every community that participates in the project, nor is it necessarily realistic to expect enough applicants to fill these roles. This might be an opportunity for a collaborative grant among several participating communities with CANHR’s guidance, to gain funding for a position that might be shared among multiple villages. This position would be filled ideally by someone who already lives in one of these communities full-time and can gain training to perform this position on behalf of CANHR. Many people have verbalized interest in engaging in activities that will improve their health, and help them lose weight in particular, but do not feel well-supported in this interest. The locally-known educator would be able to fill the role of on-going support for people in the community, would be familiar with the “river” of knowledge in the community as it changes through time, and would preferably be someone who has the people’s trust already, having lived there as part of the community.

CANHR has tested the community research assistant concept in the region in the past, with varying degrees of success, from CANHR’s perspective. The person who is hired for this position would have to be full-time in the position, and not have other work obligations. He or she should be actively engaged in meetings held with CANHR investigators, either by physically traveling to the university in Fairbanks, or by the videoconferencing technology that is available in Bethel and outlying areas. Finding someone who is available on a full-time basis, dedicated to
the job and able to leave the community for frequent training and travel would be a challenge. However, it is worth attempting to find such a person to join CANHR’s team.

5.1.4 On Different Braids in the River

Although new tributaries enter the river to bring new information to the community frequently, there are people who do not receive the new information, and it does not filter through the community like some information would. This is one area for future investigation. In the meantime, although participants young and elder alike expressed that some people will be interested in the information that CANHR has to share, and some just won’t be interested, I was encouraged to try to make the information more interesting to people so that more people will want to learn about it. CANHR can’t expect to reach absolutely everyone but ought to at least try. This means approaching dissemination from a variety of angles, and with diligence to ensure that it is as culturally appropriate and relevant to as many people as possible, given differences in age, gender, leadership status, and other roles. As a prominent leader in the community suggested, the information is good for everyone, so CANHR shouldn’t be complacent with knowing that some people won’t be interested as a reason not to push to reach everyone.

5.1.5 Back to the Genetics Tributary

In this section, I describe my main suggestions regarding how one might approach disseminating genetics research information in the community. First, mutual education is necessary, meaning that not only will the researchers share basic information with the community, but the community must share information with the researchers, in a bi-directional
transfer of knowledge. It is necessary to understand what people already know, believe and how they talk about the subject, as well as how they don’t talk about it. Consequently, it is also necessary to know which other sources of related information might enter and influence the community’s understandings, and how this might be true for different people in the community.

Second, the partnership needs a more accurate, complete, and appropriate way to describe and define concepts of genetics, drawing from what people already know and discuss. A local collaborator is needed to provide a dedicated interpreter in order to navigate these potentially sensitive issues.

5.1.5.1 Emerging From the Water at the Confluence

To approach this study, we again need to conceptualize what community members already know and believe about genetics, or what water exists in the river on the topic. Then, it is helpful to understand the different tributaries that might exist, bringing information in from different sources. Finally, we must recognize that people in different roles in the community might be on different braids in the river, and so might miss the entry of new information into the river; or the information might be filtered before reaching them, thus changing the content or emphasis of the information. In the paragraphs that follow, I make recommendations based on these aspects of the case study to improve communication of genetics research in the community.

Participants often recognized the basic idea of genetics as “the things that are passed down in our blood through families,” such as hair color and cancer. While elders were generally not familiar with the term “genetics,” (as there is no word for “genetics” in Yup’ik) they had their own understandings of the concept, rooted in teachings from their elders, as described in Chapter 4. However, because participants gave examples of diseases that are passed down through
families and included diseases such as HIV and tuberculosis, it became clear that the definition
we have been using to express this concept only covers a portion of the point we’re interested in
conveying. Unbalanced and incomplete knowledge of genetics can lead to negative
consequences for the community, so it is necessary to clarify further, with the help of a local
translator. A local leader, who has also translated for some CANHR work in the past, confirmed
my suspicion that we need to develop a more complete definition so as to avoid perpetuating such
misconceptions. This half-definition problem was familiar to him, having tried to translate
“genetics” into Yup’ik, and finding it challenging to supply an adequate, yet succinct, definition.

So, before being able to discuss genetics research at length with a community group,
there is first some general mutual education that must take place. When talking about genetics,
researchers should start by delving more deeply into local understandings of what is “carried in
the blood,” and how things are “passed through the blood.” Then, educators can introduce the
genetics concept using terms and a context that people already understand, such as “the things
that run through the family” and “diseases that are passed in our blood to our children,” or other
terms, with a more complete understanding of how those words are interpreted locally. If the
definition does not already do so, the distinction should quickly be made between genetic and
infectious diseases (such as HIV). As described in Chapter 4, an image provided by one of the
elder women who spoke with me likened genetics to a landslide, which only goes in one
direction, from parents to children, and cannot go back from children to parents, or to the side,
from the parents to friends or other relatives who are not their children. Another potentially
helpful explanation was provided by an elder leader, who had attributed his understanding to

52 This image included more than just familial characteristics, and included a more holistic view of a
person’s life, as is consistent with the traditional concept of health, (see Chapter 4).
what the kass’aqs told him at the Genetics Education for Native Americans (GENA) workshop. He explained, “We don’t all have the same blood. Since the couple’s children have the same blood, they can inherit their parents’ disease, through the blood.” Using elements from the GENA workshop might fill out the definition and ensure a more successful transfer of the concepts.

When actually presenting health information, I was told that using simple and familiar examples that relate directly to what people already know and understand will help direct a more accurate interpretation of research information. This result confirms what participating Councils have told CANHR investigators in the past. One specific idea that was offered was that when explaining genetics, start with a very simple picture using only a few basic colors, focused at a broad scale, then focus the picture in on the specific area that was studied. Teach about genetics by using examples that people commonly reference, about traits observed on the outside of the body. Keeping the explanations simple and related to information that is already known to the community is the best way to approach the discussion of complex ideas with a diverse audience.

Health information enters the community by way of a variety of tributaries. These include school classes, trainings, workshops, meetings, presentations by outside visitors or outside of the community, television, magazines, and increasingly, the internet. People in different roles in the community have access to different sources of information. For instance, young people learn about the science of genetics in their high school science class. The high school science teacher showed me their textbook and explained that their curriculum covers details of DNA, inheritance patterns, current gene technology, and genetic diseases, and touches on a range of topics that would be studied in a college-level principles of genetics course. Students and staff at the school have access to the internet at the school, and some others in the
community also have internet access in their homes. The high school students are required to conduct a web-based research project on a genetic disease, so have exposure to a broader source of genetics research information. Leaders in the community, that is, members of the Councils, have access to trainings and presentations such as the GENA workshop, CANHR research presentations, and various meetings with state or regional health organizations. People who work in health care provider roles, such as community health aides and dental health aides, receive training in various aspects of health; and while they may not have direct training in genetics, they have an increased understanding over the general population, of some scientific and biological concepts, such as basic nutrition.

Elders, or people who speak the older Yup’ik language, have access to the ancestors’ teachings that are passed down orally. I was told that much of the traditional information has been lost with the changes that came to the community over the last century or two. Additionally, elders lamented such changes in the culture as younger people not listening as much to the elders, so the traditional teachings are not transferred to them, as once was the case. This, in addition to the additional sources of information available to younger people, explains some of the differences in the concepts held by the elders and the younger generations, although more research is necessary to understand the concepts held by teens and young adults in their twenties.

People who speak English and have access to satellite television can gather information from sources such as the Discovery Channel, which present programs on genetics research from time to time, as was mentioned in one interview. Anyone who is interested and who chooses to pay for a subscription can receive magazines through the mail that cover the topic, though again this was only mentioned by one participant as a way that he received information about genetics. These media-based ways of learning about genetics information are really only accessible to
those who have the time and enough interest to prioritize watching genetics-related programs or reading such articles. Because these formats require some focused attention on the part of the viewer/reader, they may be less available to women watching children or putting away seals, or to men fixing their boats or hunting food for the family. Although I observed that the television was on in most homes, most people did not mention it as a source of information. It may be that this is a relatively small tributary of information dammed up near the confluence of the river, not providing very much to the river of knowledge in the community. Or, it may be that this wasn’t an obvious “channel” for health information when asked, and it actually has more influence than reported, possibly on a more sub-conscious level, or because it was not perceived as an appropriate response to this question.

There is one additional method of communication that is relatively new to the community, but gaining momentum in other areas of research, especially political science (Dale and Strauss 2007). While I was visiting the community during my return trip, my meeting with some of the people at the City Council was delayed due to a one-day-long visit from the GCI cellular phone company. Representatives from the company were busy all day, educating people\(^{53}\) about their products and selling cell phone plans, on the new network of infrastructure that is spreading throughout rural Alaska.\(^ {54}\) As cell phones have been used in research and educational efforts in other areas, so might they be useful for CANHR in the future. It remains to

\(^{53}\) This might be an example of how educational efforts are successful if people have a particular interest that places that effort at the top of their priority list.

\(^{54}\) This is an example a changing culture in the community. CANHR researchers attended a traditional Eskimo dance practice a few days later, and noticed the juxtaposition of the frequent cell phone rings with the drumming and singing of the Yup’ik songs. The impact of cell phones on the community is yet to be fully seen, and such a discussion is beyond the scope of this paper.
be seen what their actual utility might be in the future, but it is worth keeping this method of communication in mind when considering future research efforts.

Participants explained several other ideas held by community members that might affect their understanding of genetics information that ought to be kept in mind during educational efforts. Participants reported that people talk about the features of the body that can be seen from the outside, such as a person’s height, and whether they have a receding hairline like the other men in their family. They do not discuss features that affect the inside of the body, such as diseases. These inside-of-the-body observations of family members are limited to explaining why a person has a disease, and are not involved in predicting whether a person will develop a disease. Some participants explained that people would probably modify their behavior to decrease their risk of developing a disease if they were 100% certain they would get the disease.55

This leads to questioning how the community deals with uncertainty in life and medicine. More research is needed to understand how different age groups in the community conceptualize uncertainty. This understanding would have implications for how CANHR deals with genetics information, which is inherently uncertain. The idea that the balance is tipped toward behavior change if people know they have a 100% chance of developing a disease would have significant implications for genetics research dissemination and what kinds of information people want to learn. It’s also necessary to reconcile the fact that genetically based observations are not currently used in a predictive manner in the community56 with the fact that predicting individual

55 However, there is no 100% guarantee with multifactorial genetic diseases.

56 It is possible that this is a result of the fact that there is no reliable way (so I have been told) to predict these diseases in the river of traditional knowledge. As the elders explained, children don’t always get the diseases that their parents have, and sometimes diseases skip generations, the reasons for which are not understood. So, it would be unwise to predict that one would develop a disease simply on the grounds that
risk is a goal of genetics research and testing. We must figure out how this could be taught in a way that would not offend community members. These questions will be explored further in the “Future Questions” section of this chapter.

Some people say it’s better not to worry about developing a disease, because “people get what they expect;” but other people think that learning about their own health status is important to being healthy and changing their behavior to decrease their disease risks. This difference in opinion of health knowledge might indicate a shift in the way health information is understood locally. The elder generation expressed more of these “ignore it” ideas\(^\text{57}\) than the younger generations did. While western biomedicine takes a stance that involves taking action regarding one’s disease or risks for disease and specifically not ignoring it, CANHR should be careful not to contradict the elder population outright. They have expressed feeling a loss of respect from the younger people, though the intergenerational transfer of knowledge is so important to the culture and is one of the reasons cited by elders for their support of CANHR. While CANHR researchers generally come from the kass’aq education system and are appreciated for being able to provide useful and helpful information to the community, it is important not to insert oneself inappropriately into their way of life, leading to a continued degradation of their cultural value of transferring knowledge through the generations. While CANHR’s research is intended to benefit more than just the communities, its foremost responsibility is to benefit the community, and at the very least, to do no harm to the community.

\[^{57}\text{These ideas are certainly more nuanced than I have described. “Ignoring” one’s disease is not always the best course of action, depending on the severity of the disease and availability of treatment for it.}\]
Finally, as discussed in Chapter 4, there is great potential for offense based on sensitivities related to genetics, including but probably not limited to the role of God in one’s life, questioning parentage (and implicitly, bringing up other unspoken strife surrounding other social relationships such as the context of an adoption or extra-marital interactions), calling to mind diseases of the inside of the body (which might be considered welcoming the disease), and mischievous use of genetics information. As CANHR wants to avoid causing rifts in the community, it’s important to remain very sensitive to different views and needs of people in the community. However, at the same time, they ought to approach the subject transparently with the community, inviting their assessment of what information is relevant to them, in order to avoid paternalism on the part of the researchers. The capacity to evaluate this must be built through a co-learning process among university investigators and a group of community members, so that all partners gain a mutual understanding of the kind of information that is available and the impacts that might be felt by the community from the dissemination of this information.

5.2 General Limitations

Specific methodological limitations and choices made due to limited circumstances have been discussed throughout the Methods and Analysis sections in Chapter 3. In this section, I will offer some broader limitations to the study as well as some useful lessons learned throughout the process that might prove helpful to other investigators preparing to conduct field-based research in the Yukon-Kuskokwim Delta.
5.2.1 Limited Time

Perhaps the most important limitation to my study is also the most obvious: I only spent a total of about three weeks in this community, which were spread out over the course of a year. In order to more fully address my research topic, I would have benefitted from spending much more time in the community, as a participant observer to gain a better understanding of how all of the factors that I have discussed in this paper function to influence the understanding of health information in the community. Many of the questions that I have left for future studies might have been answered, and I might have been able to make some of my statements with more confidence, and less speculation. Also with more time in the community, I would have been able to conduct some of my analysis concurrently while I was collecting the data. In this case, I would have been better able to identify the areas in which I needed more data, which issues to probe more deeply, and how to ask the questions to elicit the information that I sought. I might have been able to conduct additional interviews and participant observation, thereby ensuring theoretical saturation of the data in each of the different categories of community members that I was interested in comparing (men and women of various ages, with various roles in the community).

5.2.2 Qualitative Research in Bilingual Communities

While there is no practical alternative to doing so, there are inherent barriers when communicating through a translator. During the Yup’ik interviews, I was unable to follow the conversation beyond simply what my translator would relay, which was generally a paraphrased summary of what the Yup’ik speaker described (often at length). Not fully grasping what was going on in the conversation meant that I was unable to ask many questions or to follow-up and
probe as I would if I understood the conversation as it were being carried out. Thus, asking for clarification was limited to my return trip six months later, and after I’d received the translations and attempted to analyze the transcripts.

Often, too, a lack of comparable words in both languages meant that my translators were forced to interpret my questions for the Yup’ik participants, essentially answering certain questions for them. For instance, there is no word for “health” in Yup’ik. Thus, when I asked what it means to “be healthy” in the community, the translator had to describe what the word, “healthy” means in their culture, which is what I was trying to understand from the elder’s perspective. So, as I explained in Chapter 4, it was in the back-translated transcripts that I actually received the translator’s interpretation on behalf of the elder, of what health refers to, which was then supplemented with elders’ stories.

Additionally, as described in Chapter 4, when conducting interviews in English, there are dialectical differences between uses of English words in the university researcher’s culture versus in the community member’s culture; these differences made for some confusion in communication and interpretations. This leads me to speculate that there are additional misunderstandings that might have gone undetected. This assumption was supported by community members during my return visit interviews. These language challenges might be remedied (if there is no researcher available who speaks both languages) by using simultaneous translation equipment, repeated and extended community visits, having the transcripts translated between visits, and spending time with a local consultant and translator who understands the local uses of words in both languages but also understands how these words are used differently in the researcher’s culture and the surrounding cultural context.
Other differences between the Yup’ik and English interviews reach beyond translational barriers to include age, setting, and quality of questions. Generally, in this community, the elders are mostly Yup’ik speakers only, and the younger people are often fluent in English as well as in Yup’ik. All of the younger participants (those 55 and younger) indicated their preference to conduct the interview in English, while the elder participants (over age 56) all preferred to conduct their interviews in Yup’ik with a translator. This generational divide might account for some of the differences I found in the Yup’ik and English interviews. Still, I speculate that the setting might also have played a role in the nature of the interviews. All of the English interviews were conducted at the school, in a classroom or office, which required the participants to travel from their homes to the school. Thus, they were asked to go out of their way to participate, which assumed mobility as well as an extra amount of effort of which the elders (Yup’ik speakers) might not have been capable. They were also in a relatively foreign setting, implemented by kass’aqs, complete with sterile walls and fluorescent lights; it was an impersonal space that might not have lent itself to comfortable thinking and ease of answering questions. The Yup’ik speakers were interviewed in their homes, which allowed them to in a comfortable, familiar space of their own, where they were the hosts and the interviewer was a guest, which might have elicited more culturally rooted responses.

A third difference that I detected was the type of responses that I received from speakers of the different languages, a difference that my colleague Dr. Elaine Drew and I have characterized as “ask a white question, get a white answer.” When speaking in English, as a white interviewer and outsider, it seemed that interviewees were led toward thinking in the “kass’aq way” and not in terms of their own traditional and cultural knowledge. For instance, when I asked participants in English about what it means to them to be healthy, or what activities healthy people do, many responses included “eat lots of fruits and vegetables, exercise a lot.”
These are likely the types of health activities supplied to them by other kass’aqs, such as the researchers, physicians and health professionals that they encounter in the community and when they visit Bethel for healthcare services. It seemed particularly difficult to ask about traditional notions of living a healthy, or “good” life, in a way that was both respectful and informative. My interpretation is that when a non-Native person asks about healthy activities, a natural reaction is to reply with the healthy activities that they have heard about from other non-Native people, almost as if it’s a test of their non-Native knowledge. Whereas, when the Yup’ik, familiar, local resident translators asked the Yup’ik speakers about healthy activities, answers dealt more with traditional teachings and community-centric activities instead of the healthcare provider types of answers. This might stem from many different causes, as discussed above, but for some participants, the artificiality of the interview setting and different connotations associated with the different languages influenced response types.

One of my participant consultants explained during my follow-up visit, that he would expect that most people would have difficulty answering questions in a formal interview setting, as they know their answers are being recorded and so they are very careful about not saying anything that is considered “wrong.” Although I promised that their recordings would remain confidential, and they were just for me to use so that I could be sure that I didn’t write something down incorrectly, even my other consultants showed their reluctance to speak too freely while being recorded, and added to their responses only after I turned the digital recorder off. Several community members expressed that verbally questioning others was not traditionally a way that people learned about things in the community, though nowadays, it is not a foreign mode of communication, especially among younger generations.
As a remedy for the above issues, a researcher might spend time in the role of anthropologist observing to see what really goes on, and spending time to understand through informal interactions, without formally asking what people think of as healthy behavior. Anthropologist, Ann Fienup-Riordan, who has spent extensive time in the communities in the region, described how the folly of asking questions was demonstrated to her by her friends in the community deliberately lying in response to her questions. She explained in her earliest book,

I had asked about naming procedures…but with very little solid response. I was made to feel acutely nosey. And, in fact, part of the message of this story is how little progress one can make in understanding the coastal Yup’ik if one confines oneself to information acquired through a questionnaire approach. It certainly never worked for me, and in fact my best friends used to lie to me, in a good-natured way, to show me how foolish and misguided my occasional bouts of verbal curiosity were, (Fienup-Riordan 1983).

5.2.3 Bilingual PowerPoint Presentations

While Microsoft PowerPoint is lauded by academics, used for nearly every presentation given at professional conferences and for many lectures in classrooms, as a convenient method for presenting both pictures and words, it is not without challenges, especially when presenting through a translator in a rural Alaska community. In CANHR’s experience, bilingual PowerPoint presentations may be given in a couple of different ways. In one case, the researcher presents in English, and a local translator interprets concurrently; in the other case the researcher does not

58 I do not mean to suggest that I suspect that my participants deliberately lied to me in response to my interview questions.
speak but sits in the audience while the interpreter translates the English PowerPoint slides directly into Yup’ik, but remains available to answer questions as needed.

In the first case, the benefit may be that those audience members who do understand English would hear a presentation directly from the researcher, who can provide the subtext and nuance of the slides, which are necessarily less detailed than the text on the slides can provide. This also keeps the researcher’s face associated with the information provided. However, in this case, the time required to present is more than double what it would be to present in English only. The time that the audience has to devote to watching a presentation is not doubled, as is the case, for instance, during Traditional Council meetings. A researcher developing such a presentation for this format must estimate the timing and ensure that the presentation will fit into the time that is allotted for the presentation, which might mean being particularly selective about the information that is presented. With research presentations, there always seems to be more information to present than time during which to present it, and this is especially pronounced in the case of concurrent translation. An additional challenge is that nuance may be lost in translation. Scientific presentations often include terms and concepts for which there is no direct translation in Yup’ik. Therefore, it is wise to meet with translator ahead of time if possible to work through the presentation so that the translator has time to consider the best way to communicate these nuances.

In the second case, in which the translator presents in Yup’ik directly, benefits include saving the audience’s time, and the ability to present more information in the same amount of time. However, the researcher who develops the presentation must keep in mind that the interpreter will probably translate the words from the slides directly, so it is important to keep the messages simple, and as clear as possible. In addition, this translator might not be familiar with
all of the scientific terms, and so these terms must be presented in plain English to ease the
translation process. Again, it is wise to discuss the presentation with the interpreter ahead of
time, in order to make sure that he/she understands what each slide means and the essence of the
points that are being made.

5.3 Fieldwork With the Best-Laid Plans

Conducting fieldwork in any setting requires flexibility, a sense of humor and the ability
to improvise when plans go awry. Working in small, rural Alaska communities is no exception to
this rule, and presents some particular challenges that might limit the data collection process. For
one, working with people requires an understanding that a random sample of the population isn’t
always possible, because unlike a sample of plants or a sample of rocks humans can refuse
participation. Also, human participants aren’t always available during a study, and so must be
accommodated in ways that non-human research subjects do not. Special protections that are
(rightly) granted to human participants also limit some methods. Maintaining sensitivity to
cultural differences and respecting the comfort, needs and preferences of the participants result in
the opportunity to conduct the study, but place limitations on the scientific process. A researcher
must decide how much variation is acceptable when collecting data and controlling for variables
in the field. In the following paragraphs, I will highlight a few of the lessons that I learned while
conducting fieldwork for this project.
5.3.1 Time

When visiting the community as a guest, a researcher is on community time. I see my position as a researcher in the community as a privilege, and perhaps an imposition on the people who participate. A researcher must plan to be available whenever the community members might be available, which, because people travel outside of the community often, may not be convenient for the researcher. Life happens on a particular but unset schedule, and any visitor must learn quickly to go with the flow if he or she is going to get anything done. Things do tend to work out if a person remains relaxed about them; she/he can’t realistically rush anything. Because of these time limitations, a researcher might not be able to reach all of the people she/he intended to reach.

5.3.2 Integration

A fieldworker ought be willing to integrate into the community as much as she or he is able. I believe that by participating fully (when appropriate) in community activities, visitors show their respect for the community and local customs. This means suspending one’s own judgments about foods and ways of doing things, and accepting offers to try new things.

5.3.3 Flexibility

Flexibility in all aspects of one’s visit is important to a successful field experience. There might be times when one’s travel schedule has to change at the last minute due to weather, availability of participants, community events or circumstances, which prevent the research from taking place. For example, on several occasions, CANHR researchers have had to suspend their projects for a period of time and/or leave the community due to a death in the community. This
has resulted in a large financial cost to the project (new plane tickets and change fees), in addition to the large personal cost to the researchers who have to extend their time away from home and other obligations. Furthermore, there are times when the realities of the research setting are beyond the researcher’s control. To some extent, if the setting is not tenable for the research needs, then the investigators need to make the decision to either discontinue the research, or find a new situation that would be acceptable for all involved. A researcher must understand that lab-perfect scenarios are not always possible, so exceptions must be written into their project protocol.

For example, if I’m conducting an interview or focus group with kids present, then whatever needs to be done to take care of the kids will be done. I would prefer to gain the interview, making exceptions for the necessary childcare, than to lose the opportunity to interview that participant, who might not have a babysitter. If I’m interviewing in someone’s house, then it’s entirely up to him or her what goes on in the setting. Other people might be present, the television might be on, and kids might be running around, but it is up to me to adjust, and to keep my concentration for that hour. The presence of other people in the room could have the effect of limiting the liberty that the participant takes in their responses. Conversely, being in their own home and with their family members might have the effect of putting that person at greater ease, thus providing more information or of greater quality than a researcher might otherwise collect.

Again, flexibility and a sense of trusting the community members are necessary when conducting fieldwork, in order to maintain the trust of participants and access to the data sought. I sensed that people became annoyed with me when I called to confirm plans, or when I repeated what we’d agreed upon, when I wasn’t convinced that we were both in agreement with a plan. Of
course, if life happens, people will think nothing of attending to their priorities instead, and not worrying about missing an appointment with a researcher. While that appointment might feel urgent to the researcher who is trying to schedule all of the appointments with participants that are needed for the study, nothing is gained by expressing to the participant disappointment or any anger that the researcher might feel. Calling too often can be construed as coercion to participate. A careful judgment must be made between being courteous and giving a person who missed an appointment as many opportunities as possible to complete the study, and badgering the person into coming in and completing when they no longer wish to participate. Sometimes it might be difficult to detect the difference.

5.3.4 Listening

Committing to listening more than talking is a key factor in being successful when working in the community. In Quyana, the pace of speech was initially unfamiliar to me, and I quickly learned to allow for what I perceived as extended pauses between thoughts or before a person answered a question. Participants explained to me that they were taught to think before they speak, and I observed that by filling in silences prematurely, a person cuts off this thought process for the respondent. I learned that when I asked follow-up questions or made a comment instead of remaining quiet and allowing the participant to direct the conversation, I did not gain the same amount of information as when I allowed the person to speak freely, for as long as they wished. People offered information as they were interested and comfortable, and by simply being receptive to what they thought was important to tell me, I gained more trust and knowledge to ask more specific questions later. In addition, by remaining quiet, I was able to observe and learn valuable information that I would not have learned by asking questions.
5.3.5 Homework

Preparing for the field by learning as much as possible through readings and talking with other researchers, anthropologists, and local informants is vital to one’s ability to collect the desired data. It is important to understand the basic structure and workings of the community, not only to avoid offending people with ignorance, but also in order to make decisions on the fly when things change. For example, when I learned about the Council’s unavailability to meet with me, I had to quickly revise my protocol, which required understanding something about how groups in the community might be divided in order to recruit an appropriate sample.

5.4 Methodological Limitations

While I described many limitations and methodological choices to my study in Chapter 3, I discuss some additional limitations that I encountered in the following paragraphs.

5.4.1 The Approval Process

I developed my project protocol with limited research experience, and prior to having taken a social science research methods course. Once I submitted the protocol for the Yukon-Kuskokwim Health Corporation’s approval, I was unable to make significant changes to the protocol once I learned more about methodologies that might be appropriate. Given the short timeline of a Master’s program, the two-month lag time between project development and data collection and the inability to make significant changes to my project protocol after I submitted the initial proposal, might have limited the quality of my study.
5.4.2 Focus Groups

The group-based interviews are meant to provide a breadth of ideas in a relatively short amount of time. However, in this community setting, there might have been some reluctance to provide a contradictory idea in the group, for fear of offending another member by disagreeing with them. While these discussions yielded lots of ideas, this fact underscores the importance of also conducting interviews, and informal conversations, as well as more than one focus group. Given extensive time and resources, additional focus groups would have been advised in order to detect whether people in a group tended to agree with one another. As mentioned in Chapter 3, my study would have benefited from conducting focus groups with men and women separately, in each of the three age groups. Although conducting even six focus groups in addition to the interviews that I gathered would have been a very large sample for a Master’s thesis, I would have been more able to discern differences within and among groups more effectively with multiple groups of each of the six demographic groups.

Hindsight indicates that the types of questions that I asked might have limited responses. Because I was interested in learning about community ideas, and some generally held beliefs, and community structure, I asked general questions that I believe would have been reasonably appropriate for a cohort of participants from my own culture. However, I learned that these kinds of questions didn’t work well with the groups that participated in my study. People were not inclined to make comments or speculate about what others might think, or what might be general perceptions in the community. After trying these types of questions a few times, I realized that it is more effective to request each person’s own ideas about the topic of interest. For example, instead of asking “do people in the community tend to go out or stay in during a storm, relative to what they do in nice weather?” it is more effective to ask, “do you see more people out when there is a storm or when the weather is nice, or do you see the same number of people regardless
of the weather?” Another example would be, instead of saying “what do elders say about…,” ask, “what have any elders told you about…” People are more accustomed to thinking and talking about their own experiences, so framing a question in terms of a person’s own experiences elicits informative responses while asking about the community in general elicits an “I don’t know” response. Had I known this from the start, I believe I would have received more instructive answers earlier in the data collection process.

Finally, focus groups might be best used to evaluate a product, rather than to solicit people’s personal experiences or perceptions in this community. Again, because of group members’ reluctance to disagree with one another, it might have been more effective to keep the conversation focused on a topic that is somewhat removed from people’s direct experiences; but people would have to use their own experiences in order to contribute. Also, to ensure that negative aspects will be discussed as well as the positive aspects, perhaps posting two large pieces of paper with titles that indicate the purpose for each paper, one for listing the good qualities and one for listing the bad qualities of the product and how they might be improved would help elicit both positive and negative responses. Participants have tended to talk about what is good about the CANHR project when I have asked, and haven’t talked about the negative aspects, so special effort might be needed to gain a range of opinions.

5.4.3 Interviews

The limitations of conducting interviews in various settings, and with people from different generations, are discussed earlier in this chapter. More research will be necessary in order to distinguish the impacts of the different variables on the responses that I observed. Here,
I will discuss the potential strengths and weaknesses of conducting pair interviews, as was the case in several of the interviews, and theoretical saturation in qualitative data collection.

In qualitative research, there are situations in which it is necessary to make accommodations for the specific needs of one’s participants and other parameters that constrain the accessibility of the data that one seeks. In the case of the elder participants in my study, I often interviewed relatives in their homes. My willingness to visit them in their homes enabled me to actually speak with the elders, and to spend some extra time with them in a comfortable environment, to build some trust, and to spend time observing without asking questions before launching into a session of awkward questioning without any context. Spending some time visiting in participants’ homes before conducting the interview provided all of us the opportunity to learn a little about each other. For example, I spent one full afternoon after church at the home of a husband and wife, joined them for lunch and stayed for dinner, and played with the kids while I observed the women putting away a seal in the meantime. I allowed the elder man to tease me by asking me to say silly things in Yup’ik while enjoying a relaxed day with the family. It was after all of this that the time was right to begin the interview, which fell more naturally into the flow of the day than it would have, had I scheduled it ahead of time.

In this instance (and in two others), it also made the most sense to have both elders in the home conduct the interview at the same time. Because the homes are small, and generally full of several generations of family, it did not make sense to conduct the two interviews separately. Privacy is not possible in participants’ homes, and since the interviews took so much of the participants’ time (not to mention the translator’s and my time), it was unanimously agreed that it made more sense to have the pair of interviewees on the microphone at the same time. This saved time as the translator only had to ask each question once, and then after one participant
answered, the other participant had the opportunity to answer separately, adding to, sometimes echoing the other’s response, or providing a separate perspective. Pair interviews conducted through the translator gave me the sense that the three Yup’ik speakers had the upper hand, and I was just humbly there to get their signatures on the paperwork, run the audio recorder, and feed the question topics to the translator. While I cannot say how the participants interpreted the scene, I speculate that removing me a few steps from the discussion allowed a freer and more comfortable conversation among people who knew and trusted each other than was possible in my English conversations with single participants and no translator. The different ratios of Yupiit to kass’aqs were 3:1 in the Yup’ik interviews and 1:1 in the English interviews, might explain some of the differences in the responses observed.

In qualitative research, sample sizes are not determined by conducting a power analysis, as they often are in quantitative research. Instead, sample size is determined by reaching a goal of theoretical saturation, in which no new responses are generated when continuing to interview new participants. While this may sound straightforward in theory, it is a challenge in the field. In addition to having never conducted qualitative research before, I was challenged by not being able to analyze my responses concurrently, both due to time in the case of the English interviews, and to language in the case of the Yup’ik interviews. I was also limited by my travel budget and the time I had to spend in the community. Thus, instead of determining my sample size by theoretical saturation, I aimed to simply gather as many interviews as I possibly could, ensuring that I was interviewing both men and women representatives from the three different adult age groups, guided by the goals for theoretical saturation in the literature (as described in Chapter 3).

My interview sample was limited by the lack of youth and young adults in my sample, as I was limited in time and scope and did not want to take on the added protections required to
enroll minors in a research study. The sample is also limited by using a convenience sample to gain as many respondents as possible. As such, participants were self-selected, and all community members had access to and some interest in being part of the study. By design, I did not gain information from anyone who does not hear about CANHR events, or who does not have an interest in participating in CANHR projects. It is easily conceivable that there is a segment of the community whose experiences are completely different from those of my sample population, but I did not have access to any such members. Those responses might have been elicited by using a snowball sampling method in which the researcher asks their convenience sample of participants for recommendations of their friends or family members who might be willing to participate, but who might not have responded to the open call for participation. This also might have been accomplished by approaching a random sample of the community members, and inviting their participation expressly. However, there is still uncertainty in this method given the likelihood of refusal by those selected for the study, and those selected might not have an interest in the topics, or information that I sought.

5.4.4 Analysis

Like all graduate students, I made a lot of mistakes while conducting my analysis. Originally, I attempted to code all transcripts in detail before having a reasonably complete understanding of the bigger picture of the theory developing process, and unsure where to look for this level of understanding. I enrolled in an additional research methods class in which I learned the practical aspects of doing such analysis. At that point, I put aside the codes that I had developed the first time around, in favor of repeating the process in a more systematic manner, according to my new understanding of the process. The upshot of having to conduct my analysis twice was that I became intimately familiar with my data, which resulted in a more rigorous
analysis. By the end of the process, I’d read each transcript numerous times, in various different sequences, and reorganized the data in many different ways. All of this effort enabled me to notice patterns in the data that I might not have seen, as a novice, if I’d conducted the analysis only once. As I was working independently and not in a research team, looking at the data from so many different angles was vital to reaching a well thought-out interpretation of the data.

5.4.5 Generalizability or Transferability

I have discussed validity and reliability in Chapter 3. In qualitative research, the term generalizability has been replaced with the concept of transferability, as discussed in Auerbach and Silverstein (2003). Transferability can be characterized as the ability of a theoretical model to describe a similar phenomenon or experience in a different population. This can be determined by testing the model in future studies in additional populations, and refining the model to account for the new experiences. This was demonstrated in Auerbach and Silverstein’s study looking at the experiences of fathers in a Haitian-American population in New York City, developing a theoretical model and then extending that model to include the experiences of fathers in other populations, such as fathers who are members of the Promise Keepers religious group, homosexual fathers in New York City, and other groups. The transferability of my model could be determined by applying it to other communities in the region, evaluating the appropriateness of the model in the new community, and then refining the model to encompass additional information. More about future work will be discussed in the following section of this chapter.
5.5 Future Questions and Areas of Exploration

This study is meant to provide a first look at the issues addressed in this thesis, in hopes of guiding future CANHR work. One direction would be to extend this study by following up on a few details in the lives of community members that arose during my study but were not fully addressed. One such detail would be what the community interprets as healthy food, and the types of foods that are captured by that designation in order to provide useful health information with respect to diet. Another detail to decipher would be how community members interpret the “in the blood” description that is often used by CANHR investigators to refer to genetics. A third topic to address would be the role that religion plays in community members’ interpretations of health in various age groups.

Additional questions that might be of interest to CANHR researchers include, what constitutes good translation, and what characterizes a good translator? Are there specific “qualifications” that makes one more or less appropriate for translating scientific information? What kinds of information travel swiftly through a community, and what don’t people really talk about? Continuing to develop an understanding of how the community communicates with each other across languages would help provide the researchers with better quality data and an increased ability to conduct research. Additionally, it is important for researchers to realize what kinds of information or ways of dealing with information are considered taboo or off limits to discussion, so as not to offend community members.

How might one start a public health effort in the community surrounding genetics research? Because one of the major avenues that I suggest that CANHR follow is the school, one must understand more about the perspectives held by teens and young adults on genetics and health, and how they would respond to engaging them in this way. Participants warned that kids
will probably only agree to being involved in such a project (especially as an after-school activity, but even as part of the curriculum) if they were interested, and would not do it if they were simply forced. Engaging the students in conversation, and learning about the outcomes of the educational system by engaging young adults, would help inform these efforts.

Another question that was suggested by this study and should be addressed further is *How do people deal with uncertainty and risk?* This arose as a fundamental issue involved in understanding health information and is particularly relevant to genetics information. Learning how the community members understand uncertainty in health information has implications for determining what kinds of information they want to receive. Could investigators begin talking with the community about uncertainty in genetics research results by talking about the outside of the body, such as a person’s receding hairline? Does the general public have an interest in knowing about the subtleties of inheritance? At what level of “community” does community-based participatory research necessitate educating about the details of genetics? Some participants expressed disinterest in learning information that has no practical application to their lives; but more in-depth, focused research at different levels of community is necessary to determine how this should best be handled. CANHR and the community partners might examine the multiple different capacities in which community input and efforts might be incorporated, so as to suit different individuals’ needs and interests in the research.

An issue deserving further discussion arose while conducting this study, concerning the tension between traditional education and the *kass’aq* education system. CBPR is, at some level, committed to social change. Is there an obligation that CANHR took on by entering into this partnership that implies a responsibility to help ameliorate some of the health problems that might have resulted from the introduction of stores and influence of western culture? “Traditional,” or
time-tested knowledge has not had time to develop an understanding about the newer
diet/nutrition issues, and possible resulting diseases, such as diabetes. Given western medicine’s
history of working with these diseases and issues, and the fact that there are treatments available
and management options for patients, it would seem ethical to share this knowledge with the
communities. To some extent, western culture is seen by community members as having been
imposed on the region, though now there are many aspects that they welcome. Like a positive
feedback system, the more the community adopts aspects of western culture, the more it seems
that they need to adopt additional aspects of western culture. Now that the communities have
commercial foods, refined sugar, and new technologies that render survival easier, they are now
developing more dependence on western ways, a concern that was articulated by elders on many
occasions. They also have the additional consequences of moving to a more westernized diet,
such as the need for different dental hygiene practices in order to maintain healthy teeth (a change
whose value appears to be up for debate). Participants expressed an interest in learning about
nutrition to understand how to keep themselves and their families healthy, and to prevent
diseases, now that foods and diseases are present, which traditional knowledge does not address.
Yet, there appears to be some resistance to changing more radically from the traditional way of
life, especially from the elders’ perspective. Many people of various ages admitted that the
western influence that they welcome and enjoy has had negative consequences for the
community. The question that must be clarified is how should CANHR position itself within this
tension?59

59 One way that CANHR currently attempts to address this tension is by identifying the protective factors,
not simply the risk factors for Type 2 diabetes, and integrating those into community educational efforts.
5.5.1 The Next Steps

Going forward, I suggest that first a general educational effort (in collaboration with a dedicated community partner) should be made to lay a basis from which to begin to discuss genetics information in general. Then a working group can begin to decide what kind of genetics research information they want to learn. The Center for Genomics and Healthcare Equality 2007 Summer Seminar at the University of Washington collaboratively developed some ways this could be done. During this seminar workshop, the group generated the idea of using hypothetical scenarios in community working groups to plan ahead for how to provide genetics information when the outcomes embody varying levels of uncertainty. To carry out this plan, first the genetics researchers would ascertain a range of different results possibilities depending on the research that they are conducting. They would convene with the working group of community representatives to discuss these various possibilities and explain what each might mean so that there is a shared understanding among all group members about the data and associated implications that they’re considering. The working group would discuss how each of the hypothetical results would likely be interpreted in their community, and the appropriate level of detail to be provided, taking into account cultural norms and values. Eventually, this intervention would be piloted in the community, evaluated and returned to the working group for further refinement.

My study and research that extends from it would help to inform these working group discussions by including broader community perspectives on the topic, and by building the capacity of the researchers to understand community perspectives relevant to this end. I have made suggestions for issues to consider on a number of fronts and provided some ideas of how to proceed in working toward a long-term dissemination strategy for CANHR.
5.6 Concluding Remarks: Revisiting the CBPR Principles

Dissemination of health research, especially genetics research results must come from a commitment to transparency in research, mutual trust in the partnership, and relevance for the community. Building community capacity for research is an important step toward reducing community vulnerabilities, empowering communities to determine their own research priorities, and creating on-going partnerships. The genetics research horse has left the barn: now more than ever, policies are needed to guide such research, to ensure community protections (as articulated by the relatively new principle, Respect for Communities (Emanuel and Weijer 2005)) while reducing and preventing health disparities. In this final section, I will address the principles of conducting community-based participatory research, listed in Chapter 2 (Israel et al. 2003), evaluating how my work is situated within these guidelines.

1. CBPR recognizes community as a unit of identity: Many of the community members whom I spoke with don’t want to waste their time learning things that are not relevant to their lives. For pragmatic purposes, in order to conduct genetics research with a CBPR approach, CANHR should define the “community” that they’re trying to engage in the co-researcher process. It’s clear from my conversations with community members, that the community co-researchers are not, at this time, the general public. CANHR would benefit from determining a stable group of co-researchers to this end, so that they can provide the genetics research to a representative community group; then this collaborative group can work together to determine the best approach for providing information to the rest of the community. For this, various different roles might be outlined for community members in different roles. The point is that researchers should be careful not to saturate the general public with too much information of questionable irrelevance.
2. **CBPR builds on strengths and resources within the community**: The recommendation to approach dissemination through a group based in the school would both build on an existing strength and resource within the community (the youth), and build the skills they possess, including using their knowledge about the community to develop appropriate projects through which to share information. In addition, the process suggested in the next steps acknowledges and depends on local expertise of community members to understand what their needs and priorities are, and especially to learn which course of action would be appropriate for that population.

3. **CBPR facilitates collaborative, equitable partnership in all phases of the research**: I suggest that with a defined group of community representatives that can identified as “community partners,” the CANHR project will see increased success in drawing on community knowledge and opinions, and a more balanced input from both partners. Perhaps instead of engaging a single group that comprises the “community partners,” the community’s effort might be divided among several groups or individuals with distinct roles in the community partner effort.

4. **CBPR promotes co-learning and capacity building among all partners**: This project contributes to the education of CANHR investigators and recommends future directions for its effort to proceed with capacity building in the community. Capacity for research is a quality, inherent in university scholarship, but not necessarily so in community groups. Thus, each partner in the CBPR endeavor brings to the table its own strengths and expertise. However, over the course of the partnership, these skills are meant to be transferred in both directions in order to increase the community members’ input in the research project, and the university investigators’ competence in effectively working with and interpreting input from the community involved. I hope that what I have learned and shared in this project can help CANHR effectively transfer
knowledge to community partners, and work with them to increase their input into the project, as
they see fit.

5. **CBPR integrates and achieves a balance between research and action for the mutual
benefit of all partners**: A dissemination effort can only be effective insofar as it addresses what
people are able to become interested in, if they are not already engaged in the issue. CANHR
appears to already have increased awareness of diabetes risk as a concern in at least some of the
community, evidenced by the number of times that it was mentioned as a health concern, coupled
with the low prevalence in the communities, and compared with the other health concerns which
seem to have a higher prevalence in the community. CANHR has already seen success in its
effort to conduct research that contributes to the scientific literature while providing information
to the community that helps people understand their health status. Current research projects are
working to extend beneficial action to include relevant nutrition and physical activity
interventions, to help community members improve their health as they see appropriate.
Dissemination of health research information, therefore, is integral to the broader benefit of the
community. My framework for looking at the different ways in which this action may impact
people in the community differently helps to guide the effort to develop appropriate
dissemination methods.

6. **CBPR emphasizes local relevance of public health problems and ecological
perspectives that recognize and attend to the multiple determinants of health and disease.** A
strength of the CANHR project is the multi-disciplinary focus on the different aspects of a health
concern, obesity and diabetes in rural communities. One of the traditional health beliefs that
emerged in my research is that a person’s health is seen as holistic, an amalgamation of what
western medicine separates into different aspects of health for the purposes of treatment. The
younger members of the community, however, expressed some grasp of the western way of looking at health. A dissemination effort ought to respect both perspectives on health and integrate local concerns into educational efforts.

7. **CBPR involves systems development through a cyclical and iterative process:** Dissemination efforts will necessarily be iterative, taking into account the various sources of information flowing into the community, and evaluating the various impacts of new information on the community. Any product format that is developed for the community (for example an informational television commercial or DVD) must be flexible enough to allow for changes in the actual information that is disseminated. On-going collaboration and co-education among community representatives and university investigators will ensure that the dynamic nature of information that exists and its impact on the community will not be overlooked.

8. **CBPR disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process:** This principle highlights the importance of bringing all results back to the community partners (the representative group of interested individuals from the community), including genetics information that may not have direct relevance for the population at large. It is then up to the partners to determine which information is appropriate to bring to the community and how to do so.

9. **CBPR involves a long-term process and commitment:** Effective co-learning and capacity building require a committed partnership between the community members and the university investigators. My project is both the result of a long-term partnership as well as a catalyst for moving ahead with the further development of this partnership.

One can see the dissemination of research results as integrated at a number of different levels in the CBPR process. It is not only a principle of its own, which mandates that
dissemination occurs, but also a research process unto itself. It is necessary at every step of the research process in a true partnership, as the community partners who are defined as co-researchers must receive progress information from the university investigators in order to actively contribute to the interpretation of this information. Although my thesis project is not one that adheres to the CBPR principles per se, it contributes to the overall ability of the Center for Alaska Native Health Research to fulfill its commitment to the partnership and communities involved in its studies.
REFERENCES


### APPENDIX

**Acronyms**

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AI/AN</td>
<td>American Indian/Alaska Native</td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
</tr>
<tr>
<td>ANTHC</td>
<td>Alaska Native Tribal Health Consortium</td>
</tr>
<tr>
<td>CANHR</td>
<td>Center for Alaska Native Health Research</td>
</tr>
<tr>
<td>CBPR</td>
<td>Community-Based Participatory Research</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CGHE</td>
<td>Center for Genomics and Healthcare Equality</td>
</tr>
<tr>
<td>CIHR</td>
<td>Canadian Institutes of Health Research</td>
</tr>
<tr>
<td>CLIA</td>
<td>Clinical Laboratory Improvement Amendments</td>
</tr>
<tr>
<td>DNA</td>
<td>Deoxyribonucleic acid</td>
</tr>
<tr>
<td>ELSI</td>
<td>Ethical, Legal, Social Implications (of genetics research)</td>
</tr>
<tr>
<td>FFQ</td>
<td>Food-Frequency Questionnaire</td>
</tr>
<tr>
<td>GENA</td>
<td>Genetics Education for Native Americans (workshop)</td>
</tr>
<tr>
<td>GWAS</td>
<td>Genome-Wide Association Studies</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>HSC</td>
<td>Human Studies Committee</td>
</tr>
<tr>
<td>IAB</td>
<td>Institute of Arctic Biology</td>
</tr>
<tr>
<td>IGERT</td>
<td>Interdisciplinary Graduate Education and Research Traineeship</td>
</tr>
<tr>
<td>IRB</td>
<td>Institutional Review Board</td>
</tr>
<tr>
<td>IHS</td>
<td>Indian Health Service</td>
</tr>
<tr>
<td>NBAC</td>
<td>National Bioethics Advisory Commission</td>
</tr>
<tr>
<td>NHLBI</td>
<td>National Heart, Lung and Blood Institute</td>
</tr>
<tr>
<td>NIDDM</td>
<td>Non-Insulin Dependent Diabetes Mellitus</td>
</tr>
<tr>
<td>PA Project</td>
<td>People Awakening Project</td>
</tr>
<tr>
<td>RSV</td>
<td>Respiratory Syncytial Virus</td>
</tr>
</tbody>
</table>
T2D: Type 2 Diabetes

TB: Tuberculosis

UAF: University of Alaska Fairbanks

UW: University of Washington

YK Delta: Yukon-Kuskokwim Delta

YKHC: Yukon-Kuskokwim Health Corporation