

Co-Learning in Community-University Health Research Partnerships:

A Southwest Alaska Case Study

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Abstract

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As theorized in the context of community-engaged health research, co-learning is based on an uninterrogated presumption that learning and change occur equally for community members and academic researchers. In practice, however, co-learning is often enacted (when it is enacted at all) as a unidirectional flow of expert knowledge from researchers to communities. Community members enter into an always-already powered setting in which dominant modes of academic socialization and ways of being and knowing constrain the range of possible interactions. Researchers may fail to recognize community members' expertise and bids to share their knowledge, resulting in missed learning opportunities as well as dignitary and relational harms. Using a combination of quantitative ethnography, discourse analysis, and descriptive thematic analysis, this dissertation explores co-learning in a longstanding collaboration between Yup'ik community members and an interdisciplinary team of university-based health researchers.

DEDICATION

This work is dedicated to the memory of Nick Therchik.

ACKNOWLEDGMENTS

My deepest gratitude goes to the members of the partnership, who encouraged this work and helped me believe in its value. I have learned so much, and I have so much more to learn. Your generosity, patience, and humor have changed my heart. *Quyana cakneq*. This work belongs to all of you, except for any errors. Those are mine.

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**Co-Learning in Community-University Health Research Partnerships:
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INTRODUCTION

This three-paper dissertation explores communication, co-learning, and relationality in community-university health research partnerships. Specifically, it examines selected discourse patterns and themes within a longstanding collaboration between Yup'ik (Alaska Native) community members and non-Yup'ik researchers in the Yukon-Kuskokwim (Y-K) Delta in southwest Alaska. I have been a coinvestigator and participant-observer in this research partnership since 2010.

This work synthesizes insights and theory from a number of disparate domains. From bioethics comes a focus on research ethics and the principles of respect, beneficence, and justice. The learning sciences offers a framework for assessing the processes, structures, and dispositions that support or hinder learning across difference. Discourse analysis facilitates the examination of language-in-use as a way to explore how actors achieve their social and political objectives.

The dissertation comprises three linked analyses, roughly following the temporal trajectory of partnership development and group formation.^{1,2} The first focuses on lessons learned regarding effective interpersonal and intergroup communication, a prerequisite for equitable collaboration. The second examines co-learning within the partnership, with an emphasis on researchers' developing understandings of Yup'ik conceptions of genetics and how individual traits, health conditions, and behaviors are handed down from generation to generation. In the third, I explore connections between group formation and onto-epistemic negotiation within Yup'ik community-university partnerships.

I have selected the three-paper dissertation option in part because the Yup'ik partners have encouraged the rapid dissemination of these results. They see the partnership as “doing something different,” enacting a new and improved approach to conducting health research with Yup'ik people, and they believe that the lessons we have learned together have the potential to improve research in the Y-K Delta and perhaps beyond. An important goal of this work is to help outside researchers become more trustworthy partners to Yup'ik people. This research may also aid Yup'ik community leaders and the regional Tribal health authority in developing their own guidelines for choosing trustworthy research partners and/or establishing standards for health research. I recently heard a Yup'ik community leader speak about the importance of outside researchers “leaving something behind for us to use,” and it is my hope that this work contains such resources. In the interest of expediting peer review, each paper in this dissertation follows author instructions for the target journal I have tentatively identified for each manuscript. As a result, some background information is duplicated across papers, and formatting is somewhat inconsistent. I beg the committee's indulgence.

BACKGROUND

Health researchers and other outside investigators have brought both dignitary and tangible harms to Indigenous¹ communities, which have been extensively, though probably not exhaustively, documented. A substantial literature describes the history and extent of resulting mistrust in Indigenous communities,³⁻⁹ together with the need for, and approaches to, “building trust” in health research.¹⁰⁻¹⁴

Implicit in this framing are three problematic assumptions. First, it implies that trust existed at some prior point and need only be restored. It is beyond the scope of this dissertation to detail the depredations Indigenous peoples have experienced since white contact, but trust has

certainly not been a hallmark of that history. Second, Indigenous peoples' mistrust is often framed as a (mere) historical artifact, rather than a reaction to current conditions. An analogous narrative can be seen in recent reports about COVID-19 vaccine hesitancy in the African American community. Outsiders have often attributed the relative lack of vaccine uptake to the Tuskegee Syphilis Experiment and other past abuses of Black people in health research and healthcare,¹⁵ but as Black healthcare providers and community leaders point out, anti-Black racism never ended. Construing community members' concerns as the result of particular historical events, while failing to recognize the ongoing nature and impact of current racial inequities, only compounds the injustice.¹⁶⁻¹⁹ Third, and most importantly, defining communities' lack of trust as the issue misplaces the locus of responsibility and thus misidentifies what – and who – must change.^{20,21} The problem is not that communities do not trust researchers; rather, it is that researchers have not been worthy of trust.

Health Research: A Path to Addressing Health Disparities?

Both mainstream biomedical research and bioethical analyses typically begin from the presumption that health research is necessary to advance the wellbeing of minoritized groups, including Indigenous peoples.ⁱⁱ Academic experts and policy makers agree that health research has the potential to address persistent, cradle-to-grave health inequities that disproportionately affect the members of minoritized groups.²²⁻²⁵

In the United States, efforts to leverage biomedical research to reduce health inequities have taken two main paths: (1) increasing both the enrollment of individuals from minoritized groups in mainstream research^{26,27} and the volume of research explicitly focused on health disparities (e.g., the creation of the National Institute on Minority Health and Health Disparities in 2010), and (2) changing the way in which health research is conducted (e.g., emphasizing

diversity and inclusion, operationalized as getting more minoritized students and trainees “into the STEM pipeline”).^{6,28-32}

The first approach prescribes a set of tactical changes intended to reform research practices without necessarily challenging the basic assumptions, affordances, and foreclosures of the status quo. Health disparities research has generated many descriptions of worse health outcomes among minoritized populations; unequal treatment in healthcare and health research; and the deleterious influence of poverty, intergenerational trauma, and other so-called social determinants of health. Most such studies stop short of addressing the problems they identify, however. For example, a recent review determined that across the US, Canada, Australia, and New Zealand, up to 92% of studies involving Indigenous peoples are descriptive; a mere 18% are intervention studies.³³

The second approach is more radical, positing that the underlying inequities that drive health disparities also structure the research enterprise. That is, there are fundamental, “powered” problems in why, how, and by whom health research is conceptualized, prioritized, and carried out. On this view, justice demands – among other things – that power and resources be shared fairly between communities and researchers, and that the right of community members to participate in consequential decisions be reflected in actual practice. Equity-focused scholars in both education and health research further posit that this kind of change should be led by, and for, the people formerly considered the “subjects” of research. Broadly speaking, funders and academics inclined toward change tend to prioritize reform, while communities and activists are more likely to advocate for transformation.

Transformative agency is a conceptual lens that sharpens our focus on the “collective will and ability of individuals to break from a given frame and take initiatives to transform their

activity over time.”³⁴ Creating the conditions of possibility for transformative agency demands researchers move beyond “allowing” community members more “input” into existing oppressive systems; it means actively eliciting their direction and being open to implementing the changes they envision. This requires taking seriously ancestral and cultural funds of knowledge, allowing for differences in communication style and affective presentation, respecting incommensurable onto-epistemological understandings, and shifting from description (e.g., research characterizing high rates of COVID-19 mortality in minoritized communities in the US) to action (e.g., working with communities to develop novel approaches to address vaccine hesitancy in populations with ample reason to mistrust such interventions).^{33,35-37}

Community Engagement as a Corrective

Proponents of research transformation have proposed numerous reformulations of research ethics and methods to address the power imbalances and past harms of health research with minoritized communities. Meaningful community engagement is a central component of these approaches. Among Indigenous peoples, the risks and harms of health (and other) research done by outsiders in the absence of such engagement are well known.^{4,7-9,23,35-40} Many of the most incisive critiques of current research practices, as well as a wealth of equity-focused ethical principles and alternative approaches to the conduct of health research, come from a growing international community of Indigenous scholars.^{11,41-56}

Mainstream models for community-engaged research (CEnR), such as community-based participatory research (CBPR), have also been proposed.^{57,58} These models share a core set of starting assumptions, i.e., that equity and social change should be explicit aims of health research; that communities shape health-related behaviors and environments; that researchers can engage community members to act as change agents; and that meaningful, ongoing community

engagement is critical to ensuring the usefulness and sustainability of resulting interventions.⁵⁹

Israel and colleagues' model of CBPR is arguably the leading CEnR approach as of this writing.^{58,60,61} It comprises nine core principles, including recognizing the community as a unit of identity; engaging the community in all phases of the research process, from devising research questions to the dissemination of results; empowering communities to pursue their own questions by building research capacity; and balancing knowledge creation and intervention for the benefit of all partners.

CBPR and related models of CEnR have been endorsed by both funding agencies and communities. For example, many funding opportunities from the National Institutes of Health (NIH) now require a community engagement component.⁶² In addition, some Tribal governing bodies mandate the use of CEnR, in addition to Tribal review, for research conducted within their communities.⁴⁴ However – and unsurprisingly, given the reform vs. transformation tension described above – substantial variation exists in the degree to which meaningful engagement is carried out. A systematic review of 107 US-based studies involving Indigenous peoples, for example, found only two papers that reported seeking feedback from Indigenous reviewers, and none that sought community input or review.⁶³

The question also arises of who is qualified to conduct research that is truly accountable to communities. Some scholars, leaders, and communities argue that it is insufficient for outside researchers to ascertain community priorities and collaborate with community members. These critics argue that white researchers simply do not belong in minoritized communities: in order to be ethical, culturally congruent, rigorous, and responsive to community priorities and values, research must be led by members of those communities.^{37,64-66}

Much research with the stated aim of advancing justice and reducing disparities in fact continues established patterns of colonial domination, extraction, and structural racism. This occurs at multiple levels: in interpersonal dealings (e.g., relegating community members to instrumental roles as research participants, recruiters, or translators), institutional relations (e.g., academic institutions retaining the vast majority of research funds while limiting the access of communities to data), and epistemic valuation (e.g., failing to recognize Indigenous expertise as expertise). A group comprised primarily of Black scholars recently published a critique of “health disparities tourism” that asserts that established white researchers with no prior stake in disparities research are following the (NIH) money. They claim that such investigators are monopolizing earmarked funds to conduct research in communities to which they do not belong and of which they have limited understanding. This not only continues a longstanding trend of extractive research with minoritized groups; it also displaces junior investigators who have roots and relations in those communities, and a long-term commitment to their wellbeing.⁶⁴

Others suggest that an “Indigenist” approach to research can be carried out by non-Indigenous investigators who adhere to Indigenist methods and goals and are guided by Indigenous mentors and community priorities.^{32,67} For white-outsider academics, the shift toward equitable engagement requires both intellectual and cultural humility, as well as taking Indigenous knowledge systems seriously.^{6,47,68} Seeking to identify guiding principles for the ethical conduct of research with Indigenous peoples by non-Indigenous researchers, Kilian and colleagues identified four core principles that should guide such work: mutual trust, accountability, valuing relationships, and humility, including the need for investigators to embark on a “personal journey” toward reconciliation and allyship.⁶⁹ As will be described in the next section, these commitments also have implications for co-learning.

Researchers who do not undertake these commitments may fail to recognize important onto-epistemological differences between dominant/mainstream and Indigenous knowledge systems; implement window-dressing “engagement” approaches; discount or consider Indigenous expertise as “less than;” or consider themselves accountable only to their institutions and funders, to the exclusion of the communities with which they propose to work.⁷⁰⁻⁷³

Co-Learning in Community-Engaged Research

Israel and colleagues define CBPR as “a co-learning process that fosters the reciprocal exchange of skills, knowledge, and capacity among all partners involved, recognizing that all parties bring diverse skills and expertise and different perspectives and experiences to the partnership process.”⁶⁰ Yet most published papers from studies that purport to have conducted CBPR research say little, if anything, about co-learning. This may stem in part from a lack of conceptual clarity.

Although the community engagement literature emphasizes reciprocity and respect, an operational definition of co-learning in health research has not been established. Extant theoretical models suggest that both co-learning and capacity-building are meant to be “bidirectional,” mutual processes, but concrete advice about what this means and how such mutuality may be fostered is lacking. Few empirical reports in the health research literature have explained how such work has been carried out – if indeed it has.⁶³ The ideal scope of bidirectional learning is also unclear. For example, is the goal is for partners to share their respective knowledge about a domain of shared concern (e.g., understandings of heritability)? Ought co-learning also encompass knowledge that is held by one group and not the other (e.g., information about seal hunting or grant-writing), regardless of its relevance to the topic under study? Should co-learning aim for the development of novel, jointly produced knowledge?

PROBLEM STATEMENT

Despite the growing prevalence of CEnR approaches in health research with Indigenous communities, co-learning per se (i.e., apart from capacity building, often defined as efforts to create research infrastructure within communities, less often including changes in university policies and researcher training) remains understudied. Questions include what counts as expertise, what kinds of learning are worthwhile, what ought to be learned and by whom, and the role of interpersonal relationships. Ideally, co-learning represents reciprocal learning and change, rather than a unidirectional flow of information from academic experts to communities. Reciprocal knowledge exchange holds the promise of improving both the quality of scientific inquiry (e.g., through the development of novel hypotheses that synthesize ideas from the academy and Indigenous knowledge systems) and the applicability of research results in the settings for which they are intended. Unpacking the role of communication and relationality in co-learning is thus an important step in fostering equitable collaborations between minoritized communities and university-based researchers.

OVERVIEW OF THE STUDY

In the interest of orienting the reader to the overall study, I offer an overview of the design and methods here. Methods specific to each analysis are detailed in the individual papers.

Setting and Participants

This research is grounded in a longstanding research partnership in the Yukon-Kuskowkim (Y-K) Delta in southwest Alaska, the traditional lands of the Yup'ik people. The collaboration was established in 2009 by researchers at the Center for Alaska Native Health Research (CANHR) at the University of Alaska Fairbanks (UAF); the Yukon-Kuskokwim Health Corporation (YKHC), the regional Tribal health authority; and Yup'ik research

participants and community members. This collaboration builds on the prior work of CANHR's founding director, Dr. Gerald Mohatt, a white psychologist and researcher who worked with Indigenous peoples for nearly 40 years. People in the Y-K Delta still speak of him with respect and affection, and his definition of community members as "co-researchers"⁷⁴ continues to guide both research practice and Tribal review of proposed studies in the region. I unfortunately did not have the opportunity to work with Dr. Mohatt, but his example informs my work.

The Y-K Delta is home to more than 23,000 people, about 82% of whom are Alaska Native (mostly Yup'ik), in 58 communities ranging in size from 25 to more than 1,000 people.⁷⁵ These communities are not connected by roads; travel is by airplane, boat, and (in winter) by snowmobile and four-wheeler. Harvesting and sharing traditionally harvested foods between coastal and tundra communities (e.g., salmon and seal oil from the coast and moose and caribou from inland) is an important part of Yup'ik life. In earlier times, the Yup'ik people lived semi-nomadically, following the availability of animals and plants and setting up camp for the duration of the harvest season.^{42,76,77} Winter is the traditional time of the year for storytelling, Yup'ik dancing (*yuraq*), and visiting from village to village.^{78,79}

During the period reported here, the partnership included the Community Planning Group (the CPG, comprising 10 Yup'ik individuals who had participated in prior genetic research), the Ciuliatⁱⁱⁱ (a group of five Yup'ik bi-cultural liaisons, all of whom are Yup'ik speakers born and raised on the Y-K Delta), and an interdisciplinary team of nine researchers from UAF, the University of Washington, and the Group Health Research Institute (Table 1). One of the university researchers was Indigenous (not Yup'ik), and the remainder were of European descent. Another university researcher was a fluent speaker of Yup'ik. Categorical participant demographics are displayed in Table 1 to limit the possible reidentification of individual

participants and communities.

During the period covered in these analyses, the partnership was funded by several grants, including the Ethics of Dissemination: Communicating with Participants about Genetics Research (2010 – 2015, a National Human Genome Research Institute [NHGRI] project aimed at improving researchers’ communication of study progress and results to Yup’ik and kass’aq^{iv} participants and the community at large); Pharmacogenetics in Rural and Underserved Populations (2010 – 2015, a National Institute of General Medical Sciences [NIGMS] study exploring the genetic factors underlying inter-individual differences in drug response among Indigenous peoples in Alaska and Montana); and the Program on Genetic and Dietary Predictors of Drug Response in Rural and American Indian/Alaska Native Populations (2016 – 2022), a research program project grant funded by NIGMS, focused on the effects of genetics and traditional vs. store-bought foods on drug metabolism).

Table 1. Partner Demographics

Community Planning Group (n=10)		
Age		
	Elder	4
	Non-Elder	6
Sex		
	Male	5
	Female	5
Race / Ethnicity		
	Yup’ik (Alaska Native)	10
Yup’ik Speakers		10
Ciuliat (bicultural liaisons) (n=5)		
Age		
	Elder	0
	Non-Elder	5
Gender		
	Male	2
	Female	3
Race		
	Yup’ik (Alaska Native)	5
Yup’ik Speakers		5
Academic Researchers (n=9)		
Age		
	Elder	1
	Non-Elder	8
Rank		
	Senior faculty	3
	Junior faculty / postdoc	2
	Staff / consultant	4
Gender		
	Male	2
	Female	7
Race		
	American Indian	1
	White	8
Yup’ik Speakers		1

The data on which the following analyses are based are from 10 meetings held between December 2010 and February 2016 (Table 2). We met in person in Mamterilleq (Bethel), Alaska, at least once per year. Meetings typically lasted from 1–3 days. The primary purpose of the meetings included in these analyses was to elicit the CPG and Ciuliat’s advice about how best to share complex, but not clinically actionable, genomic research findings with Yup’ik

Table 2. Data Summary

Meeting ID	Date	Primary Topic(s)	Attendees (n)	Pages (n)
Meeting 1	December 2010	Introductions, orientation	CPG = 9 Ciuliat = 1 Researchers = 5	69
Meeting 2	February 2011	GENA Workshop (workshop portion not recorded)	CPG = 8 Ciuliat = 5 Researchers = 6	68
Consultant meeting	May 2011	Not recorded; all partners plus consultants: academics with nationally recognized expertise in community-engaged research	Missing data	0
Meeting 3	December 2011	Review of results from Akiachak focus groups; communication tips	CPG = 5 Ciuliat = 2 Researchers = 6	215
Meeting 4	May 2012	How to share research results with community members	CPG = 5 Ciuliat = 4 Researchers = 7	176
Meeting 5	September 2012	What community members want to know about research	CPG = 6 Ciuliat = 4 Researchers = 7	129
Meeting 6	February 2013	How to share research results with community members	CPG = 5 Ciuliat = 3 Researchers = 6	184
Meeting 7	October 2013	How to share research results with community members	CPG = 5 Ciuliat = 4 Researchers = 6	87
Meeting 8	May 2014	Review of research results to date, how to share research results	CPG = 8 Ciuliat = 3 Researchers = 6	117
Meeting 9	January 2015	Review of research results to date, how to share research results	CPG = 4 Ciuliat = 3 Researchers = 4	96
Meeting 10	February 2016	Review of research results to date, how to share research results	CPG = 4 Ciuliat = 4 Researchers = 4	65

stakeholders.⁸⁰ The CPG and Ciuliat were also invited to provide advice regarding study design, logistics, and dissemination on a number of other studies. Both YKHC (which reviews research in the Y-K Delta through its Human Studies Committee) and NIH consider the endorsement of the CPG (in the form of Letters of Support) in their review of proposed research from the partnership.

The collaboration has since continued with additional projects, including Community-Engaged Research Toward Precision Medicine with American Indian and Alaska Native People (2017 – 2022), a NHGRI-funded project that convened Tribal leaders from three regions in Alaska and Montana to discuss Tribal priorities, parameters, and acceptability of precision medicine research).^{81,82} Approximately 2,000 Yup'ik people in 11 communities in the Y-K Delta have participated in this and related research.

Sensitizing Concepts

Sensitizing concepts are the background ideas that shape inquiry in social scientific research, informing the development of research questions and hypotheses and guiding design and analysis.^{83,84} The work presented here draws from four primary conceptual domains: (1) Yup'ik onto-epistemology and axiology, i.e., Yup'ik values and beliefs about the world, human beings' place in it, and what can be known, as well as what is good, beautiful, and valuable;^{31,64,85-89} (2) theoretical innovations and practical models concerning equity-directed social change, including transformative agency and Critical Race Theory;^{34,36,90-93} (3) selected theories of relationality, including reciprocal relationality,^{29,31,87,89,94} Basic Psychological Needs Theory,⁹⁵⁻⁹⁷ relational autonomy,^{98,99} and relational agency;¹⁰⁰ and (4) two models for examining social interaction: discourse analysis, including techniques of conversation analysis,¹⁰¹⁻¹⁰⁴ and Social Presence Theory.^{105,106} My masters' training in bioethics and prior empirical research –

particularly in studies concerning CEnR methodology, research ethics, and interpersonal communication in the context of cultural and power differences – also inform my approach to this work.

Methods

This dataset is unusual in several respects. It represents a complex partnership, involving individual participants from two primary identity groups – Yup'ik community members and non-Yup'ik researchers, most of whom are white – with additional identities and affiliations within each (e.g., Yup'ik individuals from tundra and coastal communities in the Y-K Delta, and some who currently live in Fairbanks; researchers from different institutions and with different disciplinary training). Due to geographical distances and associated travel expenses, meetings were held relatively infrequently. The topics under discussion were far from everyday conversation for community partners, a situation that held the potential to reproduce entrenched views of university personnel as experts and community members as learners. Finally, the volume and temporal duration of the data and the relatively stable composition of the partnership over time are also, to my knowledge, quite rare in the published literature.

A case study methodology provides the overall guiding logic for this analysis.^{107,108} This approach enables close study of the phenomena of interest under real-world conditions and accommodates the use of multiple data sources (here, meeting transcripts, written materials, and my and others' contemporaneous meeting notes). Consistent with case study methodology, the findings of these three linked analyses generalize not at the level of the specific case (which is necessarily unique) but rather at the contextual level, with applicability to other collaborations that have key features in common with this partnership.^{109,110}

This work also uses two forms of discourse analysis. Conversation analysis delves into the specific form and content of interlocutors' speech, staying close to transcribed data, to interpret social interactions (e.g., to identify interlocutors' objectives and the extent to which they are achieved). As such, it simultaneously analyzes action, meaning, context management, and intersubjectivity.^{111,112} Gee's approach to discourse analysis explicitly considers issues of identity, self-presentation, and what he refers to as "politics" – individual and group efforts to build a perspective regarding the distribution of social goods, including determinations about what is good, right, etc. (i.e., axiological or normative judgments).^{101,102,113} It also employs descriptive thematic analysis.^{84,114,115}

Quantitative ethnography (QE) is a novel research methodology developed by education researchers at the Wisconsin Center for Education Research at the University of Wisconsin – Madison to identify and quantify connections in qualitative data.^{116,117} Recognizing that the current "Big Data" era presents substantial challenges to conventional quantitative and qualitative approaches, QE was designed to combine the strengths of both to yield a more complete and accurate account of large qualitative datasets and to facilitate the identification of patterns that may elude traditional qualitative analysis. Whereas most mixed-methods studies employ quantitative and qualitative techniques either side by side or sequentially, QE integrates these approaches through a methodology called epistemic network analysis.

Each paper is targeted to a slightly different audience. Paper 1 examines communication dynamics using a combination of sociolinguistic approaches: conversation analysis and Gee's formulation of discourse analysis. This lessons-learned manuscript is intended for CEnR practitioners and written with *Progress in Community Health Partnerships: Research, Education, and Action* in mind. In Paper 2, I turn to discourse analysis and descriptive thematic

analysis to examine bidirectional co-learning and explore the investigators' developing understanding of Yup'ik conceptions of heredity and relatedness. This paper has more bioethics content and thus is drafted in line with the editorial requirements of the *Journal of Empirical Research on Human Research Ethics*. Paper 3 uses a combination of descriptive thematic analysis, QE, and discourse analysis to consider the interrelationship of co-learning and relationality and examine how this developed over the study period. It is written for a broader audience and follows the editorial conventions of *Social Science and Medicine*.

Ethics Review

Community members and researchers involved in the project as of 2019 provided verbal permission for this secondary analysis at a meeting in March of that year. The CPG and Ciuliat members were enthusiastic about this project and very supportive of my return to graduate school. All participants, including the university-based researchers, had previously provided written informed consent for the main study, as required by the YKHC Human Studies Committee.

This research was deemed minimal risk by the UW Institutional Review Board (IRB) on April 11, 2019, and granted approval through study completion (STUDY00007181). The study has also been approved by the full board of the YKHC Human Studies Committee, with annual continuing review required (study 19.08.02, current approval expires on June 1, 2023).

Researcher Positionality

I am a 53-year-old white woman with an abiding interest in research ethics, intercultural communication, and how and why adults learn together – or fail to do so. I have been engaged in health-related research with Alaska Native and American Indian communities in Alaska and Montana for the past 15 years, and in the Y-K Delta since 2010. In September 2012, I had the

transformative experience of being made kin by Nick Therchik, who was a Yup'ik Elder, Catholic deacon, Bristol Bay fisherman, and deeply respected culture bearer in the Y-K region. Nick named me after his sister, Arnaq, who had passed on. According to Yup'ik custom, he thereby imbued me with his sister's spirit and made us siblings.¹¹⁸ The naming ceremony also made me a cousin to two members of the Ciuliat and another member of the CPG, as well as a relative of all the others who carry the name Arnaq. I am still growing into that identity and web of relations, which guide my steps as a kass'aq researcher seeking to serve Indigenous peoples. I am accountable to the Yup'ik people in a different way now that we are family. I name Nick here out of deep respect and affection. Doing so is also in keeping with a burgeoning movement in academia toward formally acknowledging Indigenous Elders and knowledge keepers as experts.¹¹⁹

The catalyst for this work was a question from my Yup'ik brother. At the end of a meeting in May 2012, one of the researchers asked that we go around the circle in which we were seated and share what we had learned. She had turned expectantly to one of the community members when Nick's proxy interrupted on his behalf, saying that this time, he wanted to hear what we – the researchers – had learned. This marked a turning point in my thinking. Why was Nick's question so discomfiting? How, despite our good intentions, had a dynamic been created in which an Elder needed to remind us that we were there to learn – and that our learning could, and should, be assessed by our community partners? What would have been a good answer, from Nick's point of view?

This dissertation has also been shaped by a conversation early in my doctoral studies with Dr. Megan Bang, an internationally recognized leader in Indigenous education. Recently returned from a research trip to the Y-K Delta, I confessed my worry that I and other white

researchers may be reproducing the very injustices we hoped to eliminate. Dr. Bang told me that I had an obligation to remain in the field precisely because I recognized that danger. Rather than take minoritized communities as the subject of inquiry, however, I should flip the usual script to ask what equitable collaboration requires of researchers, institutions, and funders. This charge meshes well with both my prior empirical work in research ethics and my interest in the moral development of researchers and clinicians.

Coming to grips with my own positionality, and especially the ways in which I have been accustomed to learn and teach, has been an important part of this journey. Shawn Wilson (Cree) has written, “If research hasn’t changed you as a person, you haven’t done it right.”³¹ I have become a better listener, a more careful speaker, and an advocate for Indigenous sovereignty and self-determination through my participation in this partnership. I have also loosened my grip on what I (think) I know.

Working with Alaska Native and American Indian community members and colleagues, I have come to understand that it all comes down to being in right relationship. In the research context, this entails that researchers socialized in dominant methodologies and ideologies give up things we want and feel entitled to have. Authority, resources, and recognition are not ours by right, and we miss important learning opportunities when we behave as if they are. This demand – to give up things we value – transcends the bounds of traditional research ethics. Settler scholars working with Indigenous peoples must examine the ways in which we are complicit in maintaining an unjust status quo. We need to sit with that discomfort before we can discern a different way forward, always in collaboration with communities. In the words of fictional detective Armand Gamache, “There are four things that lead to wisdom . . . four sentences we learn to say, and mean . . . ‘I don’t know. I need help. I’m sorry. I was wrong.’”¹²⁰

The Joint Development of Communication Competence in Community-Engaged Health Research Partnerships

INTRODUCTION

The volume of community-engaged research (CEnR) has increased substantially in recent years, together with advances in both theory and practice.^{25,62,121,122} The CEnR literature acknowledges the importance of creating a common understanding of the research topic and its relevance to community priorities, developing shared goals, and building trust, but the role of interpersonal and intergroup communication in achieving these objectives has been largely overlooked. This is despite the fact that the broader literature points to the importance of communication in learning and the formation of viable communities of practice,^{102,123-125} as well as the particular challenges that intercultural differences can pose.^{103,126} Communication serves a constitutive function in equitable partnerships: it creates, organizes, and reflects the qualitative nature of interactions and relationships. As such, communication has important implications for equity, sustainability, co-learning, and productivity in CEnR.

Published reports that focus on communication in health research partnerships have tended to highlight community dissemination, i.e., approaches for reporting study progress and providing research findings to study participants and other community stakeholders.^{121,127-132} Conveying actionable study findings to participants and communities is a central tenet of CEnR and an important corrective to the problem of extractive research with minoritized communities, in which outsiders visit, take samples and data, and are never heard from again.^{57,60} Community dissemination can also serve as an important site for onto-epistemic negotiation, elevating the value of community-specific knowledge and ways of knowing, as well as providing

opportunities for community partners to determine what information matters and how it should be made available.^{20,80,133}

Effective, respectful communication *within* such collaborations has so far received less attention. When intra-partnership communication has been addressed, it has usually been at the level of general principles, recapitulating the theoretical and ethical commitments of CEnR, rather than providing insights about what effective communication looks like “in the wild.”¹³⁴ With the goal of helping practitioners find their way from theory to practice, this report highlights examples from a longstanding community-university health research partnership and suggests strategies to improve communication in such collaborations.

METHODS

Setting and Participants

The partnership was established in 2009 by investigators at the Center for Alaska Native Health Research (CANHR) of the University of Alaska Fairbanks (UAF); the Yukon-Kuskokwim Health Corporation (YKHC), the regional Tribal health authority serving Alaska Native (AN) people in southwestern Alaska; and Yup’ik community members. It includes the Community Planning Group (CPG) (10 past study participants recruited from eight Yup’ik communities in the lower Yukon-Kuskokwim [Y-K] Delta in southwest Alaska); the Ciuliat group (five Yup’ik bi-cultural liaisons); and nine *kass’aq^{iv}* (non-Yup’ik) investigators (four each from UAF and the University of Washington, and one from the Group Health Research Institute (Table 1).

Ciuliat (Yup’ik for ancestors, used here in the sense of facilitators) members are university-educated Yup’ik professionals who “walk in two worlds.”¹³⁵⁻¹³⁷ They currently reside in Fairbanks, Alaska, an urban center, but grew up in the rural Yukon-Kuskokwim (Y-K) Delta

and are fluent Yup'ik speakers. Their role as bicultural liaisons is to facilitate intercultural communication and support the full participation of the CPG members, including Elders, who live in outlying villages and follow more traditional subsistence lifeways.^{76,77,138} Some CPG members were among the last generation not forced to attend kass'aq schooling.¹³⁹ Although they spoke and understood English, they were often more comfortable communicating in Yup'ik. Ciuliat and CPG members were directly recruited by the CANHR researchers, who led the overall partnership.

As required by the YKHC Human Studies Committee (HSC), all members of the partnership provided written informed consent as co-researchers.⁷⁴ Those still actively engaged in the partnership as of March 2019 provided verbal permission for the present study, which was also approved by the HSC and the University of Washington Institutional Review Board.

Except for a hiatus imposed by the SARS-CoV-2 pandemic beginning in early 2020, the partnership has met at least annually. The main purpose of the meetings reported here was to elicit the CPG's advice about communicating genomic research findings to Yup'ik study participants, Tribal leaders, and the community at large, as well as study design, logistics, and dissemination for several other studies. Meetings lasted 1.5 – 3 days, affording participants the chance to reflect overnight on the first day's discussions.

The Y-K Delta lacks a road system; CPG members traveled from outlying communities by small plane or, in winter, by snowmobile. The Ciuliat and CANHR investigators flew from cities in Alaska and the Pacific Northwest. A designated Ciuliat member (C5) provided simultaneous interpretation as needed, with occasional assistance from other Ciuliat members and the CPG.

Data Collection

Meetings were audio recorded and transcribed verbatim by the primary interpreter (C5), including Yup'ik to English translation where necessary. This report is based on meeting transcripts from 2010 – 2016 (Table 2), written meeting materials (agendas, handouts), and the researchers' contemporaneous notes and recollections.

Analysis

I reviewed the full dataset and selected specific interactions that illustrate some of the lessons learned with respect to communication over the lifetime of the partnership. This report relies on the theory and methodology of conversation analysis and discourse analysis (DA), which examine the ways in which language is used to create and maintain social norms, construct personal and group identities, and negotiate power and position.^{101,104,111,113,140} DA methodologies are based on three key assumptions about the social nature of discourse: (1) language is constructive and constitutive of social life, building (not simply describing) the world; (2) discourse is an active construction, with utterances designed for a particular context and purpose; and (3) meaning is a joint production, both at the level of culture and through specific interactions between speakers.¹⁴⁰ Discourse thus both defines the social roles that are available to individuals and serves as a primary means through which they enact their identities.^{141,142} It is also one of the main ways power is exercised and powered relationships are defined, established, and maintained.¹⁰⁴

Gee's formulation of DA identifies seven "building tasks" of language: (1) significance – giving things meaning, value, and salience; (2) activities – "getting recognized" as doing or engaging in a particular kind of activity; (3) identities – "getting recognized" as taking on a particular identity or role; (4) relationships – building social relationships, signaling the kind of

relationship they have or desire with others; (5) politics – building a perspective regarding the distribution of social goods, including axiological judgments; (6) connections – making certain things relevant or related (or not); and (7) sign systems and knowledge – using language, dialect, jargon, and terms of art to privilege or make relevant one sign system over another.¹⁰¹ This analysis also employs the techniques of conversation analysis, a subdiscipline of DA, to guide close reading and interpretation of interactions, based on excerpts from the meeting transcripts.¹¹¹⁻¹¹³

RESULTS

Interpersonal communication in these meetings was subject to a combination of powered relations between individuals and groups, cultural differences between Yup'ik and kass'aq partners, and linguistic differences. Alphanumeric study codes are used to refer to individual speakers: G# identifies CPG members, C# identifies Ciuliat members, and R# identifies researchers.

Positionality and Power Dynamics

Throughout the partnership meetings, it was necessary for participants to navigate multiple axes of difference and power – not only across the cultural divides between Yup'ik community members and kass'aq researchers, but also within both groups. Differences in age, gender, education, life experience, disciplinary training, institutional constraints, and positional power were at play throughout. For example, the Yup'ik value of respect for Elders meant that younger participants were less likely to assert themselves in discussion; likewise, academic research staff were more likely to defer to senior faculty. All partners tended to defer to G9, an Elder and respected culture bearer in the Y-K region. Other cultural norms were somewhat incompatible between groups, such as the Yup'ik norm of conflict avoidance vs. the academic

norm of challenging others' ideas, or the Yup'ik norm of humility vs. the academic norm of asserting one's expertise. Also relevant to this analysis is the Yup'ik belief that words have power in the world: words should be chosen and used with care, unnecessary speech is discouraged, and speaking a bad thing can cause it to happen.^{78,118}

Yup'ik participants varied in age and gender as well as their exposure to kass'aq schooling (and thus their familiarity with scientific concepts and terms), employment experiences, leadership roles in the community, and the different lifeways of tundra and coastal villages. Among academic participants, individual positionalities were layered with institutional politics (e.g., between the grantee institution and subcontracted institutions) and historical hierarchies among different academic disciplines (i.e., basic science, clinical research, social science, and humanities).

As part of their liaison role, Ciuliat members routinely interrupted the investigators as needed to ask questions, challenge assumptions, propose alternate language or culturally relevant analogies, or guide the conversation back to community priorities. Ciuliat member C1 coined the term "yeah-butting" to describe this function. Persistent efforts of Ciuliat and CPG members were required to avoid or resolve problems arising from researchers' use of unfamiliar terms and concepts – including, but not limited to, scientific jargon – as demonstrated in the following interaction. The group was seeking a relatable way of explaining the probabilistic nature of genetic risk, i.e., that although certain genetic variations can increase the likelihood of a person developing a particular disease, a person at increased risk may or may not go on to develop the disease:

R9: In my family, both my parents have high blood pressure. So just knowing that, I know it's more likely, it *could* happen

C1: Yeah

R9: that I could have high blood pressure also. And I was trying to think about earlier, what . . . would be an analogous thing?

C1: What's "analogous"?

R9: That's something that – (*laughs with C1*) I realized that as it came out, I realized that was a dumb word to use. (*laughs*)

C1: It's a very good word, but at a different place.

Rather than answer R9's question, C1 – who knows very well what "analogous" means – flags the communication misfire ("What's 'analogous'?"), thereby affording R9 the chance to correct her mistake. R9 recognizes his question as a correction and expresses her agreement with and acceptance of the correction. Her response positions her as a novice; her word choice ("*dumb word to use*") and laughter indicate that she has not taken offense. C1's comment positions him as a teacher and cultural broker. The oblique nature of the correction and the way it is delivered aligns with Yup'ik communication norms of avoiding direct criticism.

The practice of making space for the CPG to ask questions or to ask questions on their behalf was also taken up by some members of the research team. Prompted by their colleagues' use of technical terms or nonverbal signals that someone may be confused or have a question, investigators took the floor to create conversational openings. For example, after an extended interchange between several of the investigators and C1, R2 said, "I have an observation too. And my colleagues hopefully won't be mad at me. We in science, we tend to be real fast with our comments. But what I really wonder is what our quiet CPG and Ciuliat members that are not [teachers], what they think." This interjection served two functions: it reminded the investigators to slow down, and it turned the floor over to the CPG and Ciuliat. Such openings were often taken up, provided that enough of a pause was given.

Cultural Differences in Communication

Talk Turns and Overlapping Speech

Intercultural differences in the amount and pace of talk and the length of pauses can impair communication.¹⁴³ The pace of talk is slower, and pauses are longer, in Yup'ik speech (in both Yup'ik and English) compared with patterns of American English speech. In these meetings, this difference often resulted in the investigators mistaking a pause for the end of a talk turn and unintentionally interrupting Yup'ik speakers. At a meeting several years into the partnership, after a prolonged silence following a heartfelt expression of gratitude from C4 for the way the partnership was developing, the following exchange took place:

- C1:** *[addressing the investigators]* Thanks for learning to pause and embrace that pause.
- R2:** Can I just comment on that?
- C1:** Go ahead.
- R2:** I'm really glad you said that, because I was really uncomfortable with the length of that pause. (*laughter*)
- C4:** And you did good.
- C1:** I was so impressed when no one said anything. That was good.

The next day, the following conversation took place in Yup'ik:

- C1:** [[Yesterday we were silent for a several minutes and we, the Yup'ik, like the silence, when no one is speaking. But R2 was uncomfortable]] (*laughter*)
- C5:** [[It was too long.]]
- C1:** [[“When is someone going to say something?” But, since he learned how we are, he kept quiet even though he wanted to say something. When we first started, he would be talking without stopping. Because they know how we are now, they are comfortable when there is silence.]] We've come a long way.

G9: [[With all work, we have to help [so] that everything goes well. Also (*long pause*) When people talk on top of each other, the job they're supposed to be doing comes and goes. But we, the Yup'it, when we meet we listen to people one at a time, taking turns until we become of one mind, instead of talking all at once on top of each other.]]

For some American English speakers, by contrast, overlapping speech can signal enthusiasm and solidarity. Significant regional differences exist, as demonstrated in Tannen's classic analysis of an uncomfortable Thanksgiving dinner involving three fast-talking, Jewish New Yorkers and three Gentiles, including a very polite Southerner.¹⁴⁴ One culture's cooperative overlap is another's disrespectful interruption.

Asking Questions

Yup'ik communication conventions and the norm of conflict avoidance are very different from kass'aq (and academic) norms, such that it can be socially awkward for Yup'ik people to offer critical comments or ask questions that could be perceived as providing negative feedback. The kass'aq style of asking questions can be perceived as rude and aggressive by Yup'ik people. It is regarded as especially disrespectful to ask direct questions of Elders.

The investigators often had questions for the CPG and Ciuliat, however, such as how best to approach recruitment, or how burdensome community members consider blood draws to be. Two culturally appropriate modes of questioning emerged. One was to present the question as a statement of curiosity or interest, e.g., "I wonder how people think about X." The other was to say *apyutkangqertua*, "I have a question to ask," and pause. *Apyutkangqertua* is the first half of an adjacency pair, a form of conversational turn-taking in which the first speaker's utterance prompts a corresponding patterned response – for example, the pairing, in English, of "please" and "thank you." Responses can be preferred or dispreferred: for example, a complaint may elicit

an apology or resolution (preferred) or an excuse (dispreferred).¹⁴⁵ The preferred response in this case is an invitation (verbal or nonverbal) to ask the question.

Difficulties arose when the investigators asked compound questions, e.g., “Do you think people in your community worry about how their information might be used or by whom, or is that not concerning?” The Yup’ik response to such questions was usually silence, which the investigators tended to interpret as signaling a need for more talk, rather than the result of too much. This dynamic, which sociolinguists refer to as complementary schismogenesis, can lead to a recursive spiral in which one speaker’s response elicits the opposite response from the other, widening the communication gap.^{146,147} In one example, an outside consultant had posed a rapid-fire set of questions to G1. Overwhelmed by this torrent of language, G1 said that, unlike the consultant, she had not had much formal education and could answer only one question at a time. The group returned to this “five questions at once” story many times, as an example of the default *kass’aq* communication style.

Humor sometimes helped to bridge intercultural differences with respect to asking questions. To make space for open discussion in one didactic-heavy meeting, the researchers invited community partners to interrupt whenever they had a question, or the researchers used an unfamiliar term or acronym. This quickly became something of a game, with CPG members shouting “Stop!” and waving their arms or making other comical gestures to get the researchers’ attention. The next day C1 teased,

I think G4’s nickname is “Stop!” (*laughter*) [But] I really like the fact that, you know, you felt that you had that agency to [say], “Stop and let’s talk about this thing.” And I really appreciate that, and I really appreciate the invitation. ‘Cause like that by itself shows that, yeah, you know, we could talk about these things and, if we don’t know, then we could ask.

In addition to building rapport within the group, inviting community members to take the floor to question or correct the investigators served several other important functions in terms of disrupting the typical power dynamic. It enacted the researchers' respect for the CPG and Ciuliat; gave substance to the researchers' expressed intentions to communicate clearly and to promote both comprehension and participation; and made the researchers directly accountable, in the moment, to the Yup'ik partners.

Community partners viewed this as a good practice, and different from what they had experienced in other meetings convened and managed by outsiders, including researchers and various government agency staff. Later in the meeting, G6, a CPG member, commented, "I liked the process [yesterday, when] R2 wanted us to [say] 'Stop' if we have any questions. At other meetings [hosted by outsiders] that I've attended, they state if you have a question, wait until it's [over], but by that time, you know, I tend to forget the question I needed to ask." Similar enactments of community agency and investigator accountability have become an ongoing feature of our conversations.

Discourse Markers

The most common Yup'ik discourse marker in these discussions was *i-ii*, "yes." It was often said in a hushed voice while another was speaking, as an American English speaker might use "mmm," or other vocalizations to indicate active listening, agreement, or support. Another was *tua-i*. At the end of a talk turn, this word indicates that the speaker has finished speaking. It can also be used as a question – either *tua-i* spoken with a rising tone, or in the form *tua-i-qa* (*qa* functions as a question mark) – to ask whether another speaker is done talking. (If the answer is yes, the speaker responds with a confirmatory *tua-i*.) It has been explained to me as meaning "that is all," or "it is enough." It may be the case that Yup'ik partners made more

frequent use of this term in our mixed-company meetings than amongst themselves, with the goal of reducing confusion resulting from the different pause durations in kass'aq vs. Yup'ik talk described above.

Written Materials

Another feature of negotiating cultural differences was to reduce the investigators' reliance on written materials. Written communication, including email, is the default mode within much of the academy, especially for projects like this one, that involve people in different locations and time zones. The Yup'ik people, by contrast, have nurtured an oral culture over many generations.^{79,87,118,148} The CPG and Ciuliat have repeatedly emphasized their preference for videos, visual aids, and hands-on learning tools.⁸⁰ There are a range of factors that could play into this preference: reading English (especially for Elders) requires greater effort; conceptual differences between English and Yup'ik, coupled with the lack of specialized scientific terminology in Yup'ik; and the historical fact that unintelligible English "papers" have been an instrument of great harm to Alaska Native and other Indigenous peoples.

For kass'aq people – and even more so for academics – authority is invested in written documents that have been produced by experts and vetted by their peers. The legitimacy of claims is bolstered by citing such publications. The CPG and Ciuliat are aware of this norm. For example, G6 said:

I think for . . . some Elders back home, [when researchers have come] studying, and [Elders] try to convey their knowledge, where in the past, you know, because it wasn't in writing, [researchers] dismissed that, because it's their norm that everything has to be recorded. But a lot of that has been passed on through generations. When scientists publish their findings, the Elders would say, "We already knew that." (*quiet laughs from group*) It's just validating what the traditional knowledge has shown.

At the end of an involved discussion about Yup'ik concepts of how things are passed down in families, G6 laughingly said that the investigators should write down what the CPG had said. Then, he teased, it would be(come) true knowledge.

Visual Materials

Visual representations of information emerged as an effective and more participatory way of communicating complex ideas within the partnership. In a small-group discussion, G1, who had been very quiet in prior meetings, stood up and used the flipchart to draw a diagram representing how things could be passed down. Her drawing became a reference point for the rest of the meeting, as partners stood up and pointed to parts of the diagram to clarify what they were referring to, to situate questions, or to add missing elements. Several other participants, including both Yup'ik speakers and investigators, thanked G1 for this contribution, noting how useful it had been to have the drawings to refer to later in the meeting. In subsequent meetings, participants often referred to these diagrams, and both Yup'ik and kass'aq partners went to the flipchart or white board to illustrate their thoughts for group discussion.

Another instance in which drawing played an important role was in Meeting 6, in which the group was revisiting the community focus group results and discussing the reframing of community dissemination as a two-way dialogue rather than the usual model, which is a one-way broadcast. One of the investigators had drawn the broadcast model on the white board, depicting the researcher as a stick figure with a megaphone directed out toward the community. As the group talked about the ways in which this model was unsatisfying, R6 went to the white board and added an ear horn to the researcher figure: now the researcher was listening to the community, not only talking at them. This was a fruitful and enjoyable discussion, in which the

community participants played an active role in developing a conceptual model that was later published.⁸⁰

Communication Tips for Kass'aq Researchers

Building on observations from the early days of the partnership and a meeting with outside consultants, R9 and C1 developed a written set of communication tips for kass'aq researchers working in the Y-K Delta (Box 1). They presented these recommendations to the group for review in December 2011, and the CPG and Ciuliat endorsed the content. Some participants said that they appreciated the university partners' explicitly attending to intercultural communication. Several CPG members suggested that this information should be shared with healthcare providers who are new to the region.

Box 1. Communication Tips for Kass'aq Researchers

Yup'ik vs. English	<ul style="list-style-type: none">• Most Yup'ik people speak English.• English is a second language for many Yup'ik people. Some Elders communicate only in Yup'ik.• Relatively few Yup'ik people read and write Yup'ik, which has existed in written form for less than 50 years.• Slow down. The usual pace of kass'aq speech may feel rushed or even aggressive to Yup'ik listeners.• Choose words with care. In Yup'ik culture, words are powerful and can do good or cause harm.
Communication and Learning	<ul style="list-style-type: none">• Yup'ik learning is experiential: children learn by observing and pitching in.• Yup'ik people may prefer verbal communication, storytelling, visual aids, and hands-on exercises over written materials.• 1:1 terms in Yup'ik do not exist for some scientific concepts, but this does not mean the concepts themselves are unfamiliar.• Recognize that stories can be the answer to a question, even if the connection is not immediately obvious to you.• Eliciting culturally relevant stories, metaphors, analogies, etc. can facilitate deep conceptual discussions that enhance understanding for community members and researchers alike.• The group should consider together how much specialized knowledge is necessary for the task at hand (e.g., to offer feedback about genetic research with Yup'ik people, community members need not understand the science the way an academic does).

Building Good Relations

- Some in the community distrust research and researchers based on prior negative experiences with researchers and government agencies, not limited to health research.
- Sharing stories, and respectful listening and learning on the part of researchers, builds trust.
- Effective communication in community-university research partnerships requires attending to the informational, cultural, and relational aspects of communication.
- Listening respectfully and paying attention – not fidgeting, attending to laptops or phones, etc. – is vital, including when community members are speaking Yup’ik.
- Elders are highly respected and should be treated with deference.
- Allow silence, and do not assume that it signifies a lack of understanding or interest.
- Do not talk down to people.
- Don’t be afraid to say “I don’t know.”

Specific Recommendations

- Ask one question at a time. Allow time for Yup’ik partners to consider their answers.
- Consider indirect phrasing for questions (e.g., “I wonder why”).
- Be aware that raised eyebrows indicate an affirmative response.
- Leave time for silence.

Speaking of Change

The technical terminology used among researchers is often unfamiliar to nonacademic audiences – even those who are fluent English speakers with secondary-school science education. In addition, a direct 1:1 equivalent between English and Yup’ik terms is often lacking. For example, although Yup’ik partners have a deeply nuanced understanding of heritability and kinship,¹¹⁸ there is no Yup’ik equivalent for the word “genetics.” To illustrate the kinds of challenges that can arise, this section presents a detailed example of how the partners identified and resolved a communication misfire around the term “genetic change.”

“Genetic Change”

The term “genetic change” is commonly used by genetics researchers, but its exact meaning is context dependent. Hereditary changes, also known as germline mutations, are present in the parent’s egg or sperm cells and thus can be passed from parent to child; such changes are present in virtually every cell in the body. Non-hereditary (somatic) changes occur

in only certain body cells during a person's lifetime and are not handed down to offspring. For example, prolonged exposure to cigarette smoke can cause certain mutations in lung cells, and some of these changes can lead to lung cancer. The use of the term "genetic change" for both germline and somatic mutations is in line with the plain-English understanding of the word "change," i.e., to make something different from some prior state.

Genetics researchers also use the term "genetic change" in another sense, seemingly without recognizing the confusion this can create. In addition to the usage described above, researchers sometimes use "genetic change" to describe differences between two genomes, in which one genome is designated by the research community as the "reference genome." The reference genome is a database that compiles the latest data about human genetics. Constantly updated by investigators around the world, it is intended to serve as a standardized, normative genome – a dictionary of sorts – for use in genetic research. In this usage, a "genetic change" refers to an observed difference in a given genome, in comparison with the most common DNA nucleotide sequence, i.e., the reference genome.

The relationship between genetics and interindividual differences in medication response was central to our research and thus a necessary topic of conversation in our meetings. We were studying the causes of differences in medication response observed between Yup'ik people and the general population for three drugs: warfarin, tacrolimus, and tamoxifen.¹⁴⁹⁻¹⁵² One goal of the study was to determine whether the idiosyncratic response of Yup'ik people to these medications resulted from genetic differences ("genetic changes" in the reference genome sense), dietary habits, physical activity, or some combination of these.^v

In the first meeting of the partnership, R2 introduced the purpose of the pharmacogenetic study: "Yup'ik [people] have one genetic change that's very rare in white populations One

of the aims of our study is to sequence the DNA for those specific genes known to break down that medicine and see whether the genetic changes are the same or not, for all three [medications under study].” Four years later, the researchers recognized that the misnomer “genetic change” was causing confusion. The key exchange, which involves three researchers (R9, R2, and R8), two Ciuliat members (C3 and C4), and one CPG member (G4), is displayed in Box 2. Earlier in the meeting, G4 had inquired several times what caused the “genetic change” and when the “change” occurred.

Box 2. Unpacking “Genetic Change”

R9, staff (f):	I’m wondering if part of the communication challenge here is the word <i>change</i> implies it was one way and now it’s a different way.
C3, Ciuliat (f):	Oh, maybe that might be.
C4, Ciuliat (f):	Exactly.
R9, staff (f):	And so it’s not that it’s a change in <i>me</i> – that it used to be like this [<i>gestures with left hand</i>] in me and then something happened, and now it’s some different way [<i>gestures with right hand</i>]. That’s not what it means.
R2, senior faculty (m):	It’s a difference.
R9, staff (f):	It’s a difference. So it’s not like saying, “It was like this, and then something happened, and then it changed.” It’s like saying, “You can have vanilla, or chocolate, or strawberry ice cream. Those are the three kinds there are. Different people have different flavors.” I think maybe the word <i>change</i>
R2, senior faculty (m):	Yeah, it’s a good point.
R9, staff (f):	is part of what is confusing. The way that genetics talks about this, because they’re – when geneticists talks about a change, what they mean is we have this reference standard, which is what most people have. And when they say <i>change</i> , they mean, “something different from what most people have.” But in regular English, that’s not what a change is. You know, if everybody else has vanilla and you have strawberry, you wouldn’t call that a <i>change</i> , in regular English. So, I wonder if that’s part of what’s hard to understand about the way we’ve been talking about this.
C3, Ciuliat (f):	That might be it.
R8, senior faculty (m):	But it’s fundamentally the same [thing]. You wouldn’t say someone who has curly hair versus straight hair has been changed. It’s just, it’s different.
C3, Ciuliat (f):	Yeah, that might be it. But it’s also hard to, you know, it’s hard to [<i>pause</i>]

G4, CPG (f):	Explain.
C3, Ciuliat (f):	<i>[in Yup'ik, translating for Elder]</i> We are using the word <i>change</i> .
R9, staff (f):	And I think that's part of, you know, "What happened to make that occur?" I mean, G4's question, "When did that happen?"
R8, senior faculty (m):	Is because of that.
R9, staff (f):	is because the word <i>change</i> implies, it was this way and now it's that way.
C3, Ciuliat (f):	Exactly, yup. That's what I was
R2, senior faculty (m):	<i>[to R9]</i> You're a good listener.

The exchange begins with a staff researcher (R9) drawing attention to the misfire and highlighting the term “change.” Two Ciuliat members, C3 and C4, immediately express support for the interruption and implicitly agree that there is a misunderstanding. R9 asks the group – not calling out the researchers directly – to consider whether the confusion might be caused by the word “change.” This shifts the locus of the problem from G4, and the community partners more generally, to the investigators.

Rather than asking G4 what she means, R9 asks the clarifying question on her own behalf. Her language (“I’m wondering if . . .”) reflects Yup’ik communication conventions (Box 1), in which direct questions – especially from a lower-status person to a more senior individual or an Elder – may be regarded as inappropriate.¹⁰³ This strategy not only avoids putting G4 (Yup’ik, female) on the spot with the senior (white, male) researchers, but it also spares G4 having to say something that could be perceived as critical, which would be counter to Yup’ik cultural norms of cooperation and avoiding conflict.^{6,87,148,153,154} Opening this apparent misunderstanding to group discussion and collaborative problem-solving also aligns with traditional Yup’ik ways of teaching and learning.¹⁵⁴

R2 acknowledges the distinction R9 proposes – between a change and a difference –

immediately, commenting, “[what we mean] is a difference.” The cooperative nature of the interaction continues to develop, with another senior faculty member (R8, white, male) endorsing R9’s observation. He mentions curly vs. straight hair as another example and rearticulates the point that a difference in a particular genetically defined characteristic is not necessarily a “change” in the usual sense of that word. R9 then refers to G4’s earlier questions about when and how the “genetic change” occurred, again obliquely pointing out that these questions arose from a lack of clarity in the researchers’ communication. This interpretation is endorsed by C3.

The excerpt closes with R2 acknowledging R9’s intervention as worthwhile and underscoring for the whole group the value of careful listening (“You’re a good listener”). In subsequent meetings, the group agreed to abide by the plain-English meanings of the words “difference” and “change,” using the term “genetic difference” to refer to differences from the reference genome and reserving “genetic change” to refer to acquired mutations. On the occasions when a researcher may have misused the term “change,” others – including researchers, Ciuliat, and CPG members – quickly queried or corrected the usage.

It is important to recognize that researchers enter a world where prior understandings and traditional knowledge are always already in play. Rather than assume community partners’ ignorance of scientifically involved topics, or that the lack of 1:1 equivalents for scientific terms means the concepts do not exist, researchers should seek to connect with and build on community partners’ existing funds of knowledge.¹⁵⁵⁻¹⁵⁷ For example, CPG members cited numerous examples that demonstrated a sophisticated understanding of genetic heritability – including the complex Yup’ik kinship system and traditional knowledge about sled dog breeding

– that served to scaffold their comprehension of scientific concepts in the absence of terminological equivalents in Yup’ik.

Changes in Yup’ik Lifeways

“Change” – in its common usage – was a constant theme for Yup’ik partners throughout the partnership, as they questioned how recent alterations in Yup’ik people’s material circumstances have affected their health and wellbeing. One way for outside researchers to more accurately perceive community perspectives is to learn about the political history of the community and sensitize themselves to ways in which that history shapes current realities.^{36,158} In this partnership, for example, it is important for *kass’aq* researchers to know that in 1971, the Alaska Native Claims Settlement Act extinguished Alaska Native (AN) land claims and established a number of private, for-profit AN regional corporations and village corporations. This, in combination with the start of oil mining in Prudhoe Bay in the late 1960s, entailed a rapid transition from lifeways centered around seasonal subsistence rounds to a wage-based economy.^{76,77} To understand how deeply governmental and corporate interests have affected Yup’ik life, it is important that researchers both “do their homework” – availing themselves of available learning resources, such as those developed by the Alaska Federation of Natives¹⁵⁹ – as well as invite stories and perspective-sharing from their community partners.

CPG members have repeatedly stated that Yup’ik people today experience many health problems that did not affect their ancestors. The CPG and other Yup’ik people looked to the investigators to help them understand “what changed” – for example, could new diseases be caused by pollution or climate change, or by the shift from subsistence foods such as seal meat and tundra greens to store-bought foods?¹⁶⁰⁻¹⁶² G9 commented, for instance:

[[Back then way before you were born, at the time I was young, *kass’aq* things were scarce. Also, there would be a lot of old men and old women. Some of the

old men would use two canes to help them walk, and staying standing wasn't easy for them. And there were a lot of old women. I'm thinking maybe, at that time, when their food was all Native food with no additives, is the reason why they lived that long. And now that the food is mixed with other kinds of food that our ancestors did not eat, the old men and old women have become scarce, not like they used to have back then. So, I was thinking, maybe because of that they used to live for a long time.]]

As colonization and economic “development” have forced changes in Yup'ik lifeways (such as the abolition of communal housing and the introduction of commercial fishing) and new technologies have been adopted (e.g., snowmobiles replacing dog teams, metal jon boats replacing skin *qayak*), certain specialized knowledge, skills, social roles, and group activities have passed out of daily life.^{76,77} As G2 stated,

[[O]ur descendants are becoming educated [in the kass'aq way] and their way of life is becoming different. Our ancestors lived the subsistence way of life, trying to put food on the table from the wilderness, and now our way of life has changed to]] cash economy. [[Also the role of the people is]] shifting. When they lived a subsistence way of life and because the husbands brought the food in, they respected the men. Now the way of life has changed to [[a cash economy, some men don't have anything to do while his wife is working. She now is like the bread earner But nowadays there is nothing you can do because people have electricity bills and fuel bills to keep their stove going. Even though they may not approve we, being]] parents with responsibilities [[have no choice because it's]] shifting [[to that way of life. Even though they don't approve, our descendants have to go that way.]]

These and other changes have also reduced traditional opportunities for intergenerational learning (e.g., hearing Elders' stories while taking care of the dogs). CPG members have also drawn a connection between these shifts and increasing rates of alienation and associated behavioral health challenges among Yup'ik youth. Investigator awareness of and sensitivity to these experiences and lived realities improves their ability to hear messages that may not be stated explicitly by community partners.

CONCLUSIONS

This paper outlines lessons learned about communicating complex scientific concepts across multiple axes of difference. Communicative competence is a developmental process that happens over time and is a joint production of community and university partners. Dynamics of power, openness, and self-awareness shape the form and content of the communication practices and conventions established within individual research partnerships. To illustrate how communication may develop in community-university collaborations, this report offers concrete examples of cooperative problem-solving as they occurred in the moment.

There is a common assumption that there are two primary barriers to communication in community-university research partnerships: linguistic and cultural differences among partners, and a lack of formal scientific training on the part of community partners. Effective communication in community-university research partnerships requires attending to the informational, cultural, and relational aspects simultaneously. Our experience suggests that joint competence in the cultural and relational dimensions of communication are prerequisites for effective communication regarding unfamiliar and potentially sensitive topics.

Additionally, as highlighted by the communication misfire around the term “genetic change,” a lack of precision and consistency in researchers’ language use can also be a barrier to effective communication. This may be especially salient in oral cultures in which words are regarded as having power and speech is to be undertaken with great care and forethought. Researchers may lack awareness of their own linguistic imprecision and inconsistency, and thus fail to recognize the confusion they can generate. Similar exchanges to those described here have occurred regarding (for example) the terms “diet” (what people eat vs. a weight-loss program), “protein” (dietary protein such as seal, fish, or store-bought meat vs. biochemicals in the human

body), and “medicine” (medications vs. the practice of medicine). The researchers also learned another lesson from this interaction: when a Yup’ik Elder repeats something, it may be because we have not yet understood it properly.

Effective communication is essential to building the content-specific understanding and interpersonal relationships on which successful CEnR depends. It is also critical to the consent process, as a lack of clarity in describing study goals prevents community leaders and individuals from making fully informed decisions about research participation. Fostering a culture of openness, curiosity, and cultural and intellectual humility is essential. It supports researchers’ critical self-reflection, enabling them to recognize when something is not working well and motivating them to identify what they could do differently. Such a culture makes room for group reflection and sharing of lived experience, stories, and traditional knowledge by community partners. It also provides a sense of psychological and social safety, empowering partners with less positional power to speak up when a misfire occurs.

Broadening the scope of researcher reflexivity to include reflections on the field, its onto-epistemic commitments (the underlying, taken-for-granted assumptions about the nature of reality and knowledge), and the affordances and foreclosures embedded in its institutional structures is also important. Attending explicitly to the assumptions built into scientific jargon and institutional structures offers researchers an important opportunity for critical reflection. For example, the reference genome tends, quite literally, to reify the white norm. Experts estimate that 80–96% of genetic research participants worldwide are of European descent, despite efforts by NIH and other funding agencies to increase diversity.¹⁶³⁻¹⁶⁷

More generally, dominant science often unreflexively assumes a white norm and construes generalizability, parsimony, and objectivity as essential to scholarly rigor.^{168,169} Michif

scholar Max Liboiron describes the drive to universalism and generalizability that pervades mainstream science as “an aggressive form of European self-portraiture, the understanding that things everywhere are the same with a few variations.”¹⁷⁰ In the Yup’ik worldview, by contrast, everything is connected, imbalance in any one domain has effects in others, and multiple worldviews may coexist.^{36,37} This view, which is commonly held across Indigenous knowledge systems, is being borne out by many disparate areas of scientific inquiry, including epigenetics (e.g., how pollution exposure affects gene expression¹²⁰), forest ecology (e.g., how trees communicate with each other¹²¹), and marine biology (e.g., how feeding interactions among sea otters, kelp forests, and sea urchins are interrelated¹²²).

Process recommendations include inviting questions, monitoring for points of confusion, managing the conversational floor in a way that ensures that all who wish to speak can do so, and learning about partners’ cultural communication norms. In this partnership, open discussion about cultural differences in communication norms improved communication practice. Importantly, the investigators’ openness about their own learning and occasional discomfort in adapting to Yup’ik communication conventions – exemplified by R2’s comments about silence – also supported the development of trusting relationships.

Structural recommendations include creating a cadre of bicultural liaisons, providing simultaneous interpretation, and being flexible about meeting agendas. In addition to employing bicultural liaisons, research teams should include at least academician with expertise in communication, group facilitation, and/or ethnographic observation who can aid in identifying and addressing inevitable communication misfires. All investigators should be made aware of the importance of effective communication and introduced to basic local communication norms. Both trust and communicative competence develop over time, through the growth of

interpersonal relationships, shared goals, and cooperative problem-solving. Funders who wish to support high-quality CEnR should therefore ensure that project budgets and timelines provide for these activities, which are essential to the success and ethical conduct of such work. Researchers can advocate for these changes through peer review of grant applications and publications, as well as by applying pressure within their institutions. Decisions about how the work is to be carried out and how to ensure that resources are fairly allocated between the academy and the community, such as those concerning project budgets, hiring, and timelines, should be negotiated with community partners.

**Learning Together about Genetics:
Insights from a Community-University Partnership**

INTRODUCTION

One of the core principles of community-engaged research (CEnR) methodologies is that both community members and academic researchers have valuable knowledge and expertise that can play a role in advancing human health.^{57,58} The moral warrant underlying CEnR is grounded in respect and reciprocity, recognizing that communities ought to be more than mere “subjects” in health research. Rather, they are, and should be treated as, agentic entities with a right to determine what research may be done in their communities, by whom, and in what ways. CEnR methodologies thus share the starting commitment that research should no longer be done “on” or “in” communities but rather “with” them, and that power and resources must be shared equitably between communities and outside researchers. These are important and necessary changes in the work of transforming health research and developing equitable collaborations, but two important issues require further examination: onto-epistemic incommensurability and community engagement in basic research.

Onto-Epistemic Incommensurability

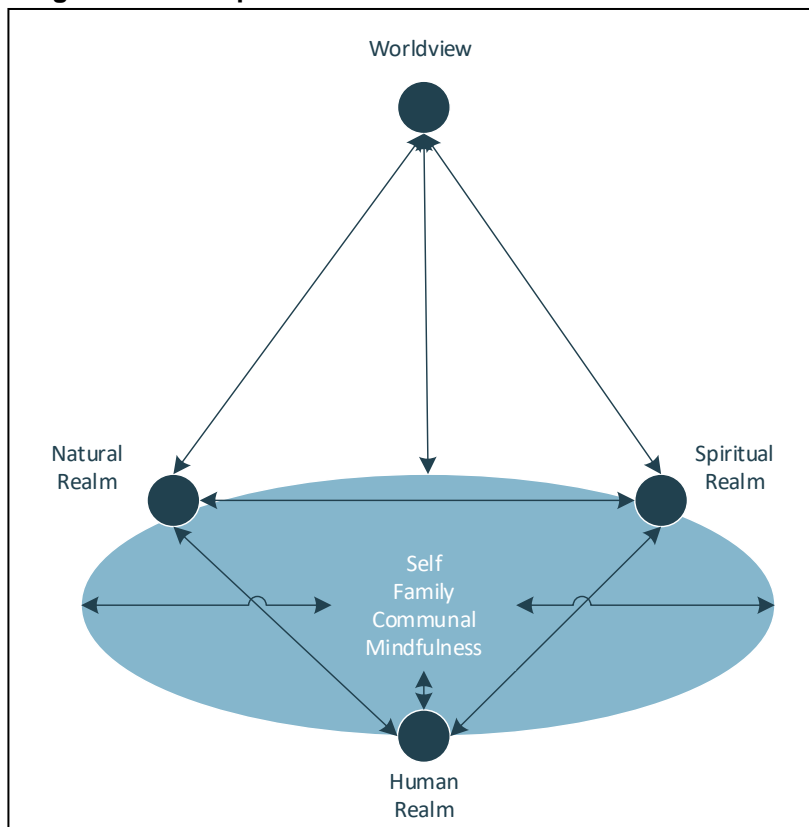
Onto-epistemic incommensurability is the idea that certain ontological (understandings about the world and reality) and epistemic (understandings about knowledge) positions are fundamentally incompatible: they cannot be judged by the same set of standards. In many Indigenous knowledge systems (IKS), for example, knowledge can come from many places, whereas dominant western knowledge systems typically consider reason as the sole source of reliable knowledge.

Different cultures hold different beliefs and understandings about the world, about the nature of knowledge, and about how humans are related to – and should relate with – the natural and spiritual realms. Working across onto-epistemic differences is a challenge in health research, as in other areas of intercultural collaboration.^{77,103,146,171} A detailed comparison of western-scientific onto-epistemology with the Yup'ik worldview is beyond the scope of this dissertation. In broad strokes, however, the dominant western worldview typically privileges rationality and views non-human creatures and non-sentient entities as resources, available for human use.

In the Yup'ik worldview, the universe is understood to be sentient, interdependent, and moral.^{78,87,172} Kawagley depicts the Yup'ik worldview using the metaphor of a tetrahedral structure (Figure 1).⁸⁷ The tripod is the shape of the wooden racks that Yup'ik people use to dry and preserve fish in the summer. When the components are properly aligned, it is a very strong, stable structure. The large

ellipse in the diagram represents the universe and the circle of life. The double-headed arrows show the two-way flow of communication from realm to realm, and the way in which they interact with each other and work together to support a unified worldview. Rituals, ceremonies, and the intercession of the shaman

Figure 1. The Yup'ik Worldview



(*angalkuq*) were ways of giving thanks and maintaining (or restoring) balance.^{42,87} Most Yup'ik people identify as Russian Orthodox, Moravian, or Roman Catholic, but religion has largely been accommodated to Yup'ik spiritual beliefs rather than the other way around, despite the sometimes violent suppression of traditional dances, mask-making, and other Yup'ik spiritual practices.^{6,42,118}

In Yup'ik onto-epistemology, human beings are neither superior to nor separate from the natural world. Kawagley explains that the creation story of Raven bringing the world into being has important implications for how Yup'ik people think of their place in the universe: "Some say that the creative force took the form of the Raven to make the world so that the Yupiaq [Yup'ik people] will never think that they are above the creatures of the earth. How can they be when their creator is a creature of earth?"⁸⁷ As in some other Indigenous traditions, the Yup'ik Raven is a trickster and, sometimes, a bumbler: if the creator can make mistakes, humans too are fallible and should behave with humility.¹⁷³

It is often argued that synthesizing IKS and dominant-scientific methodologies will result in more ethical research practices, better science, and more useful applications of research results ultimately delivering tangible benefit to participating communities. A drawback of this framing, however, is that in practice, such synthesis often amounts to co-optation of IKS, assimilating ancestral knowledge (and in some cases, human, plant, and animal genetic information) into the western model without fully understanding or acknowledging its origins.^{52,174,175}

Worse, such assimilation denatures IKS, omitting or downplaying essential onto-epistemic features such as connection to the land and responsibilities to more-than-human relatives.^{6,87,88,176} This is a form of epistemic injustice, i.e., the prerogative of dominant western-scientific institutions and practitioners to privilege their knowledge systems over others deemed

inferior, incomplete, or uncertain.^{177,178} The history of Indigenous peoples in the United States (and beyond) is rife with both physical and epistemic violence, including massacres, various forms of abuse, the banning of ceremonial practices, prohibition of Indigenous languages, the forcible removal of children from their families, and other government actions designed to eradicate entire peoples together with their knowledge and culture.^{139,179-181}

An alternative approach to epistemic assimilation is Two-Eyed Seeing (*Etuaptmumk* in Mi'kmaw), a framework promulgated by Mi'kmaw Elder Dr. Albert Marshall and (according to him) based on the wisdom of prior generations.¹⁸²⁻¹⁸⁵ In Two-Eyed Seeing, researchers learn “to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of mainstream knowledges and ways of knowing . . . and [learn] and to use both these eyes together, for the benefit of all.”¹⁸⁶ Indigenous knowledge is thus not “integrated” or “incorporated” into mainstream western science, but rather maintains its own integrity and value alongside dominant-scientific knowledge.¹⁷⁵ Researchers can call upon the different strengths and tools of each approach, as the situation requires. An underexplored question is what capacities and dispositions outside researchers must develop to employ the Two-Eyed Seeing approach in practice, as well as what structural and operational supports are needed within collaborations and in the broader institutional (university, funder) landscape.

Another Indigenous model of research collaboration is based on the Two Row Wampum-Covenant Chain treaty between the Iroquoian (Hodinohso:ni) Confederacy and Dutch merchants in the 1600s, in which the rows represented the canoe, the Dutch ship, and the river between, with both parties retaining their respective values, rules, and customs. It proposes five principles to guide equitable research collaborations: (1) research relationships are dialogical – there is an ongoing back-and-forth between groups, and differences are recognized and respected; (2) the

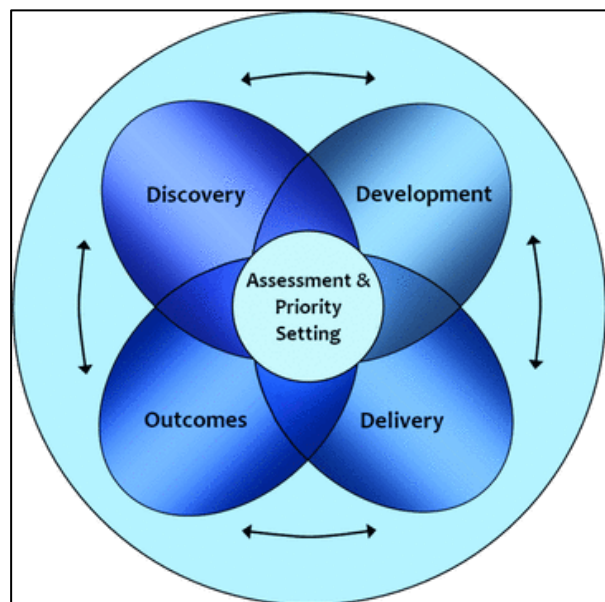
importance of place-conscious ceremony – partners must be ready and willing to suspend their usual operating assumptions, and ceremony can create that break from business as usual; (3) equity within distinctiveness – differences do not imply that one group is superior and the other inferior; (4) internal pluralism and diversity – neither group is homogenous; and (5) sharing knowledge, not owning it – understanding that knowledge is not created or owned by humans, it cannot be the exclusive property of anyone.¹⁸⁷

Community Engagement in Basic Research

Another principle common to CeNR models – again, grounded in recognition of community agency – is that research should be driven by community priorities rather than researchers’ or funders’ externally imposed ideas about what is important. In many cases, this is a relatively straightforward matter. A community that seems to be experiencing increasing rates of a particular health problem may value research aimed at understanding what is happening and why, for instance; or a community that has identified the cause of a problem may seek to develop and test a targeted intervention.

Not all biomedical research is so directly connected with health outcomes, however. For example, studies aimed at understanding the mechanisms of disease or identifying potential drug targets for therapeutic development are an important part of the translational cycle (labeled “discovery” research in Figure 2).¹⁸⁸ Such studies are often the first step in a process that (ideally) leads to the

Figure 2. Translational Cycle of Research



development of health applications and interventions (“development”), which can then be tested (“delivery”) and evaluated (“outcomes”), leading to new research questions and beginning the cycle anew. Yet it is difficult to imagine a community approaching a university-based investigator with a request for basic science research. This leads to several questions, beginning with whether CEnR is possible in basic biomedical science research. If so, what might it look like?

This paper explores co-learning in a longstanding research partnership between Yup’ik community members and university-based researchers in southwest Alaska. The partnership began in 2009 and continues as of this writing. It has supported numerous studies covering a wide range of topics, including pharmacogenetics, Yup’ik conceptions of wellness, and obesity. A central goal of the partnership during 2010 – 2016, the period covered in this analysis, was to determine what Yup’ik study participants and community members would like to know about genetic research progress and results, and in what way(s) that information should be provided.

METHODS

Setting

The partnership was established in 2009 by the Center for Alaska Native Health Research (CANHR) at the University of Alaska Fairbanks; the Yukon-Kuskokwim Health Corporation (YKHC), the Tribal health authority serving Alaska Native people in the Yukon-Kuskokwim region; and Yup’ik research participants and community members.^{13,71,74} Investigators from two other sites, the University of Washington (UW) and the Group Health Research Institute (GHRI), joined in 2010. This collaboration was founded around two main research projects (see Acknowledgments for specific funding information): a bioethics study aimed at determining how best to operationalize the ethical obligation to share research findings with participants and

communities and a pharmacogenetics study examining the contributions of diet, genetics, and physical activity to interindividual drug response.

Participants and Recruitment

The partnership consists of the Community Planning Group (CPG), 10 Yup'ik community members who had participated in prior CANHR studies; the Ciuliat (literally, ancestors, used here in the sense of facilitators), a group of five Yup'ik bicultural liaisons; and an interdisciplinary team of nine non-Yup'ik researchers from CANHR, UW, and GHRI. Selected participant characteristics are shown in Table 1. CANHR investigators invited Yup'ik individuals with whom they had previously worked to join the CPG and Ciuliat. Travel expenses and meals are paid for by grant funds, and CANHR and Ciuliat members received honoraria for their participation in meetings as well as additional tasks they undertook (e.g., participating in the analysis of focus group data).⁷⁴

The primary studies that funded this work were approved by the YKHC Human Studies Committee (HSC), the University of Alaska Fairbanks Institutional Review Board (IRB), and the Group Health Research Institute IRB. As required by the YKHC HSC, all partners, including the investigators, provided written informed consent as co-researchers. The present analysis was approved by the YKHC HSC and the University of Washington IRB.

Data Collection

Between 2010 – 2016, partners met as needed and feasible in Mamterilleq (Bethel), the regional hub serving outlying villages in the Y-K Delta (Table 2). Meetings generally lasted for 1.5 – 3 days, with time for overnight reflection, visiting with family, and sharing meals. As a guide for discussion, study staff developed and shared a written agenda prior to and at the start of

each meeting, with the explicit understanding that the agenda was open to change depending on how the discussion unfolded.

All Yup'ik participants were fluent in Yup'ik, and all spoke English. Ciuliat member C5 provided simultaneous interpretation as needed, with occasional assistance from other Yup'ik speakers. Meetings were audio recorded and transcribed by C5, who also provided written Yup'ik to English translation. Some of the researchers took contemporaneous notes at some meetings; where available and relevant, these were included in this analysis, as were agendas and other meeting materials. Prior to analysis, I proofread, deidentified, and standardized the format of all transcripts.

Data Analysis

I uploaded the reacted transcripts into ATLAS.ti (Windows v.8.4.26) and performed a descriptive thematic analysis,^{114,189} beginning with several close readings of the full dataset to gain a sense of the corpus. As I read, I drafted detailed notes about the content of each meeting. Through this exercise I identified Meeting 3, held in December 2011, as the critical target for detailed analysis. This was one of the longer meetings (3 days) and featured in-depth discussion of Yup'ik terms and a review of community focus group results. Although it did not have the highest number of attendees (12 of 24 possible), this meeting featured more participation from the CPG than in prior meetings, perhaps because of the small-group discussions, the presence of only two Ciuliat members, and/or the fact that Yup'ik partners slightly outnumbered researchers.

I then developed and applied set of codes (Table 3), revising the codebook as needed and recoding where necessary. When coding was complete, I ran a set of queries in ATLAS.ti to produce summary reports of each code, from which I identified the higher-level themes reported here.¹⁹⁰ I then returned to my summary notes to identify any additional transcripts to revisit in

relation to the identified themes. I reread the relevant sections of text and incorporated any additional supporting evidence from those meetings to the thematic results reported in the next section.

RESULTS

In what follows, text presented within quotation marks or block-indented represents participants' verbatim comments. Terms in general use within the partnership appear in quotation marks but are neither dated nor attributed to individual speakers, because I cannot positively identify their first use (i.e., some terms may have been introduced in conversations that are not part of the dataset). Comments that were uttered in

Table 3. Coding Scheme for Thematic / Discourse Analysis

Code	Definition
Comprehension check	Comments about whether something is or is not understood, including clarifying questions
Critical historicity	Stories and other comments about the sociopolitical history of Yup'ik people, other Indigenous peoples
Expertise	Claims to expertise and recognition of others' expertise
Hypotheses	Possible research questions, including but not limited to study topic
Language & terminology	Comments about language and terminology – refers to scientific terms as well as Yup'ik
Partnership assessment	Comments about the progress or status of the partnership in relational terms, productivity, etc.
Partnership goals	Comments about the purpose of the partnership, near- and long-term goals
Passed down	How things (traits, behaviors, disease, etc.) are handed down from generation to generation
R – didactic	Researcher teaching talk
R – onto-epistemology	Researcher comments regarding commitments/beliefs re the world and knowledge
Research	Perceptions, beliefs, experiences regarding research (not limited to health)
Risk & uncertainty	Comments about risk, uncertainty
Self-assessment	Evaluative comments about the speaker's own learning, role, feelings, etc.
Spiritual	References to spiritual / religious beliefs and practices
Stories	Stories themselves (traditional, historical) as well as talk about stories as a category
Y – didactic	Yup'ik teaching talk
Y – onto-epistemology	Yup'ik comments regarding commitments/beliefs re the world and knowledge

Yup'ik are displayed between [[double brackets]]. Individual Yup'ik words used in English

sentences are *italicized*. To preserve partners' privacy, individual speakers are identified by an alphanumeric code, where G = Community Planning Group, C = Ciuliat, and R = researcher.

Building a Foundation

To provide a common reference point regarding genetic research, all partners attended a well-established two-day workshop, Genetic Education for Native Americans (the GENA Workshop),¹⁹¹ early in the collaboration. The workshop combined didactic presentations and hands-on learning activities. More than 10 years following the workshop, our conversations still refer back to some of those activities (e.g., building a model organism using marshmallows, gumdrops, pipe cleaners, and toothpicks as a way of learning about genetics)¹⁹² and metaphors (e.g., comparing the arrangement of base pairs in DNA to slices of whole wheat, white, and rye bread).

Conceptualizing Research and Learning

Researchers' framing of research was sometimes inconsistent – including, at times, by the same speaker in the same meeting. Early in the partnership, researchers offered explanations of the process of health research, as in this example: “Sometimes the way research works . . . when you ask a question you don't have a direct answer right away. You just get another clue that you can lead, may lead to something else down the road that may be, you know, very helpful.” (R7, Meeting 1). In these didactic instances, research was presented as a specialized, expert-driven process that follows the scientific method, happens mainly at universities, requires ethical review from universities and Tribal entities, and is funded by NIH. This expert-centered view also emerged in discussions about such topics as grant-writing, research funding, human subjects review, and scientific dissemination.

In other instances, researchers asserted that Yup'ik people conduct research as part of their daily lives and have done so since time immemorial. For example, in Meeting 3, R4 said, “[T]he thing is, everyone does research in communities. You do your own research. It’s just not biomedical research, or maybe, or labeled a certain way, but Elders know. They know the best way to do things, because people have done it different ways, and they know which one works the best, and in which circumstances.”

Although Yup'ik partners seldom spoke of research per se as a traditional Yup'ik activity, they often shared their views about learning, teaching, and knowledge. Practical wisdom – how to do things and developing skill through practice and self-reflection, rather than developing knowledge for its own sake – was emphasized, as was the view of learning as a journey. This quotation from G9 at Meeting 1 demonstrates both points:

As you go along, you will find [learning] easier and easier. Like a screwdriver unscrewing a screw a little bit at a time, the more you learn, the easier it will be. You know, when we do something for the first time, also like in the wilderness when we haven't gone to that certain place, we don't know where to go. But when we learn, we know where to go. That is how I am. if I've never been to that place, I won't know which way to go to get to that place. But if I keep going there, I'll know how to get there. It becomes familiar to me.

Similarly, in a small-group discussion about heritable disease, members of the CPG and Ciuliat described traditional prohibitions against marrying relatives deemed “too close,” lest their offspring be born with congenital health problems. Participants in one of the small groups talked about observation and experimentation as both an important element of the scientific method and a feature of Yup'ik ways of knowing. In his report out to the full meeting, C1 said,

[We learn] because we are so observant. We see these things. Even without doing [research], you were collecting data, and your people were connecting data enough to say, because of, because of A and B and C and D that have occurred in the community, we saw that the result was always the same, and therefore we cannot [marry close relatives]. We cannot practice this anymore. That's research. Because we, we shut up and we listen [to the world around us]. And that's why

we learn. [[Using the Yup'ik way]], you guys found out that, yeah, (when they do this, the result is this.) And, and when you [[cut fish]], you know, try this, "Oh, I'm going to try it this way," but it didn't turn out right, because the way that I cut the fish, it didn't dry properly, or you know, this method didn't work. It just spoiled the fish. Let me try it [another] way.

Similarly, G5 described research as a process of problem-solving and trial and error:

I do things in puzzle And I always work on them, even when I work on snow machines or outboard motors. And in my mind, I tell my mind, you know, "This is where it works, this is what happens, what's wrong with it, which is the best way to get it done quick." I taught my son how to do that. He was outdoors, said, "Dad, I can't fix that part." I told him to take it off, and I told him sit down, look at the [snow] machine. "You see? You've got the runners there, the engine to make it, the belt that drives it, nothing wrong with the engine, it runs good. But your slider is broken. You've got to take that off." And I left him, he came back in, said, "I'm done, [it's] fixed." So, things, you know, you learn, if you learn to put things in puzzles. They'll work out, you know.

Yup'ik partners described research with outsiders as a process requiring patience and persistence. In Meeting 4, G9 shared his views regarding group formation using the metaphor of a traditional sod house (*qasgiq*):

[Coming together like this] is like building a house and not rushing it and work on it carefully. If one isn't careful . . . if we build a *qasgiq* and not do it right, the dirt will fall off the sides and the ceiling. If we do it the way our ancestors did it, by using grass to stuff the holes and creaks, the dirt isn't going to fall off of the sides or the ceiling. Also, it won't drip when it rains, because that job was done carefully and correctly. Even [if] it rained hard on that dirt, it isn't going to drip inside, because it was done correctly. If they work on their job without rushing it, taking what they have learned and not messing them up and stick to one thing they like, the right one. Then take that right one and work on it, and it'll be like the bad weather isn't going to get to it. It'll be airtight and nothing will leak inside.]]

The partners returned to the *qasgiq* metaphor repeatedly in subsequent meetings. It not only describes the partnership development process, but also points to the key criterion by which research partnerships should be judged, in the Yup'ik view: how well they serve the purpose for which it was conducted. Careful construction practices – whether in building a sod house or

carrying out a study – produce a solid foundation that can withstand challenges and support further construction.

Speaking of Genetics

What began as a seemingly straightforward search for terminology and analogies that would help to explain genetics to Yup'ik community members became a much more involved conversation about complex concepts and the distinctions among closely related ideas. Having to think about translating concepts into another language often highlighted a lack of precision in the researchers' own ways of thinking and talking. As R3 reflected on these conversations in Meeting 3, she said, "I think . . . the researchers will benefit from having a story or a better way to talk about this, amongst even the researchers. A lot of researchers don't have a clear way to talk to each other about what we're talking about."

Looking for Language

The fact that "there is no Yup'ik word for genetics" was an explicit topic of discussion from the beginning of the partnership. Yup'ik partners explained that their language lacks terms for physical objects too small to see with the naked eye, and that genetics – and indeed research in general – is not something Yup'ik people think about "when you guys aren't here." The investigators recognized that a lack of terminological equivalents does not necessarily mean that the concepts are unfamiliar, however, and sought to relate genetics to Yup'ik participants' existing knowledge. For example, R2 commented in Meeting 1, "You guys have known forever that, you know, people too closely related shouldn't marry each other. That's genetics too. So you know about genetics; you just haven't said, 'genetics'."

CPG members shared other examples of genetic inheritance and variability with which they were familiar, including species and regional differences among salmon, different kinds of

Arctic-dwelling foxes, and the intentional breeding of sled dogs for certain characteristics. They agreed that the lack of specialized Yup'ik vocabulary need not necessarily hinder understanding. In Meeting 3, G6 reminded the group that Yup'ik people have always devised new terminology to keep up with changes in the world:

Thinking back, you know, there wasn't any words in Yup'ik for, you know, airplane, when they first saw them. But they relate it to the term [[fly]], and so they call it an instrument for flying, [[airplane]]. And same thing with pen or pencil, instrument for writing, [[pen, pencil]]. But there are words that they totally don't, or can't relate to, like the barge [that is used to ship goods from the Lower 48 States], they went ahead and called it *paacaq*, right? And some instruments, like spoon, they didn't have words for it, but they called it . . . *luuskaaq* . . . I understand it's a Russian word, *luuskaaq*.

G6 challenged the stereotyped view of Indigenous peoples as frozen in time and not adapting to the conditions of modern life. These counternarratives offered by CPG and Ciuliat reminded the investigators that – on the contrary – the Yup'ik people have successfully adapted to rapid and sweeping change repeatedly. In the case of genetic terms, Yup'ik partners proposed either “Yupifying” (C1) – making Yup'ik – relevant English scientific words by adding a Yup'ik postbase (e.g., *genetics-aq*), borrowing appropriate words from English, or creating new Yup'ik words. These terms could then be further explained and contextualized using familiar Yup'ik words and examples.

As the CPG explored Yup'ik terms for words like “disease” and “genetic heritability,” there was lively discussion regarding the differences between terms, as in this discussion from Meeting 3 involving G6, a CPG member; R5, the only Yup'ik-speaking investigator; and Ciuliat member C4:

G6: *Apquciq* has two meanings for me. Like, when we're talking about genetics. Genes passed down, that's the word that I thought of, but it has two meanings. It's a type of sickness. And other *apquciq* is, you know, it's genetic, has a, maybe the right word would be it has a genetic background, where it's being passed on down. I don't know.

- R5:** So if I say *naulluun* or if I say *naulluugua*, maybe I have a cold or the flu or (*pause*) or TB? And if I have an *apquciq*, what would it be? Some examples of an *apquciq*.
- G6:** It's something, to me, it's something where that – not like a cold, everybody catches cold, right? But it's also some rare, um
- C4:** My *apquciq* is multiple sclerosis. Is that what you mean?

As suggested by this example, Yup'ik participants identified several key distinctions that the investigators may not have considered in the context of heritability. These included conditions one is born with vs. those one acquires; genetic disorders vs. communicable diseases; acute vs. chronic sickness; conditions that can be treated or cured vs. those that cannot; discrete health issues that occur only once vs. those that are recurrent; and signs and symptoms (e.g., coughing) vs. disease. Another topic of conversation in this area concerned traits and diseases that can be “passed by blood,” and the distinction between inherited disease “in the bloodline” – within a family or an entire community of related people – and diseases that are communicable through blood.

Concepts of Relatedness

Relatedness among individuals – what makes people kin to each other – brought deep conceptual and cultural differences to the surface. Whereas the research team understood relatedness in a biological (specifically, genetic) sense, Yup'ik participants expressed a much more expansive definition. They stressed the importance of “knowing who you are” and – as part of that understanding – “knowing who your relatives are.” They explained that the traditional Yup'ik kinship system differs substantially from the way *kass'aq* conceptualize and name relations, with many categories (such as cross-cousins) that do not exist in mainstream European

American culture. When Yup'ik people meet for the first time – including in the initial meetings of the CPG and Ciuliat – they immediately turn to determining how they are related.

CPG and Ciuliat members used a variety of terms, images, and metaphors to describe ways in which people can be related. For example, the biological relationships within families were described metaphorically as “trees with one source,” (G9) and as colors that mix and bleed together, like paint (*urlluni-*). But biological relations were not the only kinship category discussed. CPG and Ciuliat members said that family can also be made through adoption; through the practice of naming (in which a person is given the name of another who has passed on, and thereby takes on the responsibilities and spirit of that person); and through being part of the same community. The dominant-scientific definition of “relatives,” meaning biological family members, with the nuclear family at the center, accounts for only one of these categories.

Ideas about Heritability

In contrast with the researchers' conceptualization of heritability as a function of genetics, Yup'ik partners said that what is shared in families can be passed down in many ways. These included stories – both *quliraq*, legends passed down over generations, and *qanemciq*, stories of historical events told by known persons – and experiences, traditional teachings, and “wise words” (*qanruyutet*) shared by Elders. Individuals may also take on the spirit, characteristics, and behaviors of their namesake, as described above.

CPG members also explained that the Yup'ik conceptualization of heritability contains a spiritual element: for example, several partners spoke about the Biblical teaching that all humans are descendants of Adam and Eve and expressed their belief in this explanation of human origins as a historical and biological fact. CPG members also reported that a shaman's curse can affect the wellbeing of multiple generations of a family, noting that in the Yup'ik worldview, the

thoughts of other people – even those who are not shamans – are powerful and can cause certain things (good or bad) to happen. According to Yup'ik partners, it was important for the investigators to recognize the role spirituality plays in heredity and health in the Yup'ik worldview, and to avoid framing heredity as exclusively a genetic phenomenon. Here is an example from Meeting 3:

G6: [T]he research group is now aware that genetics to the Yup'ik culture can incorporate the [[shaman]] and the Christian beliefs, and, you know, that concept is known. I'm talking about the researchers. Whereas if this was not brought up . . . the research team might not be aware of the reference made to [[shamans]] or the Christian belief I think the information that's brought up from this meeting or group as we get the information out to the people that are going to be involved with the study could be aware that the research team already [understands that Yup'ik people consider spirituality as part of heredity] –

R4: Mm hmm. I know, we [researchers] understand genetics within our spiritual beliefs and other things too.

G6: Yeah. So if the research team is um, you know . . the status quo [understanding of investigators], I think in the past was [that things are passed down only] by blood, you know, from genetics. And the people involved with the study, if they were aware of the three factors [i.e., genetics, Christian beliefs, and shamans], and then, you know, if the research team is interested when we have blood [samples being used for genetic studies] . . they can make whoever's involved [aware that they understand that all three aspects are important to us].

As the partnership continued, the researchers expressed their evolving understanding of heritability and causation, together with insights about how the dominant approach to science can foreclose the development of certain ideas and paths of investigation. The following exchange from Meeting 7 revisited the role of spirituality in health and illness. R7, the first speaker, is the only Indigenous member of the research team:

R7: Why can't the conversation include spirituality? Why can't we have [Bible] stories such as G9 has told as part of the conversation? It's about making space and allowing those perspectives to come into that dialogue

and shaping your own ideas what genetics should, where it should fit in that context. That's where the co-learning happens, right? . . . There's no reason the scientific knowledge should push out the knowledge that's already in the room or in that community. It should be another source of knowledge, and it should not be there to replace it. And that's where you can start having some sort of common discussion, common knowledge, common knowledge generation. Something where everybody feels like they have something to contribute and something they're going to take away from it. It may not be, "This is what pharmacogenetics is, and I'm going to start understanding [it] the way a scientist does." You have space for that spirituality and traditional foods knowledge, traditional healing, or whatever that group wants to share.

C3: It's all connected.

R5: It's all connected in relation to the choices people make, both about what they want to know and about what they want to do.

C3: Very true.

R6: So, does that mean the question is really, "How should we think and talk about passing things from one generation to the next?" Because if you did it that way, I mean, I feel like what you just said is part of what I'm learning, and I'm just at the beginning of it, I'm still wrapping my head around it. But in a way, the thing that in western science we call "genetics" is just one piece of how things get passed from one generation to another. And sometimes it's an important piece and sometimes not, but it always interacts with those other pieces.

To be clear, the investigators had previously understood that behaviors and other non-physical characteristics are often shared within families via non-genetic pathways, but prior to these discussions, they may have perceived a brighter line between genetic heritability and other forms of transmission.

Likewise, Yup'ik partners described a much broader range of what can be passed down from generation to generation, including not only physical characteristics and health conditions, but also knowledge, habits, behaviors, and beliefs. One example the group discussed repeatedly came from a focus group in a rural village, in which a participant spoke about how a young girl cut fish exactly the way her grandmother had, despite their never having met. In another

instance, the partners discussed whether a great hunter and provider – a *nukalpiaq* – learns his skills from his father (i.e., through observation, teaching, and apprenticeship) or inherits them in some other way.

Negotiating Onto-Epistemic Differences

What Can Be Known

Differences were observed between the Yup'ik participants' and the kass'aq researchers' beliefs and assumptions regarding what, at least in principle, can be understood by human beings. The exchange below followed a discussion about the root word *kanginge-*, “understanding the origin [of something]” in Meeting 3:

- G9:** [[I used to hear this story when I used to go to catechism about a man, I think he was a prophet. He was walking along the edge of the ocean. As he was walking, he came upon a child who was ladling ocean water into a little hole using a small ladle. And he asked the child, “Why are you ladling that big ocean [in]to that [little hole]?” That child responded, “Before you understand God, I will empty the ocean using this ladle.” That man who was trying to understand about God, the child told him that before he could understand about God, that the huge ocean would be emptied into that.]]
- C3:** Mmm
- C1:** Mmm
- C3:** It's going to take forever. (*laughs*)
- C5:** Like, yeah, the guy was trying to understand God and was told that he never would.

This story was one the group returned to in subsequent meetings. In this first telling, researchers evinced different understandings of its meaning. Some interpreted it to mean that some things will never be explained by human reason, while others understood it to say that it will take much time and effort to reach the goal of understanding. G9's own understanding was the former; he stated repeatedly over the years that there are mysteries beyond human understanding.

Stories as Knowledge and Teachings

Yup'ik participants frequently shared stories with the group, including both traditional stories and stories of events they had experienced or heard about. Yup'ik partners emphasized that stories are central in Yup'ik teaching, learning, ethics, and meaning-making. As C1 put it, "If we're looking at this thing here (*gestures*), and it has no story, it's not going to mean anything to me. I have to have some kind of story." G6 said,

[M]y age group and older . . . grew up, you know, at the tail end of hearing stories. [[Stories, you know how they used to tell stories.]] And it didn't happen any part of the day, it just happened during the night, when everybody was getting ready to sleep. And one of the Elders or parents – it didn't usually happen at home, but when we went out hunting, one of the Elders would start telling stories. Some might be, you know, true, you know, things that happened in their lives before, stories that passed on from generations, and we'd like to listen to them. I mean, they were like action movies to us, you know. (*laughter*) But they had elements in the stories where we learned, you know, morals or how we should be living.

He went on to speak about the political activism of American Indians in Washington State in the 1950s and 1960s aimed at securing treaty-based Tribal fishing rights, and how stories of those efforts have shaped the way Indigenous people in the USA think about and interact with government agencies and other outsiders.

At Meeting 3, R9 and C1 presented a set of guidelines and communication tips they had developed for kass'aq researchers new to working in the Y-K Delta. Their recommendations included information about how to receive and understand Yup'ik stories. In presenting the draft guidelines to the CPG for review and comment, R9 said,

From the academic point of view, when we listened to a story, we tried to understand, (*puts on exaggerated voice*) "What's the point? What's the main thing? How's it going to end?" It's hard for us to sit still and listen, and, and really understand that the story will go where it goes, and we have to go there. (*laughs*) Rather than, "We're going to pull the insides of the story out. We're just going to take, somehow get the important piece of the story." That's not how stories work at all. So again, what we were talking about, that narrow slice, the,

that's the way academics think. They want to find the little (*gestures with fingers, "something small"*) – what's the important thing to know about the story. But the story isn't like that. The story is the whole story. And so it's a kind of training for us to listen, and be patient, and listen to the whooooo story (*laughs*), instead of . . . trying to look at that one tiny little thing. So that's a, that's training for us to do, to be better communicators, is to respect stories as a different way of understanding the world, and understanding each other, from this kind of, cut-everything-up-into-tiny-pieces (*laughs*) way that we often think in universities.

She observed that sometimes the researchers seemed to “tune out” when they asked a question and an Elder responded with a story. These stories were often told in Yup'ik and then translated into English, but even with translation, some of the researchers appeared to view them as non sequiturs, distractions from the research topic. However, R9 proposed that these stories may represent the Elder's answers to the questions the researchers had asked. G6 endorsed this point, saying, “I would very much agree with you, [R9] . . . You mentioned about the stories that contained elements of, you know, what – like, for instance, probably, for the researchers do not [understand when they] ask questions and the Elders start telling stories, but they do contain answers in the elements, like you mentioned.” Stories often served as touchstones in the partnership, recalling the group to a particular teaching and building group cohesion through sharing memories of past meetings.

Despite being aware that storytelling is an important element of Yup'ik culture – a fact that is both readily observed and often discussed by Yup'ik people – some of the researchers admitted that they had not initially understood stories as a form of knowledge and a way of teaching. Referring to the story of St. Augustine related above, R2 said,

I'll just make a comment – kind of a confession. I've heard some during the meeting how hard it is for some of the Elders, like G9, to understand genetics. And I want to share that it's hard for me, but I'm learning to understand the importance of stories. I've heard stories from C4 today, and I hear G9's story, and I go home and I think about some of these stories, going to the hotel, and I wonder, why am I so tired? (*laughter*) And it's – I think there's a lot for people

like me to learn about the importance of these stories, and the challenge of getting the message.

This quotation acknowledges that this kind of learning requires not only effort and energy on the part of outside investigators, but also the humility to admit one's lack of understanding and the perseverance to continue to engage with learning outside one's comfort zone. It also suggests that self-reflection can play a key role in recognizing the epistemic value of stories as well as understanding that kass'aq researchers could – and perhaps should – take up the challenge of expanding their definition of what counts as authoritative knowledge.

Reductionism vs. Relationality

Throughout the partnership, participants negotiated tensions between the reductionist tendencies of dominant scientific thought and the Yup'ik worldview in which “everything is connected.” For example, at the GENA Workshop described above, the researchers presented the core insight of epigenetic research – i.e., that gene expression can vary depending on how genes interact with environmental and other factors – as novel and surprising. But in the Yup'ik worldview, which centers relationality, it makes perfect sense that such connections exist, and that no single factor (genetic or otherwise) would be dispositive.

Yup'ik participants in this partnership found it humorous that some researchers seemed surprised (if not dismayed) to find that human health and other biological and natural systems are deeply intertwined: how could it be otherwise? For example, C3 – referring to G9's story about St. Augustine – explained:

[[Trying to understand]] diabetes [[is like using a tiny ladle. And there are many other researchers who are studying who are faced with the same situation.]]
(laughs) [[They would learn this little thing and then discover that there was more to learn.]] Remember when [at the GENA Workshop] one of the scientists explained that, even though you would get that gene, or slice of bread, there are other indicators that might influence that gene? You may have found that gene,

but then there's other things that affect it also. And [the researchers are] like, "Oh, there's more?" (*laughs*)

For their part, the researchers were aware of the dominant scientific tendency toward reductionism and the fact that, rather than advancing understanding, an overly narrow focus may make complex phenomena – such as gene by environment interactions – difficult or even impossible to understand. For example, R7, the only Indigenous investigator on the study team, reflected on the results of a series of focus groups that had been held in one of the villages:

[What we are hearing about genetics] actually connects me to stories people have told me back home. The world is not thought of as separating your health or your biology from the land or from the sea, or from the mountains or birds or animals or plants. That's not how a lot of people think about the world, and (*pause*) it, the biology is an important piece of it, but it doesn't operate on its own. It's not – it needs that connectedness to other things in the world. And I think for me, that's just kind of where I'm at right now, thinking about what we heard in these focus groups. And I think it's really important, not just for what we're trying to do with this project, but I think also for scientists to understand that. I work with a lot of scientists, I work with a lot of undergrads who want to be scientists [and clinicians] . . . and our training is a lot about, like, separating the biology out. Separate it out. Separate it out and isolate it so we can understand things. And it's, the world just doesn't really work that way. We can't separate the biology from our emotional or our spiritual pieces.

Similarly, R6 commented in Meeting 6, following another discussion about Yup'ik terms that could be used to share information about genetic research:

I want to say that I think, in the genetics that we do in western medicine, we have trouble making that distinction between the fact that there are some things that are, what I might call "very genetic" – so, very strong causal links – versus other things where genetics is part of it, but it's a much more complicated picture. There are many other things in the environment, including things that parents might teach the children that might influence their health. And I'm really interested in understanding better how the Yup'ik language presents those concepts, 'cause it feels – as I'm listening, it feels like maybe . . . the Yup'ik words are doing a better job of, of capturing the complexity which is there, it's not, it's the complexity that it's not just genes, but it's many other things that influence health . . . so it's complicated. And thinking how to think about that aspect of genetics is hard. At least it's hard for us. I, I, I feel like maybe there's some words that we're hearing that help to underst—, sort of help me to have a different way of thinking about it.

Relatedly, participants needed to negotiate between the academy's drive toward specialized knowledge and expertise, and the Yup'ik emphasis on broad knowledge and practical wisdom. At Meeting 3, G6 shared this reflection on these epistemic differences and the way they play out in teaching and learning:

If research is done in a village, and without exactly understanding the Yup'ik beliefs and values behind it We're very much holistic, and it wasn't until back in the 1980s when I start[ed] taking some college courses where I found out that the western culture is educationally oriented, you know, because they want their children . . . I mean, it starts narrowing, as they go into college. They learn [about] everything in elementary [school], and in high school they start narrowing down to which classes they need to be taking, and then they start specializing, you know. But the concept of our ancestors, the way that we should be brought up, is [that] we should be able to hunt, you know, build, like for men, build sled, know where the fishes are, and you know how to overhaul an engine [W]e don't specialize in those fields, but we have knowledge of different fields, you know, just enough to get by.

The difference was also recognized by the researchers. For instance, R4 commented, “[S]cientists tend to focus on a very narrow part of [the world]. And to talk about and think about and conceptualize genetics in Yup'ik, we need to look at the whole picture. And that it, it's very broad. And I'm not sure we can even identify all the parts to it, how broad it is. It's something that's beyond our ideas.”

Uncertainty, Risk, and the Future

Onto-epistemic differences were also seen in the ways in which researchers and Yup'ik partners conceptualized uncertainty, risk, and future events. Research as an undertaking begins from a position of not-knowing, and the researchers were careful to frame research in this way, as in the following quotation from R8 at Meeting 8:

We think we understand the genetics [of warfarin metabolism] pretty well. We're not probably going to do much more [with that], but this is the one area where this environment — this dietary piece, that there's still a lot of uncertainty about it that we would like to study. So, we'll study the foods [Yup'ik people eat], we'll study

how these bacteria that live in our intestinal tract, how they function, and what the body does to that form of vitamin K that they make. Does it get converted to the form we use? That's the question. We think it might happen, but we want to find out.

Although the researchers were careful to acknowledge that uncertainty is inherent in research, they often spoke of future planned events in a definitive way, e.g., about submitting a particular grant application for a certain deadline or going on a trip. In the Yup'ik way, the custom is to hedge such statements, sometimes using the phrase *Ella assikan*, which was explained to me as meaning something like the Arabic *InshAllah*, or God willing. Yup'ik people speak of future events as planned, possible, or things that "might happen," as in this example from Meeting 9:

- C1:** It's kind of strange – I'm not speaking for the Yup'ik group – to be talking about something that hasn't happened yet. And so, but we trust that this conversation is going to lead to that which could become um something that's going [to help Yup'ik] people, and I think there's some hesitance because we don't know what it is that we're going to be dealing with. It's like going hunting saying, "Well, I'm going to go hunt seal. I'm going to go hunt moose." We never say we're going to because we're not there yet, because there's lots of factors that um, um we might have to consider before we even think about saying what we're going to get.
- G6:** Yeah, that's true. Yeah, most of the time I catch people say, even myself, you know, "I'm planning on, I could plan on going hunting today," but I'd say, "I want to go hunting."

An exception is the fact that many traditional teachings are centered on the consequences of an individual's actions in a sentient world. As C1 explained, "[Yup'ik people] think, 'If we do A, this is going to happen,' and 'If you do this, this is going to happen.' And we grew up that way as Yup'ik people. You know, [[if you do this, this will happen to you.]]"

Concepts regarding uncertainty and risk are particularly important in the context of genetic research, which is often aimed at developing probabilistic risk estimates for a particular

disease, as well as in healthcare settings, where clinicians attempt to implement clinical interventions and motivate behavior changes that can mitigate (modifiable) risk. According to the CPG and Ciuliat, without careful explanation from researchers and clinicians, Yup'ik people are likely to interpret information about health risks in the deterministic sense described above – that, e.g., if a person has an increased risk of cancer, they will develop cancer. C1 said, “That term, [[increased risk, it’s new to us]], but it’s something that I think we need to keep in mind [[when they talk about]] genetics [[to our relatives]].”

DISCUSSION

This study investigated co-learning in the context of a longstanding health research partnership between Yup'ik community members and academic researchers. The paper provides a series of snapshots that illustrate what co-learning can look like “in the wild,” together with examples of how participants in a longstanding health research partnership negotiated onto-epistemic differences in real time. Given the lack of Yup'ik terms for genetic constructs and scientific jargon, early conversations within the partnership focused on conceptual explorations of Yup'ik understandings of heredity, including non-genetic ways that traits and knowledge could be passed down, and an exploration of Yup'ik words and analogies that could help to explain genetics in more familiar terms. In the process of determining how best to discuss genetic research with Yup'ik people, the investigators uncovered conceptual murkiness in our own understandings and identified ways in which the reductionist tendencies of mainstream science can constrain our thinking. The investigators also began to develop new skills and insights – such as recognizing the epistemic value of stories – that were independent of the research topic.

In speaking together about what it means to be related, investigators learned that a view that considers only (or privileges) biological definitions of relatedness is not universally normative. The creation of Yup'ik families is not limited to marriage, reproduction, and legally sanctioned adoption. According to Yup'ik participants in this partnership, relations created through naming are real: names carry relational power and convey certain responsibilities. Researchers should be aware that the imposition of white-normed definitions of relationality is a form of epistemic and cultural violence that can have real consequences in economic, social, and psychological terms. For example, Indigenous scholars and leaders have identified blood quantum and other such categorization schemes as an ongoing form of colonization.¹⁹³⁻¹⁹⁵

We also began to see how Yup'ik onto-epistemology, with its emphasis on interdependence and balance, offers a different way of thinking about the world, one that comports with emerging understandings across many areas of science.^{50,196,197} As the CPG and Ciuiat have said repeatedly over the years, and as is illustrated in Kawagley's graphical representation of the Yup'ik worldview, "everything is connected."⁸⁷ Being aware and respectful of this orientation – which is likely unfamiliar and deeply counterintuitive to many western-trained, non-Indigenous scientists – is important in building and sustaining equitable collaborations. Importantly for precision medicine research and other novel approaches to understanding human health, a relational orientation may open the door to new hypotheses that more fully account for interactions among the human genome, environmental exposures, behavior, and a wide range of social determinants of health.

In contrast with the view that everything is, in principle, comprehensible to humans, and as we were often reminded by G9, Yup'ik onto-epistemology retains a space for knowledge that is beyond human understanding.¹⁷⁶ Partners in this kind of collaboration must also acknowledge

potential differences in the goals, and therefore the moral warrant, of scientific inquiry within these two different worldviews. For example, Kawagley claims that the goal of western science is ultimately to control Nature, whereas the Yup'ik approach to science aims to understand Nature in order to support respectful reciprocal relations between humans and Nature.¹⁷⁶

Limitations

Informal interactions among partners were not audio recorded. These included conversations during breaks, walking to and from lunch, and at mealtimes. It happened more than once, for example, that a CPG or Ciuliat member approached me in the hallway or the washroom to say something they felt uncomfortable mentioning in the meeting room. These informal interactions provided a space to deepen relational connections and contributed to co-learning, but they were not included in this analysis.

The results reported here are not generalizable at the level of specific findings, and they should not be construed to apply to all community-university health research partnerships or even all Yup'ik-university partnerships. Rather, I have used a case study logic to highlight methodological processes and approaches that may have broader application to collaborations that share structural features with the partnership described here, and to offer opportunities for outside researchers to reflect critically on their own practices.¹⁰⁸ Due to the SARS CoV-2 pandemic, lack of reliable or affordable Internet/phone access for some participants, and the death or departure from the project of several community members, I was unable to conduct detailed member checks with participants.¹⁹⁸ Due to privacy concerns, the volume of data, time constraints, and the highly particular, culturally specific nature of the data, I did not involve others in the coding process, which is typically an important step in ensuring the trustworthiness of qualitative interpretation.¹⁹⁹

CONCLUSION

Yup'ik community members had a sophisticated prior understanding of many of the topics we discussed concerning genetics and heredity. In some cases, compared with the mainstream scientific view, the Yup'ik worldview seemed more aligned with emerging understandings of complex phenomena in human health and wellbeing. The new, comprehensive model of precision health – which seeks to understand how the interaction of genetics, environment, behavior, social determinants, and other factors shapes human health and disease – is one such domain. In some interactions, the Yup'ik worldview challenged the investigators' prior understandings in productive ways, as in considering the different ways in which certain traits and behaviors may be shared between people, outside the human genome. As often happens in good CEnR, the investigators learned more, and about a broader range of topics, than originally anticipated.

Although a growing number of investigators and funders acknowledge the need for community engagement and co-learning in health research partnerships, and despite the emphasis in the CEnR literature of involving communities in the formative stages of research, it is often still the case that explicit focus on learning tends to be limited to the study question as defined by the investigators. Investigators thus retain their habitual position as the experts and the primary creators of knowledge. But as this study demonstrates, communities have their own prior understandings and knowledge systems that, if taken seriously, could contribute to the development of new hypotheses and avenues of investigation.

Research Agenda

This study suggests several possible directions for future research. One is the development of principles and tools to negotiate co-learning goals within health research

partnerships and assess co-learning progress. Like the common practice of establishing authorship guidelines at the outset of a research collaboration, community-university partnerships could make co-learning an explicit goal, with established roles, objectives, and periodic assessments. To correct for the assumption that researchers are the (only) experts and support enactment of the values of humility and accountability, these discussions could explicitly frame co-learning as a mutual endeavor. Investigators could also invite community members to identify learning goals for themselves and for the study team.

In concert with agenda-setting for co-learning, further research is needed to develop ways of assessing co-learning within community-university collaborations. A useful contribution would be to test the effects of a pre/post 360-degree approach. This might involve asking all partners what they hope to learn from their participation, what they hope others will learn, and what knowledge they would like to share, with regular follow-up to determine what participants have or have not learned, what they believe others have learned, and updated learning goals for themselves and others. Such assessment should also explore ways for measuring effects on participant satisfaction and relationality within the partnership as well as eliciting participants' perceptions of the effects of making co-learning an explicit goal.

Recognizing and valuing community expertise is an important element of co-learning. In the partnership described here, the GENA Workshop was a valuable step in developing a shared, hands-on learning experience and vocabulary about genetics. Such educational efforts are a feature of some partnerships, but they tend to focus on scientific knowledge. Future research could explore the effects of dedicating time, early in a collaboration, to complementary community-led education sessions. It would be interesting to know, for example, whether educating researchers about cultural practices not directly relevant to the study question affects

their beliefs and behaviors, and how any such effects may in turn influence co-learning and the development of equitable collaboration practices.

Exploring how the composition of the investigator team influences co-learning is another potentially profitable area of study. In this partnership, for example, the study team represented a range of disciplines, including clinical medicine and nursing, genetics, pharmaceutical chemistry, anthropology, and ethics. Several researchers took it upon themselves to attempt to broker communications between Yup'ik and kass'aq participants, complementing the formal role assigned to the Ciuliat as bicultural liaisons. It may be informative to examine whether and to what extent investigators' disciplinary training, research interests, and lived experiences shape their engagement in facilitating co-learning, as well as their personal orientation and expectations with respect to learning from community partners.

Educational Implications

Required training of graduate students and postdoctoral trainees in the responsible conduct of research tends to focus on the federal definition of research misconduct, which focuses on data falsification, fabrication, and plagiarism.²⁰⁰ Under US law, individuals receiving federal funds to conduct research involving human volunteers must also receive training in human participant protections.²⁰¹ Those training in clinical disciplines (e.g., medicine, nursing) receive additional education in medical ethics, which engages with questions of fiduciary responsibility to patient-participants; negotiating organizational ethics, intercultural communication, and the competing demands of public health and individual patient interests; and intra-professional conflict. None of these necessarily includes training in the ethics of community engagement or equitable collaboration, however. A valuable tool for health researchers new to working with Indigenous communities is the rETHICS (Research Ethics

Training for Health in Indigenous Communities) curriculum, which provides a detailed, culturally grounded introduction to the kinds of issues that can arise in such research.²⁰²

This study highlights the need for university-based researchers to seek to educate themselves about the worldview, cultural norms, and history of their community partners. I have been extremely fortunate to be able to draw on a substantial anthropological and educational literature concerning Yup'ik culture,^{76,77,87,118,172,203-208} several texts that gather stories and teachings from Yup'ik Elders,^{79,85,209-211} and numerous research reports from CANHR and other investigators who have conducted strengths-based health research in partnership with Yup'ik communities in the Y-K Delta.^{42,71,74,171,212-220} Where such resources exist, researchers should familiarize themselves ahead of time. Doing so demonstrates respect and interest in the people as people – not merely as “subjects” – while raising the investigators' critical consciousness concerning the sociohistorical context into which they are inserting themselves. This, in turn, can reduce the likelihood of serious investigator missteps.

Finally, and perhaps most importantly, these findings point to the need for supported self-reflection for outside researchers and perhaps partnerships. This is consistent with a recent analysis that found commitment to collective empowerment – which encompasses attention to partnering practices, community fit, collective reflection, and influence – was the strongest theoretical driver of relational quality in CBPR partnerships.²²¹ Entering into collaboration with community members as a learner, rather than an expert, can be unfamiliar and uncomfortable territory for investigators. As noted above, clinicians receive a modicum of training in metacognitive activities designed to improve their communication skills and their ability to assess their performance in interpersonal interactions, but such training is largely absent for non-clinicians. Self-reflection could be scaffolded in several ways, ranging from journal prompts to

group debriefing sessions to developing and sharing digital stories about meaningful experiences. Regardless of the approach, providing opportunities for scientists to practice self-reflection and gain comfort with vulnerability may enhance their effectiveness and confidence in the field.

**Learning To Learn Together: Group Formation in a Community-University
Health Research Partnership in Southwest Alaska**

INTRODUCTION

Community-engaged approaches to health research continue to gain traction, and in some cases are required by communities and/or funders.^{44,62} A substantial and growing theoretical literature exists, together with numerous reports that detail the outcomes of such work. Less common are real-world accounts of how community-university health partnerships are operationalized, particularly with respect to the formation and maintenance of interpersonal relationships and co-learning. This is surprising, given the centrality of trust in the theoretical literature, and an important gap for investigators and communities alike.

Although each partnership is unique, given a wide range of variation in research aims, community setting, culture, and history, more granular accounts of the inner workings of partnerships between community members and researchers could be useful in guiding communities' and researchers' decisions and practices. These include determining whether a potential partner is a good fit; deciding how best to govern community-university research collaborations; establishing criteria and strategies for measuring their quality and performance, including process measures to support needed course corrections; and identifying priorities for improvement and methods development for the field.

To begin to address this gap, this paper offers a close look at how group formation and movement toward transformative agency unfolded during a six-year period within a longstanding health research collaboration involving Yup'ik community members in southwest Alaska and

three academic research institutions. Four conceptual lenses help to frame this inquiry: group formation, transformational agency, politicized trust, and reciprocal relationality.

Group Formation

Tuckman's 1965 model of group formation is a useful lens for considering the processes by which groups come together and coalesce, or not, around a shared aim. The model posits that groups follow a predictable developmental trajectory as teams mature and enhance their ability, build interpersonal relationships, and evolve toward power sharing and participatory leadership.¹ The group formation model defines groups as developing simultaneously along two tracks: interpersonal relationships (referred to as the social realm, or group structure) and interactions concerning the work to be done (referred to as the task realm). Within both realms, Tuckman proposes four stages: (1) forming, a period of uncertainty and conflict avoidance; (2) storming, in which contention arises around issues of power, leadership, and structure; (3) norming, in which group members devise new ways of being and working together, resulting in increased trust, intimacy, and group cohesion; and (4) performing, in which the group is able to flexibly adapt to members' needs and becomes productive. In this final stage, Tuckman notes, "interpersonal structure becomes the tool of task activities." A subsequent empirical study found that group formation is more challenging when groups are larger, more diverse in their membership, and/or lack a clearly defined task.²²²

Transformative Agency

Equity-focused scholars across several disciplines have asserted that reforming research is insufficient: it must instead be transformed. The literature posits that such change should be led by, and for, the people formerly considered the "subjects" of research. In the context of research with institutionally underserved or excluded groups, meaningful engagement is seen as

especially critical as a step toward correcting past injustices. The concept of transformative agency sharpens the focus on community agency, specifically the “collective will and ability of individuals to break from a given frame and take initiatives to transform their activity over time.”³⁴ Creating the conditions of possibility for transformative agency in health research demands that investigators and institutions move beyond “allowing” community members more “input” into oppressive systems. Rather, they must actively elicit community direction and be willing to implement the changes that emerge – up to and including community leadership. This requires taking seriously ancestral and cultural funds of knowledge,^{6,87,148,223} allowing for differences in communication style and affective presentation,^{103,224} and respecting incommensurable onto-epistemological understandings.^{87,178,208} It also implies a shift from describing problems (e.g., characterizing disparities in health status for nondominant groups) to developing solutions (e.g., exploring how to resolve those disparities and testing and evaluating different approaches).^{33,35-37}

Although the free and full participation of community in health research is recognized as an essential component of ethical research, researchers’ engagement efforts often fall short of this goal.^{34,35,63} Making space for under-represented voices and perspectives may rest on unexamined assumptions that they are in some sense deficient and need to be chivvied into taking a more active role.^{34,35,225,226} Racialized institutional scripts, which define certain identities and actions for different roles, contribute to this construal.³⁴ In both health care and research, minoritized patients and families are often labeled “noncompliant,” “difficult,” “hard to reach,” and lacking “sophistication.”^{227,228} Such deficit labels give cover to or may even be used to justify discrimination and mistreatment. By contrast, “good” patients and study participants are described as “activated,” “compliant,” “adherent,” and – somewhat ironically, given that the

axiological judgment here is about submission to authority and professional expertise – “empowered.”²²⁹

When health researchers seek to recruit community members to participate in study design, planning, and analysis, they often select individuals from the “grass tops” (e.g., the president of a disease-specific nonprofit) rather than the “grass roots” (e.g., patients who are living with the disease but have not formed a professional identity around it). These choices are generally presented as pragmatic, using the seemingly commonsensical rationale that it is more efficient to work with community members who already possess relevant knowledge and skills; but these decisions may also rest on unexamined beliefs about race and class, who has the capacity to understand and contribute, and what kinds of activities deserve the investment of research dollars (e.g., purchasing new lab equipment vs. explaining scientific concepts to community members).

By situating the “problem of participation” in nondominant individuals and groups, racialized scripts distract attention from the myriad social, economic, educational, and environmental factors that limit nondominant people’s access to health-related resources (e.g., convenient and safe places to exercise or access to fresh fruits and vegetables). Racialized scripts thus limit opportunities for learning, collaboration, and agentic action. They also obscure other, potentially addressable, barriers to full participation at levels beyond the individual and limit the collective political will to address social determinants of health.

Alaska Native and American Indian people have poorer health status at baseline, due primarily to socioeconomic disparities including poverty, lack of access to healthcare, and toxic environmental exposures, which are compounded by historical trauma and ongoing racism.

The continuing, massive disparities in COVID-19 mortality are illustrative. As of November 2022, the cumulative incidence of cases among Alaska Native and American Indian (ANAI) people is substantially higher than among non-Hispanic whites (20,182 vs. 12,141 per 100,000).²³⁰ ANAI people with COVID-19 are also more likely to be hospitalized (1,112 vs. 562 per 100,000), and age-adjusted COVID-19-associated mortality among ANAI people is also higher (304 vs. 207 per 100,000) compared with non-Hispanic whites.²³⁰ Addressing this and other disparities will require attention to systemic inequities and the mistreatment of ANAI people in the health domain, in addition to the choices individuals make regarding vaccination or mask-wearing.

Proposing a shift from conventional inclusion and engagement to equitable collaboration in education, Ishimaru outlines four areas where change is required: (1) changing nondominant communities' roles from clients and beneficiaries to leaders who have relevant expertise and resources to share; (2) revising goals from remediating communities' lack of interest, motivation, sophistication, etc. to creating a culture of shared responsibility and systemic change, i.e., transforming power rather than people; (3) replacing strategies aimed at implementing incremental, technical changes with strategies geared toward building relationships and capacity; and (4) re-visioning reform as an inherently political process that occurs within a powered, racialized context.³⁴ Such "role re-mediation" offers new and different opportunities for equitable collaboration.²²⁵

Politicized Trust

Successful community-university research partnerships depend in large part on trust. A full exploration of how trust has been conceptualized and enacted in research partnerships is beyond the scope of this paper, but the default framing of trust as something researchers need (to

obtain, and in more pointed formulations, to earn) from “the researched” has proven insufficient. The concept of politicized trust recognizes that race and power mediate relationships.^{231,232} Politicized trust has three components: political understanding, including intersectional identities, historical and place-based understandings, and the racialized history of institutions and their practices; respect, including knowing when to “step up” and when to “step back” and acknowledging epistemological differences; and solidarity, including shared identities, commitment to equity, and recognition that good intentions are not enough.²³² Race-conscious political understanding, in particular, serves as a check on the kinds of dignitary harms too often inflicted by well-meaning liberals, including attempts to assimilate or appropriate Indigenous knowledge and methods. Explicitly considering how race, racialization, and the powered dynamics between individual partners, communities, and institutions adds a dimension that is missed in analyses that focus on interpersonal communication and behavior without reference to identity or positionality. It also underscores the need for non-Indigenous researchers to “own” their multilayered identities, recognize the privilege and power associated with their positionality, and bring that understanding to the work in the service of equity.^{13,34,233}

Reciprocal Relationality

In Indigenous cultures, including among the Yup’ik, the thriving and futurity of the community – rather than the individual – is paramount. The interplay of generosity and gratitude is central to Indigenous lifeways, in that it creates the conditions for relational, rather than transactional, reciprocity. Among Yup’ik people, it is common to hear the expression of a broad, open-ended sense of gratitude, not directed to any individual. People say *quyana*, thank you, not only as a matter of etiquette – for example, when someone passes the salt in response to a request – but to express gratitude to the sentient universe. I once asked an Elder how to say “you’re

welcome” in Yup’ik, and he told me there was no Yup’ik an equivalent to the English phrase. Yup’ik people would simply say *aa-ang*, an affirmative response, a linguistic convention that underscores the essentially impersonal, non-transactional nature of giving.

Kawagley represents the Yup’ik self as a circle, a container that holds in balance the spiritual, emotional, intellectual, and physical domains.⁶ When the domains are intact and the circle has integrity, individuals are able to get along with and help each other, “working together with one mind,” in the Yup’ik phrase.¹¹⁸ Cooperation ensures the continuation of Yup’ik wisdom and lifeways and maintains the necessary balance among the human, natural, and spiritual realms; it is grounded in the understanding expressed in the Yup’ik adage “*Ella-gguq allamek yuituq*,” literally, “The world is populated by no one else but persons.”¹¹⁸ In a translation of Elder Paul John’s oratory, *yuituq* is translated as “relatives” rather than “persons,” making the relationship closer still, and broadening the reach of connection to include more-than-humans.²¹⁰ G2 once told me that he understands the saying to mean there is no Other: we are all related.

METHODS

Setting and Participants

The partnership was established in 2009 by researchers at the Center for Alaska Native Health Research (CANHR) at the University of Alaska Fairbanks; the Yukon-Kuskokwim Health Corporation (YKHC), the Tribal health organization serving southwest Alaska; and Yup’ik individuals from several rural villages in the lower Yukon-Kuskokwim (Y-K) Delta. In the period reported here, the partnership included additional researchers from the University of Washington and the Group Health Research Institute. An innovation of the partnership was the inclusion of past study participants from rural communities (the Community Planning Group, or CPG) and a group of college-educated, urban-dwelling Yup’ik professionals (the Ciuliat) who

serve as bicultural liaisons (Table 1). Yup'ik community members were directly recruited by CANHR leadership.

Data Collection

The group convened in person 10 times between 2010 and 2016 in Mamterilleq (Bethel), the regional hub providing commercial and government services in southwest Alaska (Table 2). Meetings were audio-recorded and transcribed by a member of the Ciuliat, who translated Yup'ik to English as needed and provided two-way interpretation in the meetings. I removed identifiers of individuals and communities in the transcripts prior to analysis.

The original study under whose auspices these data were collected was approved by the Institutional Review Boards (IRBs) of the University of Alaska Fairbanks and the Group Health Research Institute as well as the YKHC Human Studies Committee (HSC). Written informed consent was obtained from all participants, including researchers, for audio recording and transcription. The present analysis was approved by the YKHC HSC and the University of Washington IRB; verbal permission to use the data in this way was provided by individuals still active in the partnership as of 2019.

Analysis

The overall analytic process involved several steps. I began with a thematic description to identify constructs of interest for epistemic network analysis (ENA). Next, I developed a coding scheme for ENA and performed the analysis using the ENA Web Tool. I then returned to the data to confirm and interpret the ENA findings on the back end using thematic and discourse analysis techniques. This is a departure from the usual order of operations¹¹⁶ in ENA, in which the ENA precedes thematic analysis; however, this approach aligns with the exploratory, proof-of-concept nature of this part of the dissertation. A key goal was to test how well ENA

techniques, including automated coding, could accommodate this large, longitudinal, intercultural dataset.

Thematic Analysis

To gain a sense of the development of relationality and co-learning in the partnership, I first performed a directed descriptive thematic analysis. Compared with other common qualitative analysis techniques (such as grounded theory analysis), thematic description is a relatively low-inference approach to identifying, categorizing, and summarizing the main concepts within a given dataset.^{114,189} Consistent with the case study logic that ties these three analyses together, this form of thematic analysis stays close to the data and aims to preserve particularity where salient.¹⁰⁸

For the analysis presented in the second paper in this dissertation, I completed several close readings of the data, drafting analytic memos as I did so, which eventually led to development of the coding scheme shown in Table 3. For the present analysis, I identified a subset of relevant codes: (1) comprehension check, which included comments and clarifying questions about whether something is or is not understood, (2) partnership assessment, which captured remarks about the progress or status of the partnership in terms of relationality, productivity, and other criteria, (3) partnership goals, which comprised comments regarding the purpose of the collaboration and its near- and long-term aims, and (4) self-assessment, which included participants' evaluation of their own learning, feelings, role, etc.

Epistemic Network Analysis

With assistance from the Epistemic Analytics group at the University of Wisconsin, I then performed an exploratory, proof-of-concept epistemic network analysis^{117,234} using the ENA Web Tool (version 1.7.0).²³⁵ ENA is a quantitative ethnographic technique for modeling the

structure of connections within a coded dataset. ENA is based on the assumptions that (1) a set of meaningful features in the data (“codes”) can be systematically identified; (2) the data contains a discernible internal structure (“conversations”); and (3) the connections between codes within conversations are meaningful.^{116,117,234} The ENA Web Tool uses statistical analysis of coded qualitative data to generate a weighted network of co-occurrences, which can be represented graphically. The software also maintains links to the data, enabling the user to determine how data manipulation influences the networks, as well as to verify the networks against the data.

ENA was originally developed to model theories in which the connections people make through the use of language (broadly construed) are central to analysis.²³⁶ Examples include the ways in which people connect different kinds of knowledge and theory to develop new knowledge and systematic understanding.^{237,238} Shaffer characterized learning as the development of an epistemic frame:²³⁹⁻²⁴¹ an organizing pattern of knowledge, skills, habits of mind, and other cognitive elements that characterize communities of practice.^{124,242,243} Although ENA was originally designed for application in the field of learning analytics, it has been usefully applied in healthcare settings. To date, ENA has been employed to study the use of procedural simulators in medical education,^{244,245} patient decision-making,²⁴⁶ and communication in healthcare teams.^{247,248} ENA is a useful technique for modeling group dynamics in community-university research partnerships because it can illuminate the relationships among group formation, identity (including intersectionality, though that is not a focus of the current analysis), relationality, and learning occur over time.

I worked through several potential theory-guided coding schemes, arriving at a final set of regular expressions (Table 4) that identify conversational markers for the constructs of interest, as related to the phenomena of relationality and co-learning within the partnership. In

addition to drawing on my experience as a participant-observer in the partnership, the coding scheme is grounded in the principles of three main methodologies: discourse analysis^{101,104} and conversation analysis¹¹¹⁻¹¹³ for the discursive elements, and Social Presence Theory to capture some of the ways in which individuals project social presence and connect with others.^{105,106} It also maps to Tuckman’s model of group formation as including both social and task-focused development.¹ The coding scheme thus combines elements of how partners speak and what they speak about. For example, it captures both utterances that display relationality (e.g., the Gratitude code) as well as those that address relationality (e.g., a comment, coded as Assessment, concerning group cohesion). Likewise, in the co-learning domain, both discursive markers (e.g., the Question code) and comments about comprehension and learning (Assessment) are included.

Table 4. Coding Scheme for Epistemic Network Analysis

Code	Definition	Search Terms	Domain	Theoretical Basis
Questions	Substantive questions (ie, do not include questions about what’s for lunch, flight arrangements, etc.)	Punctuation (question mark) Wonder* <i>Apyutk*</i> (requesting permission to ask a question) NOT time NOT lunch NOT flight	Co-learning / task realm Relational / social realm	Discourse / conversation analysis Social Presence Theory (“inquiry”)
Humor & teasing	Funny stories, jokes, teasing, running jokes	Laugh* Chuckl* Tease Teasing	Relational / social realm	Discourse /conversation analysis Social Presence Theory (“humor”)
Vocatives	Referencing another partner by name	Study ID of partner other than speaker	Relational / social realm Co-learning / task realm	Social Presence Theory (“cohesive response”)
Assessment	Reflections and evaluations about learning and co-learning, at group or individual level; checking in to see if info is understood; also reflections on group formation	Learn* Understand* Expla* (explain, explanation) Sense (“make(s) sense”) Get it Got it Taught	Relational / social realm (e.g. how the partnership is developing) Co-learning / task realm	Discourse / conversation analysis

		Teach* Hear*		
Gratitude	Expressions of thanks, gratefulness, appreciation	Thank* <i>Quyana</i> (thank you) Appreciat*	Relational / social realm	Social Presence Theory
Passed down	How things are passed down, what kinds of things can be passed down	Passed (down) By blood Shaman Belie* (belief, believe) Inherit* Heritab* Runs in famil* Familial Genesis Origin Adam Bible Evol* Adapt* Comes from Came from	Co-learning / task realm	n/a (inductively developed from data)
Yup'ik terms re genetics	Yup'ik terms for genetics and health conditions	<i>Kingu*</i> <i>Nauvi*</i> <i>Urlun*</i> <i>Urn*</i> <i>Piliaq</i> <i>Apqu*</i> <i>Nutem*</i> <i>Ciuliaq</i> <i>Ciuliaput</i> <i>Ayagn*</i> <i>Ayuq*</i> <i>Kangin*</i>	Co-learning / task realm	n/a (inductively developed from data)

*indicates truncation wildcard for search logic. Any word beginning with these letters is included.

Using the programming language R, the deidentified transcripts were parsed into individual lines (sentences) and uploaded into a Microsoft Excel spreadsheet, together with relevant descriptive metadata (e.g., participant demographics, meeting dates). This resulted in a database containing approximately 32,000 lines of text. The data were then auto-coded using nCoder, an application developed by the Epistemic Analytics team to streamline the process of working with large datasets.²⁴⁹ The nCoder tool uses regular expressions (“search terms” in Table 4) to automatically assign codes to individual lines of text.

Working with the Epistemic Analytics team, I used the results of the initial thematic analysis to frame the subsequent ENA analyses in terms of interactions prior to, during, and following the investigators' recognizing and engaging with the CPG's and Ciuliat's attempt to renegotiate the CPG members' role with respect to community outreach. The data were thus divided temporally into pre-renegotiation (Meetings 1 and 2), renegotiation (Meetings 3 – 7), and post-renegotiation (Meetings 8 – 10) phases. It should be noted that "post" here implies neither that this was a linear process nor that renegotiations were completed by Meeting 10; conversations about respective roles and interests continue to the present day. The ENA analyses were thus designed to explore whether and in what ways specific discursive features varied per renegotiation phase.

I began by comparing the discourse of the whole group across the different renegotiation phases (Model 0), but these analyses did not distinguish between Yup'ik and kass'aq partners' patterns of talk, which the thematic analysis had suggested was important. I next compared the discourse between the two groups in the pre-renegotiation phase (Model 1). I defined the units of analysis as all lines of data associated with a single value of Yupik.Speaker (a binary code distinguishing CPG and Ciuliat members from kass'aq researchers), subsetted by ReNegotiation (pre-, renegotiation, and post-renegotiation), Session (meeting number), and Speaker (individual participant). For example, one unit consisted of all the lines associated with ReNegotiation = Pre ReNegotiation, Session = Session 1, and Speaker = G9. The codes used in all six analyses were Questions, Humor_Teasing, Assessment, Gratitude, and Vocatives.

In Model 2, I compared the discourse of the two groups in the renegotiation phase. Here the units of analysis were defined as in Model 1, with the difference that the ReNegotiation value was set to ReNegotiation. I also ran the same comparison between groups for the Post

ReNegotiation phase, but the results were essentially unchanged from ReNegotiation and are not reported here.

The remaining analyses compared within-group discourse: the Yup'ik partners' discourse comparing the pre-renegotiation to the renegotiation phase (Model 3) and from renegotiation to post-renegotiation (Model 4) and the kass'aq partners' discourse from pre-renegotiation to renegotiation (Model 5) and renegotiation to post-renegotiation (Model 6). In each case, the units of analysis were defined as all lines of data associated with a single value of ReNegotiation subsetted by Yupik.Speaker (Yup'ik or researcher), Session (meeting number), and Speaker (individual participant).

To construct the network models, the ENA algorithm employs a moving stanza window, defined as four lines (each line plus the three preceding lines).²⁵⁰ This enables the software to model how codes in the current line connect to other codes in the same temporal context. The resulting networks are aggregated for all lines for each unit of analysis in the model. In this model, we aggregated networks using a binary summation in which the networks for a given line reflect the presence or absence of the co-occurrence of each pair of codes.

The ENA software generates network graphs to provide a visual representation of the model. Nodes correspond to the codes, and edges reflect the relative frequency of co-occurrence, or connection, between two codes. For each unit of analysis, ENA calculates both a plotted point representing the location of that unit's network in the low-dimensional projected space and a weighted network graph. Fixed node positions are determined by an optimization routine that minimizes the difference between the plotted points and their corresponding network centroids. The co-registration of network graphs and projected space enables interpretation of the dimensions of the projected space and explanation of the positions of plotted points. By default,

each model provides three graphs: one for each of the two groups being compared (primary and secondary graphs) and a difference graph, in the edge weights of the two network graphs are subtracted. The difference graph facilitates visual comparison of the primary and secondary networks.

The final step in ENA is to “close the interpretive loop.”¹¹⁶ In this phase, the analyst returns to the data to assess – from a qualitative perspective – how well the ENA models represent the underlying data in order to identify any needed modifications and to aid in further interpreting the plots and statistical results. For each model, I used the Web Tool’s Data View functionality to revisit the data underlying key connections identified by the ENA analysis using thematic and discourse analysis techniques to extend interpretation of the network representations. I read the relevant lines of text to identify explanatory themes, drafting detailed notes as I did so.

RESULTS

In the following presentation of results, individual participants are identified by alphanumeric codes, where G = Community Planning Group, C = Ciuliat, and R = researcher. Pulled quotations and words in quotation marks represent verbatim remarks. [[Double brackets]] are used to indicate comments originally made in Yup’ik, and individual Yup’ik words are displayed in *italics*.

Thematic Analysis

Role Renegotiation

As predicted by the group formation model, the early meetings of the partnership featured tentative discussions about the purpose of the partnership, the respective roles of the researchers, the CPG, and the Ciuliat, why the specific people in the room had been invited to participate, and

what they were expected to contribute. In Meeting 1, which involved the CPG and the CANHR researchers, R2 explained the function of the Ciuliat this way:

(drawing on white board) So, it this the community, and this is the researchers, we have to learn how to talk or with each other, and to me the Ciuliat group is kind of in between. They have one foot at the university, but yet they are a step closer to the community This Ciuliat group is not to tell the community what to do as much as, maybe listening to the CPG, listening to you. As researchers, like me, that are not Yup'ik, you may tell me something but I may not understand. You may not say anything, and C5 might be able to tell me, "I think they're a little uncomfortable with this; I don't think they like that." She might understand better than me. So, so really the Ciuliat Group is to help bring that message back to us or if we're asking you things, she and others might say, like C1 or C2, that they might understand why what we're saying doesn't connect with you.

In keeping with Tuckman's model, these were congenial conversations, with partners demonstrating agreeableness and avoiding conflict.

In Meeting 3, at the start of the renegotiation phase, the CPG and Ciuliat initiated discussion of roles and expectations, and some expressed discomfort and uncertainty regarding their engagement. For example, C4 reflected on her participation to date:

- C4:** [T]he very first time I came here, over a year ago, first I was embarrassed that I was called to be in a Ciuliat group (laughs). I'm like, "I'm not [an expert/leader/ancestor]," you know. And so I asked C5, "Why? Why? Why?" and she goes, [[“We'd like to hear your ideas too.”]] So, and then I came, and I was just overwhelmed with mitochondria and all of this.
- R4:** Even a lot of us that work in this kind of research, we don't know everything either. I always have to go back and say, "Wait a minute, what was that again?"
- C4:** Yeah, yeah. "What was the . . . ?" Yeah.
- R4:** And how do I explain that?" And so we're always looking, because that's part of it. We don't know everything. None of us knows everything. We're not supposed to know everything. *(laughs)* And we tend to have this one little tunnel vision sometimes about one little small area. But that little small area is part of a great big whole that we need to understand too.

C4: And you get lots of people like me. And I sit there and I (*makes exaggerated “I don’t get it” face*).

In this exchange, R4 volunteers that she, too, lacks deep understanding of some of the science under discussion. This may be a bid to build solidarity and provide comfort, given C4’s comment about feeling overwhelmed by the technical nature of some of the discussions. R4’s comments also reflect her understanding of Yup’ik onto-epistemology and G9’s statement in earlier meetings that some things cannot be known by human beings. However, C4’s question about why particular Yup’ik individuals have been invited to participate has not yet been satisfactorily answered.

Later in the same meeting, CPG member G2 brought up a question about the purpose of the group, which led to a detailed exchange between Yup’ik partners and investigators:

G2: What is your point here of, you know, sitting [here]? Are we trying to come up with ways that we can explain, try to explain or give the idea to the general public of what this is about? Or what, what are, you know, what’s our, what’s my, what would be my goal? What is it that I want to know? Or how do I want to get this information out to the community? Is this why we’re here?

Someone: (*quietly*) That’s a good question.

G2: Of how we can get the message out to the Yup’ik community members? And to see what we can get out of them? Or trying to identify what genetics is in Yup’ik, what their idea of understanding is?

R4: It’s partly – well, I’ll just respond first. But partly

C1: R4, before you respond, maybe I should kind of piggyback what G2 just said. I had had one of our esteemed colleagues with us, with whom I flew in yesterday, [[he was Yup’ik]], and the person asked, “Why am I going to Bethel and spending so much money to come and sit, to listen to things that I don’t even understand? That’s, you know, it’s kind of like a waste of somebody else’s dollars.” And, and the only response I got [for them] was, because you’re important. But the thing is, I think

that there are questions here As G2 just said, what are we here for? What's our role? And how do we disseminate that knowledge, once we understand what it is that we come here to do? Um, yes? [*looking to group for confirmation*]

G2: That is the very same question I asked myself when I came in. Because, you know, it's like, I have to take time away from my work to be here. So, like, is it worth my time to? I mean, that's the very question that I had.

R4: Well, in partial response, what I see, and the way we envisioned the grant and the project to begin with was, how do we talk together about it? It's not necessarily how we disseminate or give something back to some group, or just provide a one-way interaction, but we don't know how to talk about genetics with community members. These are research projects that we have in the communities, but we don't know how to talk. And it's not just, like I said, giving something to someone, and saying "We're going to tell you this," it's, how do we talk back and forth? How do we know what you want to know about the research? We don't know ways to talk, and the only way to get to those ways to talk is maybe to spend time. And maybe we don't see how valuable it is at the moment, but the only way to know how to talk about it is to start that dialogue and start that talking. Because, if a person is doing research, and you're working with a community and you're partnering with a community, there's a responsibility that – just like if you enter a contract with someone else, there's a responsibility of both parts to be able to communicate and talk together about what you're doing. But how do you get to that point? We don't know how to get to that point, but we want to find out. But we can't do it by ourselves. It has to be both, both parties, both groups, to do that.

G5: I think I am here because I like my village I'm living in, you know, and I'm here to benefit that society up there for so everyone, you know, what we're doing will help. Not for myself, not for my wife, not for my children, but for everyone, you know, for society as a whole. For each village along the Kuskokwim, in the Yukon, or down the coast. To learn how to help, let, make them understand, you know, what the researchers are doing. How we can help them, you know, to better themselves.

R5: I guess sort of responding to – if there's researchers who are going around asking people for some of their blood,

C1: Yes. Yeah. Yes.

R5: and taking it away

C1: Right.

R5: And doing something with that blood, as researchers, they should be thinking, “Gee, those people deserve to understand what’s going on with their blood.” So our – this project grew out of that idea, from my understanding. So what would you want to know about what these people are doing? And what do you want to know about what they’re doing with the blood? And then that raises all these other questions, because the answer to that question from the researchers’ side involves thinking about the biology and all these technical things. And from the community side, it involves getting past understanding specifically what a gene or genetics is and thinking about what you want or don’t want done in your communities for research, whether, you know, the research is useful in some way, or something that you support, for future generations, if not for now. So that’s why we get kind of hung up on this question of, do we have to spend a lot of time thinking about what genetics is, and how to say the word or whatever, or is, or can we move around that in some way to get to the community issues of how you feel about having research done, and what you want and don’t want.

R4: And the other part, just to add to what I was talking about, is that this is a long-term process. This isn’t us just going out once or twice or three times. We look at this as a long-term partnership, for years and years, we hope. And that we want this to change and work, and we want to be able to talk about the needs of the community and to benefit the community, and, and, and to learn from the community about it, because we don’t know everything, you know, we learn a lot from communities when we’re out there [in the villages]. And we hope that you learn from us. And so it’s a process, a long-term process, and there’s no clear end, you know. So we want to be able to have that dialogue, and we want to be able to talk with community, and make sure they have their questions answered and they know how to ask those questions.

As this excerpt demonstrates, participants at this point in the partnership have several vastly different ideas about the purpose of the partnership, their respective roles, and their personal

motivations for deciding whether to invest their time, energy, and for some – as G2 comments later – a day or two’s pay in these conversations.

As construed by the researchers (R4 and R5 in the above example), the Yup’ik partners’ primary role was to provide insight into the values and preferences of Yup’ik people with respect to genetic research and the communication of information about research progress (“what you want or don’t want done in your communities”), as well as to build a foundation for future research in the Y-K Delta (“We look at this as a long-term partnership”). Some of the Yup’ik partners seem to have other, potentially complementary, ideas: G5 was interested in helping community members understand the purpose of research and encouraging them to participate, on the rationale that research is beneficial to the health of future generations across the region.

Some participants also highlighted questions of ethics and self-determination at the individual and community level. In the excerpt above, for example, R4 points to the ethical obligation of researchers to communicate clearly with research participants and communities about progress and results, while R5 and C1 implicitly refer to the need for prospective study participants to be fully informed about the details of research to which they contribute (“those people deserve to understand what’s happening with their blood”). Similarly, in Meeting 6, R6 says, “Where I come into this conversation is in trying to understand what researchers at the universities should be doing. What is our responsibility, to be responsible partners?”

The main topic of explicit re-negotiation that emerged through the thematic analysis concerns the role of the CPG in communicating about research in their home communities. In the excerpt above, C1 commented, “[H]ow do we disseminate that knowledge, once we understand what it is that we come here to do?” The comment was not directly addressed in Meeting 3, but it suggests an understanding that one possible role for the CPG would be to serve as research

ambassadors or peer educators in their respective villages. In subsequent meetings, occasional comments from CPG members seemed to indicate that this was their expectation and perhaps even their preference.

Despite these earlier mentions, the issue was not taken up by the investigators until Meeting 6. Early in Day 1 of the meeting, R2 said, intending reassurance, “We’re not going to ask G4 and G5, ‘Ok, now at the end of the meeting I want you to go back to [community], and I want you to tell them these things.’ That’s not what we’re asking, but rather to have a dialogue and say, ‘You know, I think this, would people be interested in [hearing about] this?’” Later in the meeting, however, the Yup’ik partners made a direct request for the investigators’ help in preparing them to provide outreach and education to their friends and family:

- C1:** I’m sure lots of us feel this way, you know. We come here, we see everybody, we return to that page where we feel really comfortable and we’re excited about pharmacogenetics, obesity, cardiovascular disorders, um and diabetes. We know this because we feel safe talking here, but then when we leave (*pause*), we don’t know who to talk to. And I think the message we’re getting from our esteemed Elders is, “How do I gain that ownership so I could go home and talk to my community? Because this is really critical for our health as Yup’ik people. What do I need? Give me a toolbox so that I could open it up and share it because, you know, our people are getting sick, or we could get better.” And [[they are asking, “Show me how. Show me what it is that I need to do so that um when I do read I feel that same energy that I get from here, so that I could save lives.”]]
- G4:** I’ve been a teacher for many years and I – it takes lesson planning and thought and preparing, so you don’t misinform your students of things. So, I think that my fear in telling the community would be limited – I’m not going to tell the whole thing about not knowing what genetics is, even though I have an idea. If I meet with groups, little group at a time, or G5 and I can, um we might do it, you know, but not the whole community, where they might throw questions at me and I, I wouldn’t be able to answer. So, I need to know what I’m talking about first before I feel comfortable enough to pass the message.

Several members of the CPG joined in to endorse the idea that the group should work on developing resources they could use to discuss research in their home communities. C1 continued to emphasize that sharing this information could play a role in improving the health of Yup'ik people. R9 asked for confirmation:

(struggling with pronunciation of the Yup'ik word requesting permission to ask a question) Apyutkangqertua-ish. Um, I feel like I'm, I might be confused about this, so please help me. I think we, the research team has been saying, "Please don't worry. It's not your job to go out and explain this." But I think maybe what you're telling us is, "We can. We want to. You [should] help us do that." I think we've been thinking, "How do we researchers go into a community and explain this?" And I think what you're saying is, "You teach us, and we will teach the community." Is that right? Am I understanding that right?

G4 indicates that she would not do so without permission from the investigators: "Well . . . My thought has been that we don't move until you guys tell us to move. I think that's what I've been thinking all along." Providing the researchers the opportunity to develop their political understanding, C1 amplifies the G4's point about power:

C1: I think we're still holding on to those, um, the historical – we have, you know, procedural display "They say, we do,"

R8: Yeah.

C1: "Yes, sir," you know, kinds of things, because we were institutionalized. And there's some fear and some angst and some, you know, feeling uncomfortable

G4: Yeah.

R9: Mmm

C1: because even though we're friends here, and we respect everybody here, there's still this element of authority and victim um going on in, in, in, in any, in any setting when, when we're talking about, um, new things or outside things, and we want to make sense of them, but we're still scared to ask. And I think what I'm wanting to say here is, we could go beyond that today. [[If we have questions, ask these]] researchers [[and don't be shy. We have been talking a long time about]] pharmacogenetics

[[this past year. If we don't know what these are, don't be shy to ask them, and they will help us. If we don't ask, we won't learn.]]

The renegotiation of roles with respect to community outreach was not fully resolved during the timespan covered by the available data. In Meeting 9, for instance, one of the Ciuliat shared an exchange she had with a CPG member, G10, who was not present. C4 commented that G10 took detailed notes at each meeting and said, “She always, always voices here, ‘What can I tell the people at home who are asking me [about research]?’ She just can’t wait to, you know, be free to do that.” Although this is not a firsthand report from C10, and C4 did not specify what kept C10 from “being free” to share information with her community, C1 and C4 shared the impression that C10 wanted to play a more active role in outreach but did not feel able to do so. It is unclear whether the barrier was permission from the researchers, a better understanding of the information to be conveyed, or something else.

Sociohistorical Context and Politicized Trust

An element of developing relationships within the partnership was the Yup'ik participants' sharing of stories and experiences as a way of educating the investigators – a key step in the development of political understanding and politicized trust. Yup'ik participants in this partnership were not naïve to research: all the CPG members had participated in prior health research with CANHR, and the Ciuliat had past educational and/or professional experience with research in their respective fields. Community members had also been exposed to research in other contexts, including anthropological research and interactions with “agency people” overseeing wildlife and natural resources management on behalf of state or federal governments.

Yup'ik participants also spoke of their own lived experiences – often negative – in the context of education, research, and healthcare. Some had directly experienced the phenomenon

known as “helicopter research,” in which researchers visit a community, take data and samples, and are never heard from again. For example, at Meeting 3, C4 commented, “One thing that I remember [from when I was growing up] is they always want to come and learn about us. Us being [Yup’ik], [they took] our blood, our hair . . . they measured our heads, you know. (*laughs*) But nobody ever comes back and tells us what we’re like, how it is it turned out, or what.”

Yup’ik partners also described lacking access to timely medical care, receiving substandard care, and being subjected to racial discrimination in government-run institutions. In one instance, C4 described being assigned to escort children to the nurse’s office to be vaccinated: “I had to go get them [from their classroom], and we’d all walk down to get a shot together. Nobody gained permission from the parents. And so that was the deal. Why are you not – even someone like my parents, who are not educated, but they know somebody did something to them, and they don’t know why.”

The CPG and Ciuliat said that experiences like these continue to color the views of many Yup’ik people today. Reflecting on when CANHR first came to her community, G1 said in Meeting 1, “Even back home [in my village], they were – including my dad – some Elders were saying they didn’t want to participate, when you guys first came. [People] I who I was asking to come with me to participate. And I’ve heard that they didn’t want to be guinea pigs. I told them, ‘It’s not that.’”

Yup’ik community members’ perceptions were also shaped by experiences of what might be termed everyday racism. For example, in Meeting 3, in discussing community focus group results, it came up that participants in one of the focus groups had mentioned a Discovery Channel episode about the evolution of different forms of transportation. It showed footage of foodstuffs being packed for emergency hovercraft delivery to a community on the Y-K Delta,

accompanied by commentary to the effect that without this intervention, the village would starve.

The focus group participants had expressed anger and frustration with this representation of

Yup'ik people, as did the Yup'ik participants in the partnership:

- G2:** (*small laugh*) I watched that [TV show] and I said, “What the heck are these guys – why do they have to say that on the national whatever it is?” We’re not starving, and [I don’t understand] why they had to make it that way. I was visualizing the world out there that was watching it, and the message that they were delivering in saying and giving the impression that – this is a miscommunication. We’re not hungry. We’re not starving.
- C4:** . . . [T]hat’s stigmatizing, to say you can’t provide for yourself and you don’t have enough food.
- R4:** And the thing is, the food in your freezer is probably a lot healthier than the food they were putting on the plane!
- C3:** Exactly.
- G5:** . . . I don’t buy meat from the store. In my freezer, I’ve got a little piece of *muktuk* [whale blubber]. I’ve got seal, moose from Yukon, moose from right down the river, caribou, frozen fish, white fish.

C3 explicitly distinguished between this kind of outsider stereotyping and the approach of the partnership, commenting:

I think this [way of doing research] is very new, R4, because researchers have never included communities and the population, you know, and the focus groups. So that’s, what they were saying [on the Discovery Channel], it’s like, here are these people talking about [us], and their conclusion was this. But they don’t know anything about our freezers and what’s inside of them. What did they conclude? That we’re going to starve.

Moments of Resistance

In addition to explicit pushback from the CPG and Ciuliat against inaccurate representations and perceptions of Yup'ik people in the dominant society in general, the data also contain moments of resistance within the partnership itself. Most of these challenges were oblique, in keeping with Yup'ik norms of conflict avoidance. For example, G6 told the

investigators that once they wrote down what the Elders said, it could be validated as real knowledge. This remark was made in a teasing tone, but it also contained a serious critique of both the western-scientific privileging of written communication over orally transmitted knowledge and the systematic discounting of Indigenous Elders' expertise and knowledge.

In another such instance, G9 related the Bible story of the Tower of Babel. The people had decided to build a tower to the heavens and were feeling very proud of themselves. God became angry with their effrontery, and to punish them for their disrespect, took away their shared language, making it impossible for them to understand one another. G9 added his own punchline, saying that if humans had not been so arrogant, we would all still be (speaking) Yup'ik. Again, this was said in a joking way, and everyone laughed; but the comment carried an implicit reproach of ambitious humans striving beyond their proper (God-given) boundaries. It also indicates that Yup'ik people were not included in the reproof – either from God, or from G9.

A more direct moment of resistance occurred at the end of Meeting 4. The group had previously established a norm of closing with a circle, in which each person had the chance to share something they had learned, were taking away, or had a question about. As the group settled into the circle, C3 asked G9 whether he wanted to ask his question or would prefer she do it. He told her to go ahead:

C3: G9 had a question for you non-Yup'ik ones. What have you learned from the past two days? He goes, "OK, we're not going to be the ones to answer that. We'll ask them too." (*laughs*)

C5: I think he was saying that we, he shouldn't have to answer that question, but you should, you know, be asked what have you learned from them. (*laughs*)

Someone: (*Yup'ik name given to R9*) You start.

R9: OK. (*laughs*)

- C4:** Tell us a story.
- R9:** Tell you a story.
- C4:** About what you learned.
- R9:** What have I learned. I was telling R5 and R1 last night that I'm working on a different project, where I was working with another researcher and we were doing focus groups. And there was one man in that group who came, and he talked a lot. And the researcher I was working with said, "He's talking a lot, but he's not answering our questions." And I thought about what I've learned here from you all, and I thought, "He *is* answering our questions. We have to listen and understand how that story is an answer to the question we're asking." She was frustrated with this one person, because she would say, "What do you think about this?" and he would tell a story about something else. And I think because of the time that I've spent here, I was listening to his story and looking for how I could understand better what he was saying. Instead of, "*You* didn't tell me what I want to know," (*laughs*) which is how I think, um
- C3:** Used to do.
- R9:** I think I used to do that. I used to think about it differently. So *quyana* to this group, because I think I have learned how to listen differently That's what I learned. *Tua-i*.
- C3:** (*to R3*) [G9]'s looking at you. (*laughter*)
- R3:** I learned from what you all shared and what G9 said yesterday. I learned that, and I felt this at the last meeting too, that when G5 was guiding us through [the closing circle] and G9 said these wise words during that process too, it just feels like our Elders are guiding us towards that solid foundation that we're building together. So I felt thankful that we had that guidance from them and to learn a lot from slowing down and how we've slowed down and are able to learn from that. (*laughter*)
- R4:** (*to G9*) Are you looking at me? (*laughs*)
- G9:** (*Chuckles*)
- R4:** So, I think the discussion today talking about naming and respect was really enlightening for me that I learned a lot about, that the naming, I had been familiar somewhat with the naming process,

but the idea of, that those names were a level of respect for those people, and the way you explained respect but maybe in a different way than what we think about in English to me was good.

C5: Who's next?

Someone: R7.

R7: Um (*pause*) I think it's been helpful having the Yup'ik folks lead us in speaking from the heart and remembering that the mind will follow, that it's OK to do that.

R5: I've been thinking a lot about (*pause*) that story that G9 was telling about being out on the ocean and knowing your expectations and benefiting from wisdom and experience and paying attention so that you won't get lost . . . and on a totally different level, I really liked C1's use of the walnuts or oranges [in a teaching exercise]. I think that's a really, just a really good idea.

R1: Well, I'll speak from the heart and say that I just feel very blessed and fortunate to be here and I've learned how kind and wise and funny this group is. I feel very welcomed and I appreciate that very much.

C3: (*to R2, teasing*) Well?

R2: I learned how to *pukuk* [pick the bone clean, referring to lunch] (*laughter*)

C3: Too easy! (*laughter*)

R2: No, seriously, I learned when C1 and others were talking about agency and asking one question at a time, I – it will be different every time I ask (*speaking in a rapid-fire way*) one question after another and another. So I learned a lot about that, and respect, and sharing agency, and I appreciate that. I learned a lot of things. I learned I like seal intestine. (*laughter*)

G9's question flipped the implicit power dynamic in the group, highlighting the way in which a group norm established by the research team based on their understanding of a Yup'ik custom (the closing circle) had positioned the investigators as experts and evaluators and the CPG and Ciuliat as learners subject to evaluation. From the way C3 began ("Do you want me to ask

them?"), it appears clear that this intervention had been discussed by at least some of the Yup'ik partners beforehand. Although this conversation could have led to a higher-level discussion about roles and learning, it did not; nor was the role reversal repeated in later meetings. However, several of the Yup'ik partners expressed appreciation for the group and the way the researchers were approaching the work, as in this comment from C3:

I want to thank the researchers, because [you're] bringing together such a group, which has never happened before. For anyone, I don't think. It's always been, "Someone's here, and they're coming in, we'll give you this, here. This is the doctor. We're going to teach you, and this is how you [need to] live your life." And this is inclusive of communities that you research. An example of how things should be [done] when you're coming into a population that may not be in the scientific realm or whatever. So this is great, thank you.

Epistemic Network Analyses

The results of the ENA analyses are presented below. Co-registration correlations for each analysis are shown in Table 5.

These measures indicate that there is a strong goodness of fit between the visualization and the original model for all models except 3 and 4.

Table 5. Co-Registration Correlations

Model	Dimension 1		Dimension 2	
	Pearson	Spearman	Pearson	Spearman
1	0.96	0.97	0.97	0.97
2	0.96	0.97	0.97	0.97
3	0.90	0.97	0.93	0.94
4	0.89	0.91	0.97	0.97
5	0.96	0.96	0.98	0.97
6	0.99	0.99	0.97	0.97

In the network graphs that follow, nodes (black dots) represent codes. The size of each node represents its relative frequency in the data. Lines (edges) between nodes represent connections between codes, with heavier, thicker lines indicating stronger connections. The centroid of a network graph (the central square) represents its center of mass, summarizing the entire network of connections as a single point.¹¹⁶ The box around each centroid represents its confidence interval.

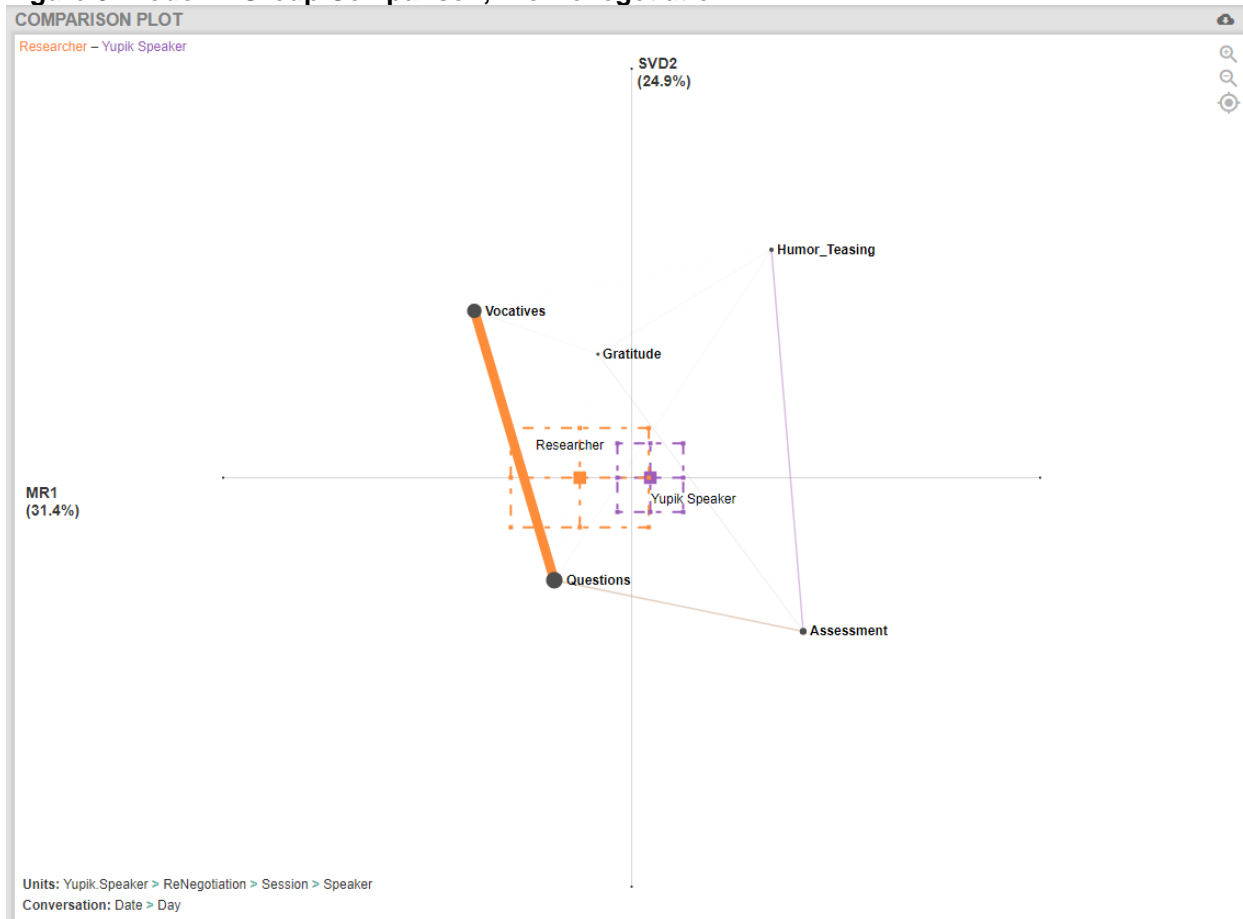
Model 1: Yup'ik and Researcher Discourses in the Pre-Renegotiation Phase

The comparison graph for Model 1, the comparison of Yup'ik (purple) and researcher (orange) discourse in the pre-renegotiation phase is shown in Figure 3. Along the X axis (MR1), a Mann-Whitney test showed that Yupik Speaker (Mdn=0, N=25) was not statistically significantly different at the $\alpha=0.05$ level from Researcher (Mdn=-0.51, N=9 U=65.00, $p=0.07$, $r=0.42$). Along the Y axis (SVD2), a Mann-Whitney test showed that Yupik Speaker (Mdn=0.02, N=25) was not statistically significantly different at the $\alpha=0.05$ level from Researcher (Mdn=0.18, N=9 U=112.00, $p=1.00$, $r=0.00$).

Consistent with the “forming” stage in Tuckman’s model, in which group members seek to establish rapport and avoid conflict, communication patterns were very similar between the two groups in the pre-renegotiation phase.¹ The link between questions and vocatives for researchers was the strongest connection in the network overall (heavy orange line), and much stronger for researchers than for Yup'ik partners. This may reflect differences in communication norms, insofar as “singling out” an individual and asking direct questions are more acceptable in the dominant culture. Researchers also made more frequent connections between questions and assessment than did Yup'ik partners. Compared with researchers, the Yup'ik group made stronger connections between humor and assessment, assessment and gratitude, and gratitude and humor.

Examination of the underlying data shows that the link between vocatives and questions for both groups was utilitarian in the pre-renegotiation phase: names were used to direct questions to a particular individual. In these early meetings, partners were learning each other’s names getting to know each other, leading to frequent use of vocatives. Researchers generally

Figure 3. Model 1: Group Comparison, Pre-Renegotiation



used vocatives together with questions and assessments in a utilitarian manner, for example, to ask whether a particular person would be joining the meeting, to address questions to specific individuals (e.g., R8 asking, “C5, what is the Yup’ik word for cardiovascular?”), or to poll the CPG members (for example, about when they would be free for the next meeting). They also used vocatives to link ideas expressed by different participants and to create scenarios to make didactic examples more relatable, as in this example from R2:

So what R8 is trying to say is if, G4, you fall right here (*pointing to graph*) in the amount [of food from the ocean, such as fish and seal], that can – our hypothesis – our idea is that your blood is going to take a little bit longer to clot, than if I’m down here (*pointing to drawing*), that amount, just because of the food from the ocean. This would be information your physician could use to come to the right dose. What R8 is saying is, if this is the amount that you eat generally, and you have to now take warfarin, what physicians tell you is, “Don’t change what you

eat. Don't suddenly drop down to eating no food from the ocean and just get food from the market." Ok? Does that make sense?

Yup'ik speakers used vocatives more sparingly, but also in a utilitarian way, generally in connection with a clarifying question for one of the researchers.

The use of humor in the pre-renegotiation phase tended to be somewhat impersonal, typically concerning either situational topics or friendly acknowledgments of Yup'ik-kass'aq cultural differences. In the first category, examples included joking about wanting to dance to C3's rock-and-roll cellphone ringtone, a local air carrier losing someone's luggage, and whether signing the CANHR photo release would guarantee participants their "minutes of fame." Examples of the latter included gentle teasing about the difficulty kass'aq partners had in trying to pronounce Yup'ik words (and encouragement to keep trying); whether particular researchers would qualify as Elders (as a joke about age and wisdom); and whether kass'aq partners could live by the traditional "wise words" handed down by Yup'ik elders (e.g., G9 asking R2, "All those rules, can you follow them?" and R2 responding, "G3 is going to keep me straight on my rules.").

Model 2: Yup'ik and Researcher Discourses in the Renegotiation Phase

The comparison plot for Model 2, renegotiation, is shown in Figure 4. Along the X axis (MR1), a Mann-Whitney test showed that Yupik Speaker (Mdn=0.23, N=33) was statistically significantly different at the $\alpha=0.05$ level from Researcher (Mdn=-0.44, N=24 U=117.00, $p=0.00$, $r=0.70$). Along the Y axis (SVD2), a Mann-Whitney test showed that Yupik Speaker (Mdn=0.21, N=33) was not statistically significantly different at the $\alpha=0.05$ level from Researcher (Mdn=0.33, N=24 U=419.00, $p=0.72$, $r=-0.06$).

Compared with the researchers, Yup'ik partners (purple) made more connections between humor and questions, questions and assessment, assessment and gratitude, and gratitude

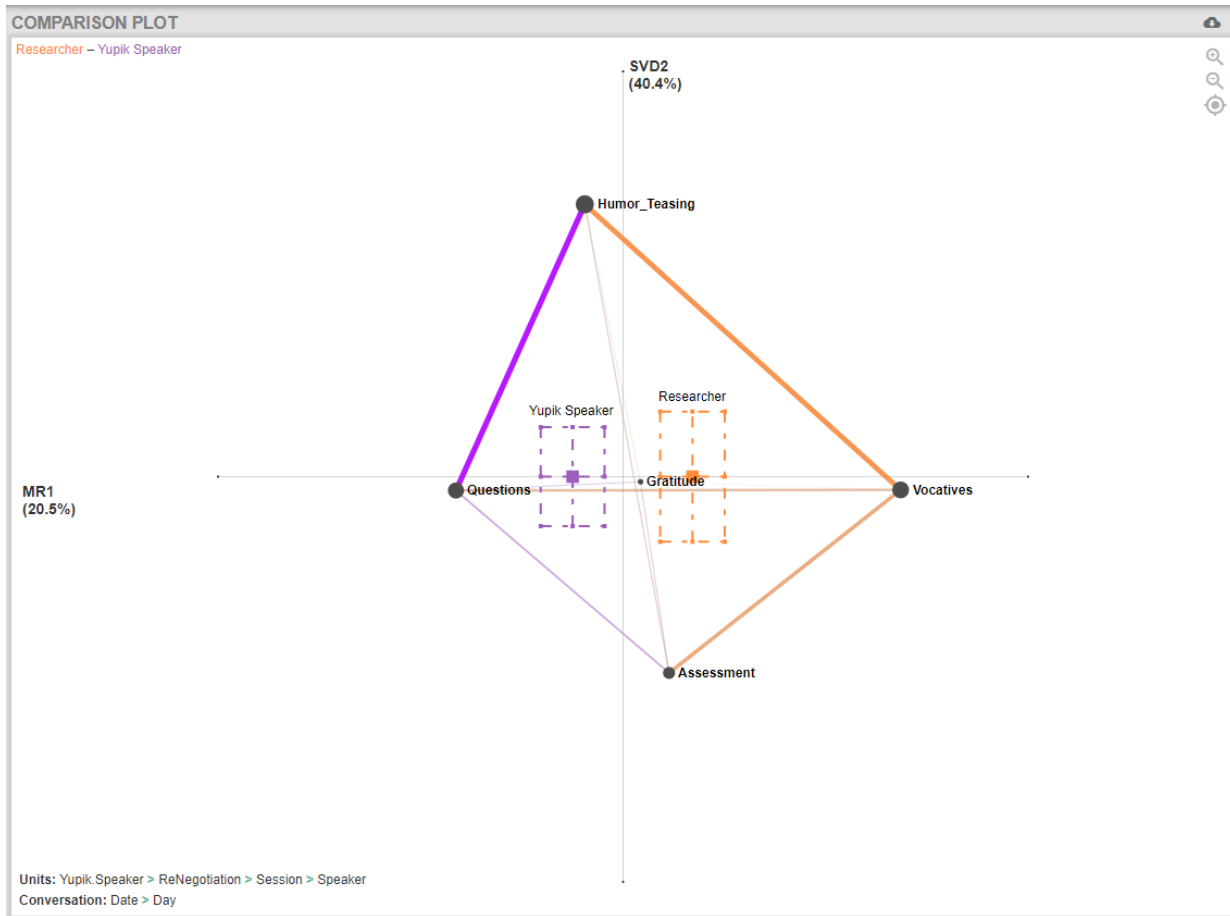
and humor. Researchers (orange) made more connections between both vocatives and humor and vocatives and assessment; there are very few connections to gratitude.

Revisiting the underlying data reveals that the association between humor and questioning in the renegotiation phase results from two main discursive patterns. Both Yup'ik and kass'aq partners used humor to support relationality, as well as to diffuse tension or express discomfort in moments of potential conflict. As illustrated in the Meeting 4 closing circle described above, in which G9 turned the tables and asked the researchers to explain what they had learned, humor sometimes signified unease. Humor was spread throughout that exchange, but it was used differently by different participants: the researchers used it to self-deprecate or diffuse tension (e.g., R4 asking G9, "Are you looking at me?"), while the Yup'ik participants teased the researchers (e.g., C3's prompting R2, "Well?").

Similarly, during the discussion of G4's request for lesson plans, C1 raised his hand and imitated a child's voice when he addressed a question to G4, a retired educator, as "Mrs. [G4]." The group laughed together, and the joke was quickly taken up by the rest of the group – e.g., with teasing requests for hall passes – as the conversation went on. This conversational move accomplished several things. It broke the tension and brought everyone together in laughter, which allowed the group interaction to continue in a way that did not break Yup'ik norms of conflict avoidance. Positioning G4 as the teacher in the room, it also highlighted G4's standing as a person with relevant expertise while representing C1 and the rest of the group as learners.

During more didactic presentations, researchers often used humor in a disarming way, as when R2 joked about his "hairy knuckles" as he wrote on a transparency that was projected onto a large screen, inviting (and receiving) teasing from the group. These conversational moves were

Figure 4. Model 2: Group Comparison, Renegotiation



a way for researchers to undercut their own positional power and convey humility and openness. These instances were related to two kinds of questions: clarifying questions (from the CPG and Ciuliat, but also from investigators asking questions on behalf of the group) and questions from the investigators to check on whether what they were saying made sense to the group.

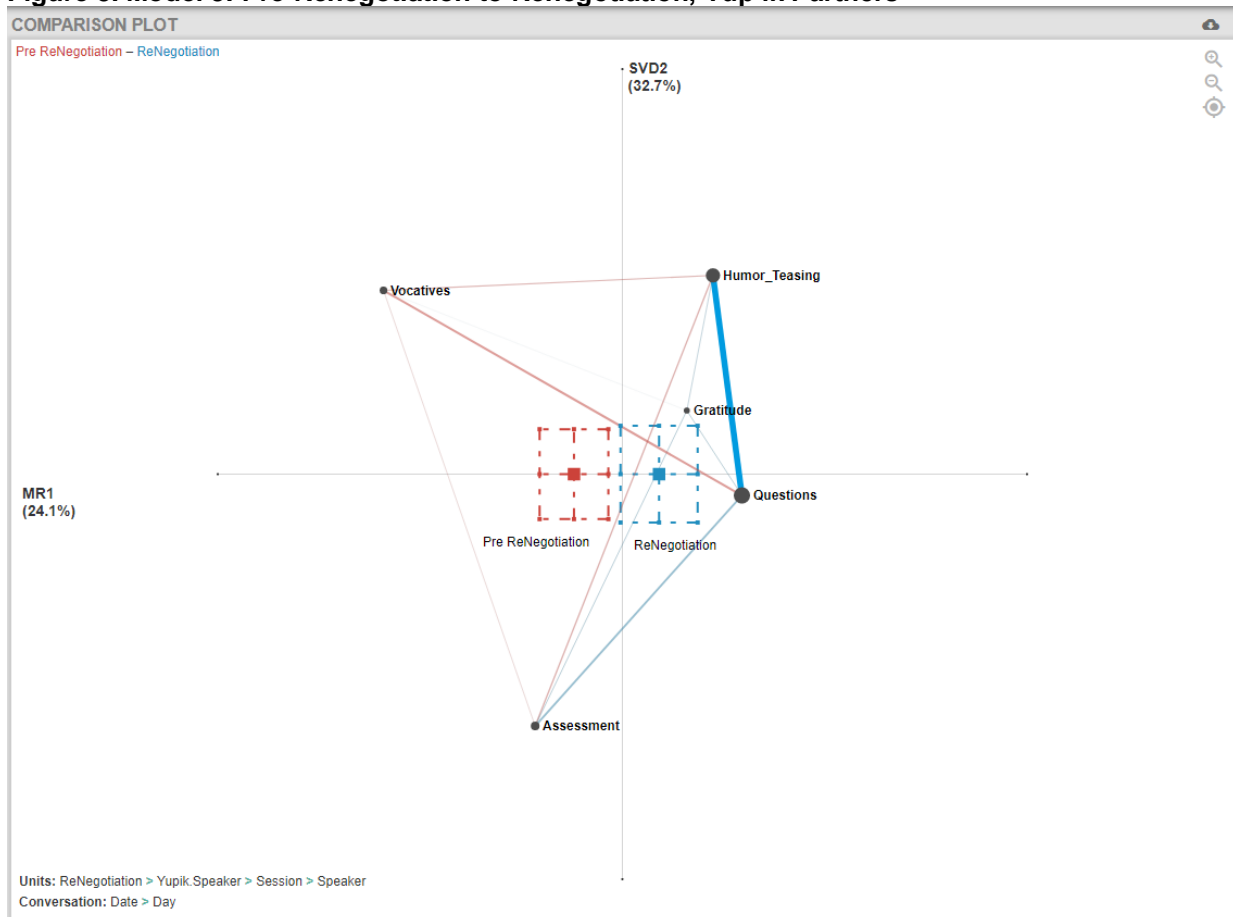
More generally, humor in the renegotiation phase tended to be more revealing of individual partners' feelings and was often directed to specific individuals, compared with the pre-renegotiation phase. There was more good-natured teasing of individuals (e.g., a running joke about C3's having had herring eggs stuck in her teeth after lunch) as well as more back-and-forth teasing between Yup'ik and kass'aq partners. For example, in a small-group discussion, C1 commented jokingly, "You guys are too much" and R9 responded, "*We're* too much?!"

Models 3 and 4: Shifts in Yup'ik Partners' Discourse

For Model 3, along the X axis (MR1), a Mann-Whitney test showed that Pre ReNegotiation (Mdn=-0.09, N=25) was statistically significantly different at the alpha=0.05 level from ReNegotiation (Mdn=-0.01, N=57 U=889.00, p=0.08, r=-0.25). Along the Y axis (SVD2), a Mann-Whitney test showed that Pre ReNegotiation (Mdn=0.03, N=25) was not statistically significantly different at the alpha=0.05 level from ReNegotiation (Mdn=0.15, N=57 U=731.00, p=0.86, r=-0.03).

The comparison graph for Model 3 (Figure 5), depicts the comparison of Yup'ik partners' connections in the pre-renegotiation phase (shown in red) and the renegotiation phase (blue). In the pre-renegotiation phase, the strongest connections made by Yup'ik participants were between

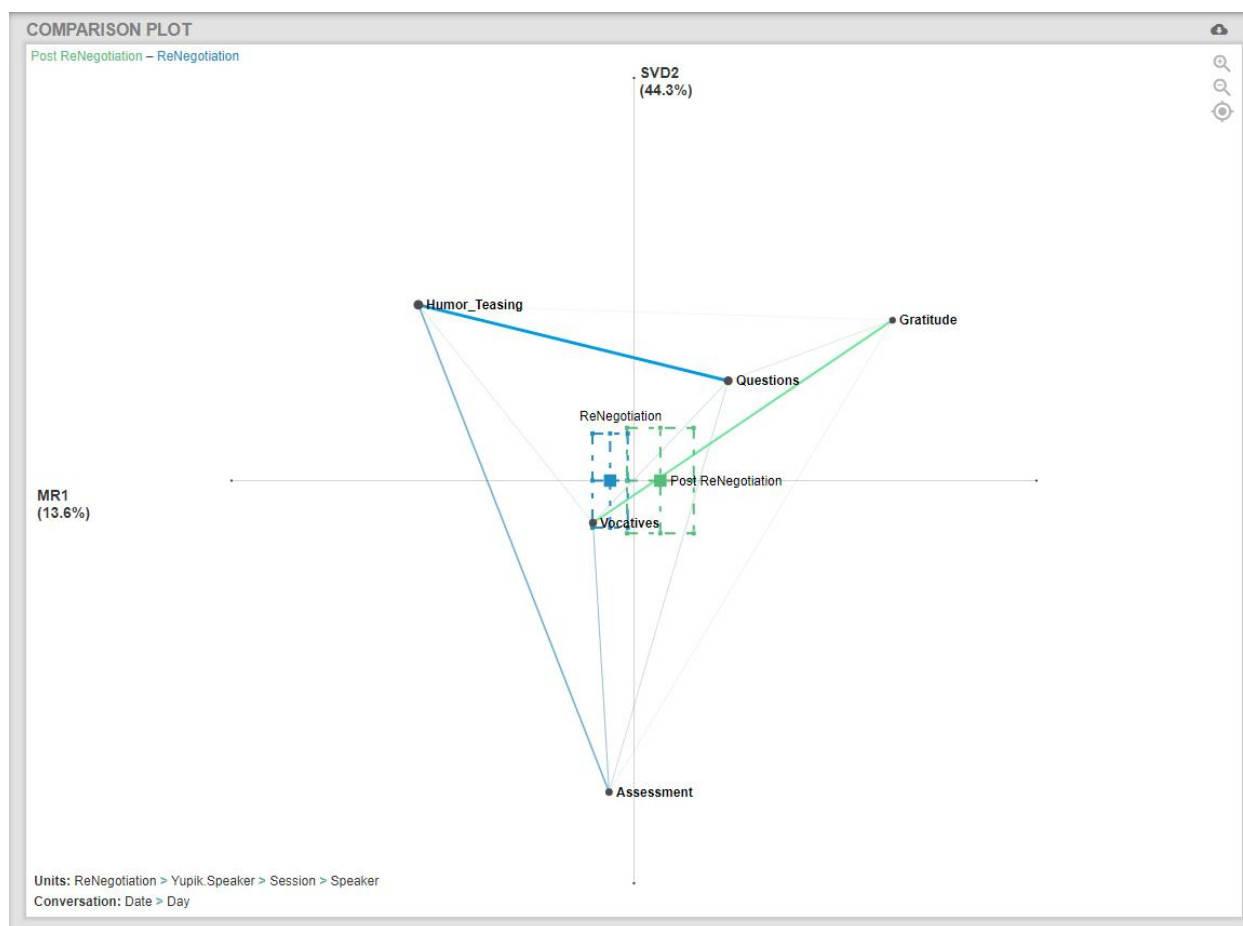
Figure 5. Model 3: Pre-Renegotiation to Renegotiation, Yup'ik Partners



questions and vocatives (for the reasons outlined above) and humor and assessment. Weaker connections existed between humor and vocatives, and vocatives and assessment. As shown, the biggest overall difference between the phases among Yup'ik partners was in the strong connection between questions and humor in the renegotiation phase. In the renegotiation phase, Yup'ik participants also made stronger connections between humor and gratitude, questions and gratitude, assessment and gratitude, and questions and assessment.

Model 4 (Figure 6) compares the Yup'ik partners' discourse patterns between renegotiation (blue) and post-renegotiation (green). Along the X axis (MR1), a Mann-Whitney test showed that Post ReNegotiation (Mdn=-0.18, N=30) was statistically significantly different at the $\alpha=0.05$ level from ReNegotiation (Mdn=0.19, N=33 U=667.50, $p=0.02$, $r=-0.35$). Along the Y axis (SVD2), a Mann-Whitney test showed that Post ReNegotiation (Mdn=0.17, N=30) was not statistically significantly different at the $\alpha=0.05$ level from ReNegotiation (Mdn=0.22, N=33 U=471.00, $p=0.75$, $r=0.05$). The stronger presence of humor and teasing during the renegotiation phase provides additional evidence that humor and teasing were an important element of the Yup'ik partners' attempt to maintain positive interactions with the researchers, while simultaneously working to renegotiate power relationships within the partnership.

Figure 6. Model 4: Renegotiation to Post-Renegotiation, Yup'ik Partners



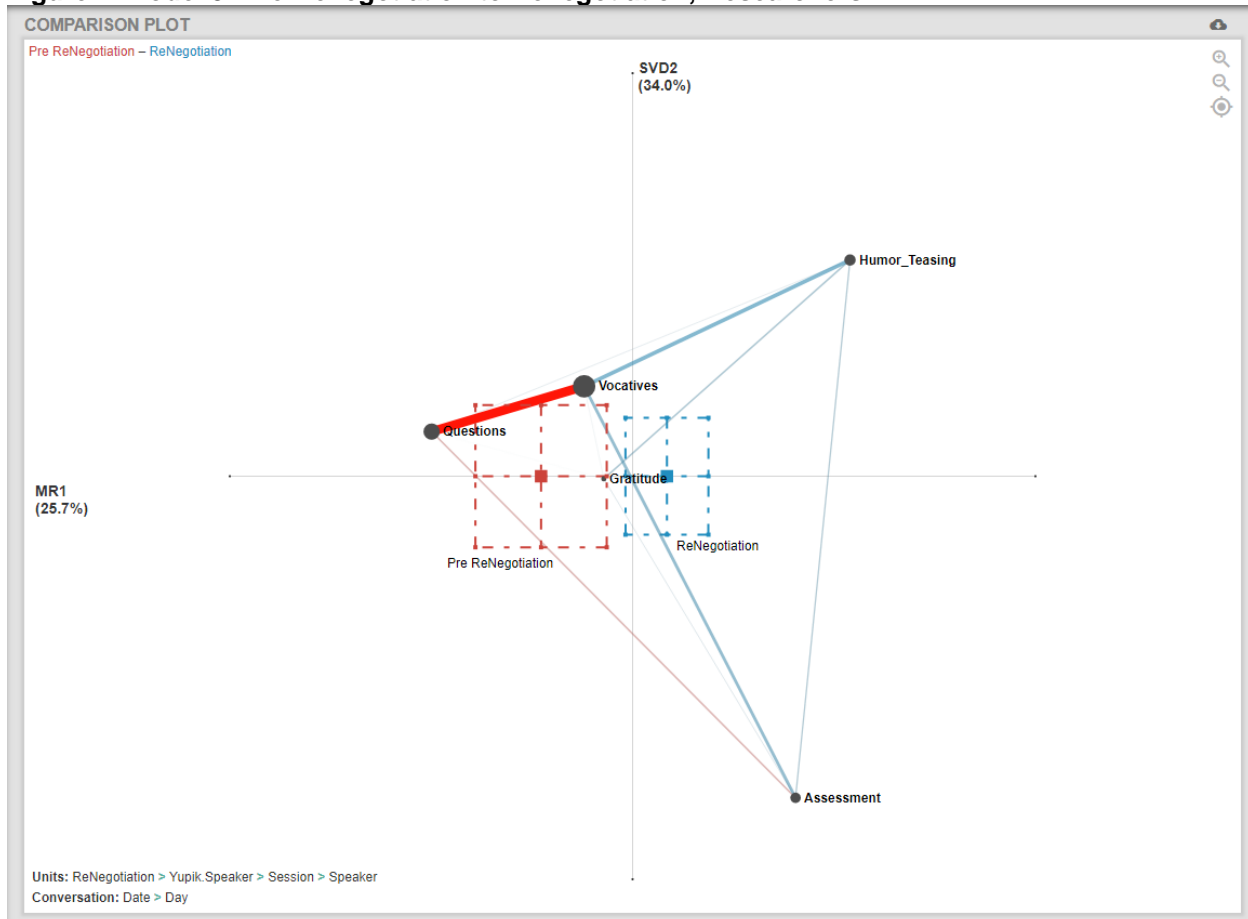
In this model, the connection between gratitude and vocatives is stronger in the post-renegotiation phase. There is also a higher frequency of expressions of gratitude in this phase more generally, perhaps in the nature of repair following the more uncomfortable renegotiation phase. For example, in Meeting 10, G2 commented,

I guess I've been the most vocal-est of our group, I mean the meetings that I've attended, I feel like I've been talking too much, [[but it's ok]]] [[I'm thankful]] that, you know, this is the most active (*gestures around the circle*), I really like, I really enjoy being with this group, you know, a lot of interaction and everybody's, I feel like being listened to and I'm able to say, ask questions openly with this genetic thing.

Models 5 and 6: Shifts in Researchers' Discourse

Model 5 (Figure 7) compares researchers' discourse patterns in the pre-renegotiation (red) and renegotiation phases (blue). Along the X axis (MR1), a Mann-Whitney test showed that Pre ReNegotiation (Mdn=0.54, N=9) was statistically significantly different at the $\alpha=0.05$ level from ReNegotiation (Mdn=-0.04, N=24 U=179.00, $p=0.00$, $r=-0.66$). Along the Y axis (SVD2), a Mann-Whitney test showed that Pre ReNegotiation (Mdn=0.21, N=9) was not statistically significantly different at the $\alpha=0.05$ level from ReNegotiation (Mdn=0.29, N=24 U=93.00, $p=0.56$, $r=0.14$).

Figure 7. Model 5: Pre-Renegotiation to Renegotiation, Researchers

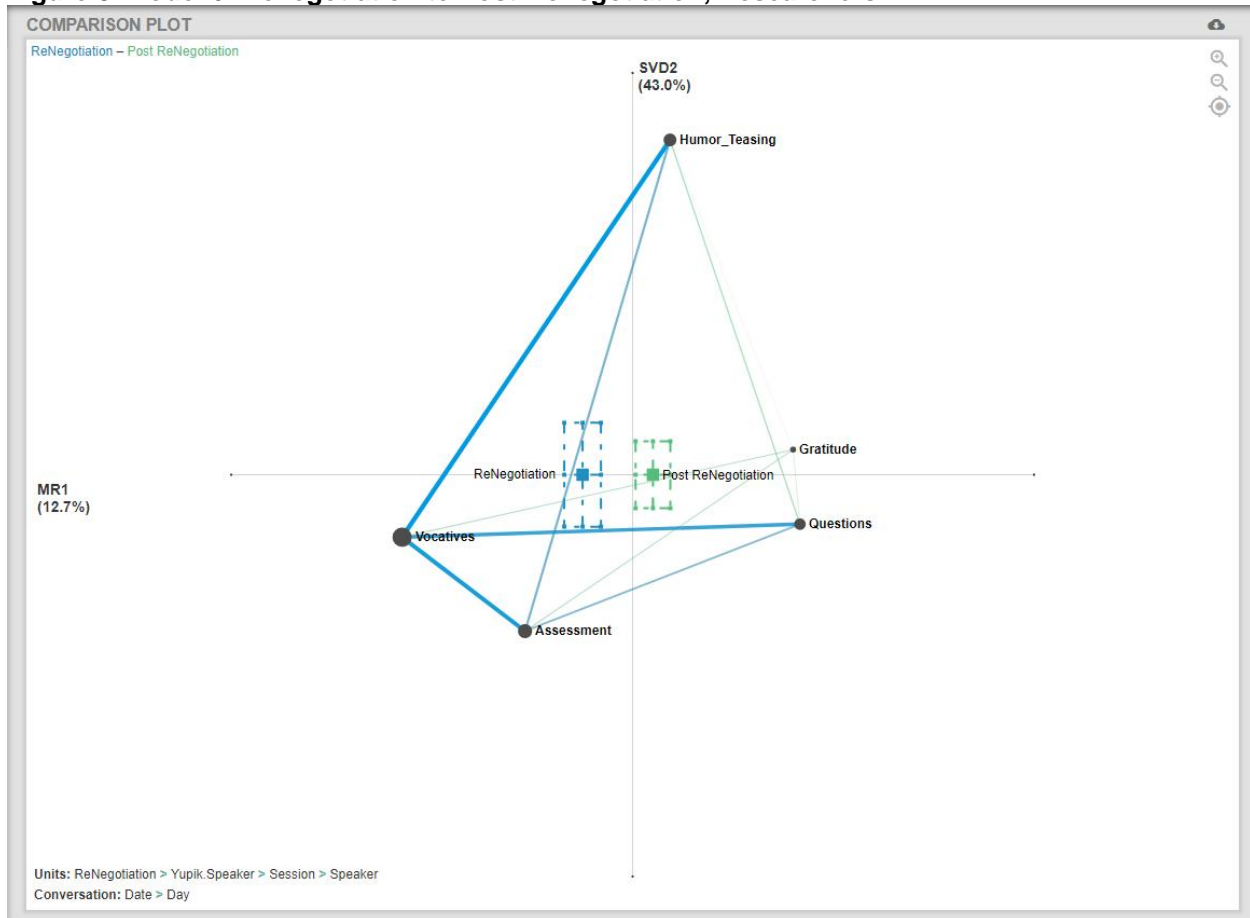


Researchers' strongest connection in the pre-renegotiation phase is between questions and vocatives, consistent with the utilitarian use of names to direct questions to individual

participants. In the renegotiation phase, stronger connections emerge between vocatives and humor, consistent with the use of humor to dispel discomfort during the storming phase of group formation.

Model 6 (Figure 8), shows the comparison between renegotiation (blue) and post-renegotiation (green) speech among researchers. Along the X axis (MR1), a Mann-Whitney test showed that Post ReNegotiation (Mdn=-0.41, N=15) was statistically significantly different at the alpha=0.05 level from ReNegotiation (Mdn=-0.20, N=24 U=248.00, p=0.05, r=-0.38). Along

Figure 8. Model 6: Renegotiation to Post-Renegotiation, Researchers



the Y axis (SVD2), a Mann-Whitney test showed that Post ReNegotiation (Mdn=-0.11, N=15) was not statistically significantly different at the alpha=0.05 level from ReNegotiation (Mdn=-0.17, N=24 U=190.00, p=0.78, r=-0.06).

Researchers' connections between vocatives and questions and questions and assessment are stronger in the post-renegotiation phase compared with renegotiation, as are links between vocatives and assessment and gratitude and questions.

DISCUSSION

My central interest for this study was to explore how relationality and co-learning unfolded over a six-year period near the beginning of the partnership, and what might be the relationship between these phenomena. Informed by several close readings of the transcripts and my own notes, I was struck by the process of role negotiation between the Yup'ik participants and the investigator team. I also wanted to explore the potential of ENA to identify and characterize latent patterns in a large longitudinal corpus of qualitative data.

Key Findings

The findings of these analyses are consistent with the central tenet of critical discourse analysis, i.e., that individuals use language to accomplish political and social goals. The changing use of humor over time and between groups is especially interesting, suggesting its strategic utility in maintaining good relations in moments of tension and challenge. It may be the case that Yup'ik partners initiated this use of humor and the researchers followed. Subsequent models could examine smaller stanza windows, which would enable more detailed examination of the interplay between groups.

A key element of equitable collaboration involves positioning research as a process of equity-directed change that makes new choices and actions possible – imagining an otherwise and creating a space for its cultivation – not only as an outcome.^{36,251} One such processual component could be inviting Yup'ik partners or the YKHC to expand the scope of their involvement, for example, by proposing their own research hypotheses for investigation. In the

period covered by this study, CPG and Ciuliat members volunteered many possible research questions, including how the transition from a wholly subsistence-based diet to one that includes more market foods may be contributing to increased rates of diabetes and cancer among Yup'ik people; whether aged urine from a younger, opposite-sex relative, a traditional Yup'ik treatment, may have antibiotic properties; how the lack of opportunities for youth to learn from Elders affects their physical, spiritual, and emotional wellbeing and how such opportunities could be expanded; and whether rainwater collected from metal roofs contains contaminants that could cause negative health effects if used for drinking and cooking.

Overall, the results fit well with the group formation model – so well, in fact, that it may be worth reviewing the model together at the outset of a new community-university collaboration. It is possible that having this frame of reference in mind could reduce partners' felt anxiety about the challenges of the storming phase, in which participants attempt to discern what kinds of interpersonal behavior are acceptable within the group by attending to the reactions and feedback of other members of the group. Although the group formation model notes that this process of social boundary-testing can be contentious, the renegotiation of the CPG's role was both less heated and slower-paced than the model suggests. There are several possible explanations for this, including Yup'ik communication norms that discourage overt conflict, the fact that many participants knew each other well prior to formation of the partnership (e.g., the CANHR investigators knew all participants before the partnership was formed, and many of the Yup'ik participants knew, and in some cases were related to, each other), and the relative infrequency and variable attendance of our meetings.

Throughout the period covered here, Yup'ik partners can be seen making bids for greater agency (the role renegotiation discussions presented here being the main example), as well as

offering important insights about how other experiences, both current and historical – with “agency people,” with healthcare providers, and so on – shape their perceptions of research and their way of interacting with kass’aq investigators. Consistent with Yup’ik social and communication conventions, such comments were seldom made in a direct or confrontational way, which may have contributed to delays in the researchers’ understanding. It is interesting to contemplate what might have happened if we had talked openly about roles in the first meetings and developed a shared understanding and procedures for checking in.

Methodological Observations

As expected, ENA found less change in the renegotiation to post-renegotiation phase than in the pre-renegotiation to renegotiation phase. An interesting finding is that, overall, discourse patterns between the two groups were relatively comparable, though changes in the researcher discourse were of lesser amplitude. It is unclear whether the relative stability of the researchers’ discursive strategies reflects a lack of awareness of changes in the partnership dynamic as they were occurring, an unwillingness to interact differently, a more constrained repertoire of communication strategies (perhaps shaped by perceived norms about professional behavior for academics in work settings or an intent to show respect – e.g., by not teasing back), or perhaps a combination of these. The ENA models also reveal that humor appears to have been used frequently, but perhaps differently, by the two groups. Future analysis could further categorize different strategic uses of humor (e.g., to build rapport vs. diffuse tension).

The ENA models were successful in identifying patterns in the discourse that were more difficult to characterize through thematic analysis and/or discourse analysis, though both were useful in interpreting the ENA results. One of the challenges of using qualitative methods with a dataset of this size is moving beyond impressionistic interpretations; ENA was able to highlight

and quantify specific structural elements in conversation. At the same time, it seems to me that it would be difficult to reality-check ENA outputs without expertise in qualitative analysis. As Shaffer notes, the final check of the accuracy and value of an analysis using ENA is going back to the data and closing the interpretive loop:¹¹⁶ relying solely on statistical validation may not be proof against error.

The analysis also identified several shortcomings in the coding scheme, which was quite limited for reasons described above. It could be substantially improved in another analysis. The Vocatives code was drawn from Social Presence Theory, in which it is categorized as a cohesive response, i.e., communication that builds or sustains group commitment, analogous to Tuckman's social realm.^{1,106} In these analyses, however, it did not align well with the other social realm codes. Review of the data shows that in this dataset, vocatives were used in a more instrumental way – e.g., to direct a question to a particular individual or ask a person for clarification about something they had said – than to build interpersonal relationships. Likewise, there was little connection (for Yup'ik or kass'aq partners) between vocatives and expressions of gratitude, a link that would be expected if vocatives were being used in a more relational way. The Social Presence Coding Scheme was originally developed for online learning contexts, including communication in one-to-many interactions, similar to the use of “@” in social media. It may be that vocatives are used differently in in-person interactions, or that they were simply used differently by this group.

The Questions code was also easily operationalized but turned out to be less specific than anticipated. It captured outright questions from one partner to another (or to the group), but it also captured statements such as, “Now we're going to step back to revisit that and say, ‘What should we bring back to communities?’” This was a distinction I had not accounted for, and that

a human coder may have noticed and queried. Similarly, automated coding for Humor_Teasing likely missed many instances that a human coder would have captured; because humor and teasing are highly context-dependent and relevant conventions differ culturally, it was not possible to develop wholly reliable regular expressions to capture these phenomena. Frequencies of the Gratitude code were surprisingly low, and the Assessment code did not account for positive and negative evaluations.

Limitations

A few limitations should be noted. With respect to data collection, these meetings represent only a series of snapshots of the partnership and its interactions. Meetings continue as of this writing, and it is my sense that the role renegotiation process was not completed or fully resolved during the window of time covered by this analysis. Not every interaction during the meetings was recorded, and some important exchanges took place at times and in places (e.g., during meals, in the washroom, or in the bed and breakfasts where we lodged) where recording would have been inappropriate. I suspect – but cannot confirm from the data I have – that afterhours debriefs occurred among the Yup'ik partners, who dined and lodged separately from the investigators. Although this separation facilitated planning and debriefing within the study team and possibly among community partners, it may also have reduced opportunities for the researchers to debrief together with community partners in a less formal, “afterhours” setting. In addition, attendance varied at each meeting (Table 2); the participation of individuals as well as the relative representation of the three constituent groups (CPG, Ciuliat, and researchers) at each meeting likely affected group dynamics in consequential ways that are not accounted for in this analysis. The quality of transcription was excellent, for which I am most grateful; yet standard

transcription cannot fully capture nonverbal communication, which may be especially salient in intercultural collaborations.

It would have been useful to have more detailed field notes to add to the analysis. For example, it is impossible to tell from the transcripts who participated in shared laughter. It might be important to know whether there were things that only the Yup'ik, or only the researchers, were amused by; and an increase in shared laughter might be a reasonable metric of group development. Similarly, although participants discussed the importance and meaning of changes over time in individual partners' choices about where and with whom to sit (e.g., researchers clustered together vs. mixing with CPG and Ciuliat members), my notes contain seating diagrams for only two meetings. This is unfortunate, as prior studies suggest that this information can be useful in measuring relational change and openness to co-learning in both community engagement and education settings.²⁵²⁻²⁵⁴ I will make a point of capturing the arrangement of bodies in space in future studies of partnership dynamics.

Due to the ongoing COVID-19 pandemic and other logistical challenges, I did not conduct follow-up interviews with partners to confirm or disconfirm my interpretations. Such interviews could have provided an additional reality check on whether my interpretations resonate with partners' perceptions. Although it is sometimes argued that participant interviews are necessary to verify the results of discourse analysis – i.e., to prove that speakers were purposefully deploying language in particular ways to achieve the objectives claimed – this is not central to the methodology. Rather, discourse analysis assumes that all people have a lived, intuitive understanding of how to use language to do things in the world. The degree to which individuals intentionally employ particular discursive strategies may be important to assess in certain settings, such as examining how a political speechwriter invokes certain historical events

and for what purposes (i.e., what connections are being made to a broader societal discourse), but was not central to this study. ENA has the advantage of depicting connections as they actually occur in the data, together with statistical calculations substantiating the strength of those connections.

The ENA models were designed as exploratory, proof-of-concept analyses; the coding was not validated, which would have involved a minimum of two people manually coding a subset of the data. A larger number of codes would have provided a more comprehensive picture of interactions within the partnership. For example, it would be interesting to test more granular coding of interactions around group formation and role renegotiation (e.g., resistance → renegotiation → repair). In addition, my desire to explore whether the use of regular expressions to auto-code the data could adequately capture communications in an intercultural partnership that discussed a wide range of topics led to the use of relatively low-inference, but theory-derived, codes. The codes thus did not capture potentially important discursive elements concerning relationality – such as displays of emotion or instances of self-disclosure – that were difficult to define in terms of regular expressions.

**Co-Learning in Community-University Health Research Partnerships:
A Southwest Alaska Case Study**

CONCLUSION

This set of analyses was intended to address the gap in the community engagement literature between principles and concrete “how to” guidance for health researchers and communities involved in, or contemplating, collaborative research. It suggests that equitable collaborations can benefit from attention to interpersonal communication, both within and between groups; explicit and ongoing discussion of co-learning goals, responsibilities, and progress; and monitoring the developmental trajectory of group formation in both relational and task-oriented domains.

Future Directions

I hope this is not the end of my work with Yup’ik people or with these data, although this will depend largely on whether the partners and the YKHC Human Studies Committee see value in further study. The analyses presented here suggest several additional lines of inquiry.

Solidarity

Although trust is a necessary component of CEnR, it is incomplete as an account of the moral and relational dimensions required for equitable collaborations between communities and researchers. I am interested in exploring solidarity as an organizing principle in CEnR. As a component of politicized trust, solidarity need not rest solely on shared identities or experiences of marginalization.²³² Between people and groups with different positionalities, recognition –

i.e., a dynamic of respectful, reciprocal engagement and concern that supports equitable power sharing and onto-epistemic and participatory parity²⁵⁵ – may be key to establishing the kinds of connections that could support a journey into the unknown.

Dispositional Development

One area of future possible research concerns the dispositional development of university-based investigators and clinicians, i.e., how to cultivate and measure the qualities of mind and heart – such as openness to challenge and difference, vulnerability, tolerance for ambiguity, and humility – that incline an individual toward epistemic justice (i.e., recognizing and respecting the role of community partners as knowers and creators of knowledge) and equitable collaboration with Yup'ik communities and potentially other Indigenous peoples.^{256,257} Specifically, I would like to explore ways of supporting health researchers and clinicians in encountering community partners and patients as what I have heard referred to in the Y-K as a “real person.” I am particularly interested in exploring the role that digital storytelling might play in catalyzing self-reflection and humility, as well as engendering a felt appreciation of what Archibald refers to as storywork.^{173,258-260}

In contrast with the metacognitively-oriented forms of learning that are the usual focus of postgraduate training in the sciences, learning in the hermeneutic encounter is experienced as something that happens to a person, rather than a willed, self-directed activity with predefined objectives.^{256,261} One senior colleague has described these breakthroughs as “professional conversion experiences,” having an epiphanic quality.²⁶² Such learning can be surprising, unwanted, and – sometimes – painful, as it entails the hurt of recognizing one’s past errors and any harms they may have caused. Yet my own and others’ experiences suggest that truly transformative learning often occurs through precisely this kind of experience. As an example,

the outsize role of (usually negative) experiences in physicians learning is well documented but poorly understood.²⁶³⁻²⁶⁶

Partnership Evaluation

Although numerous approaches to evaluating community participation and engagement have been proposed, they have largely focused on outcomes rather than the process of collaboration and the specific practices and structures that tend to promote or hinder co-learning.^{59,267} Relatedly, most extant measurement approaches have been developed by researchers with limited, if any, participation from community members and have tended to gather data from community members only.

Recent reviews reveal that specific measures of community participation have included community members' identities (as a metric of inclusion and diversity), retention rates, roles, expectations, time spent in meetings or on related activities, benefits and challenges of participation, and perceived influence in decision making, as well as their commitment to and satisfaction with the collaboration.^{59,267} Surveys (sometimes including researchers as well as community members) are the most commonly used approach; some studies have used activity logs and qualitative approaches (i.e., interviews, focus groups, ethnographic observation of meetings) to assess engagement and participation. Butterfoss found only two surveys that elicited community members' evaluations of the balance of power and leadership in the partnerships in which they took part.⁵⁹ My own review of the literature suggests that such evaluations are most often designed and carried out by the study team, usually with little input from community participants other than as survey respondents.

Health researchers and funders may benefit from examining other fields' approaches to partnership evaluation and the participatory development of assessment methodologies.

Innovative work is being done in several disparate domains, including environmental and ecological studies, geography, and social work. For example, the Child Welfare Research and Evaluation Tribal Workgroup has developed a guide for the co-creation of evaluation strategies that starts with education about the sociohistorical reasons formal evaluation has negative associations for many Indigenous people in the US.²⁶⁸ Approaches have also been developed to assess the co-creation of knowledge, including both process and outcome measures, as well as community-university partnerships.^{269,270}

Challenging Binaries

Critical theory, including the work of Black and Indigenous feminist scholars, has brought serious equity-driven challenges to the fore in the humanities and social sciences over the past several decades.¹⁶⁷⁻¹⁶⁹ At the same time, however, positivist ideas – such as a belief in objectivity as distance and the search for a single truth – remain deeply entrenched in the life sciences. My work in research ethics over the past 20 years has made me keenly aware of the distance between these intellectual commitments and the difficulty that distance poses for equitable collaboration.

To make this work legible to, and usable by, biomedical researchers, I have intentionally framed community-university partnerships as working across multiple axes of difference. I have done so with the aim of helping researchers gain an appreciation of the Yup'ik worldview and the ways in which community partners can be true partners in co-learning, not only carrying out such instrumental tasks as recruitment and community dissemination, but also playing a meaningful role in, e.g., developing hypotheses and designing studies. This bridging approach is consistent, I believe, with the Two-Eyed Seeing and Two-Row Wampum Covenant models of

research collaboration, in which Indigenous and mainstream knowledge systems are held separate from but equal to one another.^{184,187}

This “two-camps” framing also maps to my interest in clinical communication, where the respective expertise of physicians and patients is typically framed within wholly separate domains. In the shared decision-making literature, for example, physicians are generally construed as having specialized knowledge about health and disease, while patients’ expertise is constrained to their own personal values, risk tolerance, and preferences.²⁷¹⁻²⁷³

I contend that, in both community-university partnerships and clinical communication, this division of capacities and roles fails to recognize that community members and patients do, in fact, have knowledge about the (complex, technical) topics under discussion, and that their expertise may be both important and invisible to researchers or physicians. Likewise, researchers and physicians, no less than their “lay” partners, have worldviews, cultural beliefs and practices, and personal values and preferences that are operative in these interactions. Defining these domains as “non-expert territory” obscures how they manifest in the thinking and behavior of “objective” researchers and clinicians, which in turn supports the status quo of power relations.

Notwithstanding these points, however, the bridging or “two-camps” approach I have employed in these analyses runs the risk of reifying those very binaries. Compartmentalizing researchers/clinicians and community members/patients in this way may limit the potential for co-learning, the development and enactment of transformative agency, and ultimately, mutual flourishing. My work going forward will focus on how to meet both researchers/clinicians and communities/patients where they are, facilitating a genuine appreciation of each other, while maintaining space for partners to imagine an otherwise together.

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ⁱ In the United States, “Indigenous” includes Native Hawaiian people, who are often left out or miscategorized in official health statistics that aggregate American Indian and Alaska Native peoples. “Indigenous” also recognizes that these and related concerns have been raised by Indigenous Peoples around the world, and that there is a rich and growing body of Indigenous scholarship that transcends colonially imposed borders. Most importantly, it is the term that many Indigenous people I have worked with prefer, when referring to collective groups of different Peoples.

ⁱⁱ I follow Ishimaru’s (2020) use of the terms “minoritized” and “dominant” as placeholders. The language here is complicated: as the United States becomes a “minority-majority” state (itself a bizarre locution), most other terms in common use continue to center whiteness (e.g., the use of “BIPOC” as a catchall for everyone who is not white). See also Itchuaqiyaq 2021.

ⁱⁱⁱ Yup’ik word that refers to ancestors or leaders, used here with the sense of facilitators or cultural brokers.

^{iv} Kass’aq is the Yup’ik word for a non-Yup’ik person. The word is derived from the Russian “Cossack.” Russian trappers and hunters first reached the Yukon-Kuskokwim Delta in the 1800s.

^v I notice, as I try to write this sentence, how insidious the white norm is: I am tempted to use words like “atypical” or “idiosyncratic” to describe Yup’ik drug response.