

# Ethical considerations for community-based participatory research with Sami communities in North Finland

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**Abstract** This study examines the perspectives of Sami community members and university researchers regarding the ethical considerations for engagement in Community-Based Participatory Research (CBPR) with Sami communities in northern Finland. Key informant interviews were conducted with Sami people from Finland who were exposed to or participated in research in their communities as well as with researchers who have conducted research with the Sami in Finland across diverse topics. Five themes were identified: establishing trust, research preparation, research comprehension, research ethics, and inclusion in research. The differences in participant perspectives were compared based on their community versus researcher roles. Our findings emphasize the need for (1) strategies to develop and maintain trust between Sami communities and researchers; (2) methods to bridge concepts of bias projected onto Sami communities and researchers by the others' differing world views and beliefs about research; and (3) increased education in community-engaged methods for social and natural scientists working with Sami communities. This study supports the need for the development of formalized ethical protocols for conducting community-based engaged research with and for Sami people in Finland that ensure mutually beneficial research for all involved.

**Keywords** Arctic · Community-based participatory research (CBPR) · Indigenous communities · Research ethics · Sami

## INTRODUCTION

Previous western scientific research approaches have “not shown effective results with sustainable impact to address

persistent issues in diverse cultures and minority communities” (Chung-Do et al. 2016). As a result, there is growing concern within indigenous communities regarding the *types* of research studies conducted in their communities as well as *how* this research is created, conducted, and interpreted. Current research suggests that engaging Indigenous peoples with research (1) supports the decolonizing of western science methodologies; (2) has a foundational focus within the research process of respecting Indigenous rights, worldviews, cultural beliefs and practices, and use of language; (3) equitably shares responsibility for decision-making and resources in research between the researched and the researchers; (4) ensures research is of relevance to Indigenous communities; and (5) promotes reciprocity between the researched and researchers in which Indigenous communities receive something back from the research conducted with their people on their lands and in their water ways (Denzin et al. 2008; Simonds and Christopher 2013; Stanton 2014; Tunón et al. 2016).

The historical lack of attention to these aforementioned approaches in western scientific methods and the misuse of western science research findings at the expense of Indigenous communities have resulted in Indigenous people being wary and distrusting of researchers, their methods, and their conclusions (Cochran et al. 2008; Chilisa 2012). Linda Tuhiwai Smith's influential work on decolonizing western scientific research methods (1999) argued that western research approaches to answering questions are grounded in colonialism and that Indigenous methodologies may and have been at least as rigorous as conventional western scientific approaches to answering meaningful questions for communities. In his book, *Research is Ceremony*, Shawn Wilson provides a core understanding of Indigenous methodologies by

emphasizing an Indigenous epistemology where all relationships, whether they be with a person, object or concept, take precedence above all else (Wilson 2008). In this context, relatedness between research participants and researchers is the primary outcome in a research study, not necessarily the answers to a particular set of research questions or a set of recommended practices and policies that may be the outcome of research (Castleden et al. 2012; Koster et al. 2012; Kovach 2012).

Herein lies the purpose of our study. Findings presented in this manuscript examine the ethics of participatory research practices that promote and support relationships through community engagement, shared decision-making, and power in social and natural science research with Sami people in Finland. Specifically, we explore the use of community-based participatory research (CBPR) as a primary participatory research method in the context of the Sami living in Finland and researchers from Finnish academic institutions who conduct Sami-related research.

In brief, CBPR is a 21st century science born out of historical western scientific research practices that have devalued relatedness and disconnected Indigenous people from the research process in honor of objectivity and mitigating some but not all bias (Isreal et al. 2005; Wallerstein et al. 2018). The CBPR framework includes five overarching stages: (1) community capacity/relationship building; (2) identification of the research problem(s)/research question(s); (3) research design, including data collection strategies; (4) data analysis; and (5) dissemination of the research findings. In addition to CBPR's five stages, ten guiding principles have been identified: (1) recognition of the community as a unit of identity; (2) strengths and resources are built upon from within the community; (3) collaborative and equitable partnerships are facilitated in all research phases and involve an empowered, power sharing process that attends to social inequalities; (4) promotion of co-learning and capacity building among all partners; (5) integration and achievement of balance between research and action for the mutual benefit of all partners; (6) an emphasis on problems of local and ecological relevance; (7) involvement of systems development through a cyclical and iterative process; (8) dissemination of findings and knowledge gained to all partners and involvement of all partners in the dissemination process; (9) requirement of long-term processes and commitment of sustainability; and (10) addressing issues of race, ethnicity, racism, social class, and embracing cultural humility (Isreal et al. 2005; Wallerstein et al. 2018). CBPR is a collaborative method that provides a space for both Indigenous and local knowledge as well as western science to develop and answer an array of social, cultural, political, structural, and environmental challenges facing Indigenous communities today.

CBPR has been established in North America as an effective research method with Indigenous communities because it (1) emphasizes building and maintaining community-academic partnerships; (2) supports the development of trust and reciprocity between community members and researchers; and (3) empowers communities to address research topics of importance to them in a culturally relevant manner (Henderson et al. 2002; Isreal et al. 2005; Christopher et al. 2008; Rink et al. 2016). CBPR is also beneficial scientifically because it integrates the strengths, skills, local experience, knowledge, and resources of community members with parallel strengths and skills of university-based researchers. This joining of knowledge perspectives enhances the ability to produce meaningful science that is relevant to communities, researchers, practitioners, and policy makers. CBPR as a methodological framework for conducting research with Indigenous peoples in Greenland, Norway, Sweden, Finland, and Russia is sparse in comparison to its wide application in the North American Arctic in research with Indigenous communities in Canada and the USA.

Despite CBPR's lack of application in Arctic Indigenous communities in the Nordic countries, efforts to give voice to Indigenous perspectives and decision-making in research in the North, numerous Arctic institutions, organizations, and networks have made considerable headway in the development of ethical guidelines for community-engaged research with Indigenous communities (National Science Foundation 2005). A few examples of these efforts include the following: (1) the Interagency Arctic Research Policy Committee (IARPC) with the National Science Foundation recently updated the *Principles for Conducting Research in the Arctic* highlighting respect for all individuals, cultures, and the environment of the Arctic. (2018); (2) the *United Nations Declaration of the Rights of Indigenous Peoples* that supports self-determination (2007); (3) Inuit Tapiriit Kanatami, Inuit Tuttarvingat and National Aboriginal Health Organization created *Guidelines for Research Involving Inuit* regarding how to develop partnerships with Circumpolar Indigenous peoples in which communities and researchers are equal partners (2010); and (4) the International Arctic Science Committee (IASC) wrote the *Report from IASC Action Group on Indigenous Involvement* in order to set goals for involving the utilization of Indigenous Knowledge and Traditional Knowledge in research conducted in Arctic Indigenous communities (IASC 2019).

The need to promote community-based engaged research methods that privilege Indigenous perspectives, knowledge, and lived experiences in ethical guidelines for research with the Sami in Norway, Sweden, Finland, and Russia, has been recognized for a long time (Mikaelsson 2014; Stordahl et al. 2015). Since the 1970s, discussions in seminars, research events, reports, and peer-reviewed

research manuscripts at the pan-Nordic and national Nordic levels highlight the need for ethical guidelines in research with the Sami (Drugge 2016). According to Keskitalo (1976), research has historically been conducted on the Sami by non-Sami, defined by non-Sami interests with Sami researchers being considered non-objective. Questions of research ethics, research practices, the perspective of outside researchers as well as colonialist uses of power in research with Sami people in Finland has also been presented (Lehtola 1997, 2012, 2015; Hirvonen 2008). In addition, the Nordic Sámi Institute (established 1973 by Nordic Council of Ministers, since 2005 known as the Sami University College—National Sami Education Institute in Norway) has focused on the necessity of Sami research ethics in cooperation with Sami Parliament and other Sami actors/organizations (Haetta-Kalstad 2005). Over time, there has been the establishment of other national Sami Institutes at universities in the Nordic region, such as the Giellagas Institute at the University of Oulu, established in 2001. More recent research regarding structural racism and Indigenous health in Canada and Finland continues to document the importance of collaborating with Sami people to develop ethical guidelines for research (Juutilainen and Heikkilä 2016; Juutilainen 2017). However, to date, *Samediggi*, the Sami parliament in Norway, is the only Nordic body that has developed specific ethical guidelines for health and human biological material research with Sami communities in Norway that acknowledge the importance of respect, responsibility, reciprocity, cultural safety, self-determination, and equal status in research (Samidiggi 2018).

Today, in Finland, there is evidence of multiple research studies that include Sami knowledge and Sami perspectives and demonstrate inclusion of Sami decision-making in research. For example, Helander-Renvall and Markkula (2011), in their research on biological diversity and the Sami people in northern Finland, they describe the use of traditional knowledge to understand the use of natural areas and resources and how environmental changes impact the seasonal cycles of the natural environment and thus impact Sami peoples' livelihoods. Their research recognizes the importance of integrating Finnish Sami traditional knowledge into the context of environmental impact assessments. Kuokkanen's (2008, 2011, 2015) research on gender violence and Indigenous women highlights the silencing of Sami women in Finland who have experienced domestic violence and sexual abuse, suggesting that there is an inability of a significant portion of the Sami community in Finland to actively participate in society. Juutilainen (2017) found the relationship between residential school experiences and health among Sami people in Finland and warranted the production of ethically valid and locally grounded accounts on this period of educational

history in Finland due to the differing worldviews of the academics that predominately wrote this history and of the Sami people that actually experienced the residential schools. Brattland and Mustonen's (2018) research on local, national, and international salmon research and governance structures in Finland and Norway speaks to the importance of balancing scientific credibility with local and traditional Indigenous knowledge keepers. Other examples include the EU-funded project (EU FP5, QLK5-CT-1999-01515), Human Interactions with the Mountain Birch Ecosystem: Implications for Sustainable Development (HIBECO), coordinated by University of Oulu, which included three sub-projects: Birch forest productivity; Herbivory; and Human interactions and natural conditions of the mountain birch ecosystem (Aikio and Muller-Wille 2003, 2005a, b). Final examples of Sami knowledge and worldviews inclusion in research is the co-authorship of Sami in the reports, such as Arctic Human Development Reports (Larsen and Fondahl 2014), Arctic Climate Impact Assessment (ACIA 2005), and Adaptation Actions for a Changing Arctic (AMAP 2017).

Collectively, these abovementioned examples from disparate academic fields advocate for the voices and perspectives of Finnish Sami to be included in any research that takes place about them, their traditional practices, as well as in their local lands and rivers. These studies highlight the diversity within and between Sami communities and the array of social and natural science research that takes place in and with Sami communities in Finland. However, Finland continues to exhibit post-colonial power dynamics which are subject to persistent national critique and continue to challenge equitable collaborative and respectful research in which decision-making and resources are shared between Sami community members and researchers (Lehtola 2012, 2015; Nyssonen 2013; Kuokkanen 2020). Bias persists regarding how Sami people in Finland should be involved in research decision-making despite active efforts to develop general guidelines for research with the Sami in Finland, such as the National Guidelines for Sami Research in Finland (Finnish National Board for Research Integrity 2019). The challenge of developing ethical guidelines for the Sami in Finland is nuanced by the reality that contemporary Sami people have complicated and cross-border identity positions with aspects of both traditional Sami and contemporary Nordic/Arctic roles and opportunities reflected in their daily lives (Lehtola 1997). Furthermore, Junka-Aikio (2019) acknowledges the current state of institutionalization and neo-politicization of Sami research in Finland by emphasizing the importance of giving attention to the complex political, academic, and local Sami contexts and interests that intersect when research includes a Sami perspective.

As the debate continues regarding effective strategies for community-based engagement in research with Sami and determining culturally relevant ethical guidelines for research with Sami communities in Finland, the question still remains, *how* to engage the Finnish Sami in research. By engagement of the Finnish Sami in research, we mean the inclusion of Sami worldviews and lived experiences as part of the research design, data analysis, interpretation of research results, outcomes, and sharing of the research results as well as equitable decision-making power along with researchers in these aforementioned research processes. Therefore, we sought to better understand the perspectives of Sami community members and university researchers about what was important to take into account when conducting research with Sami communities. In particular, we focused on the Utsjoki region of northern Finland and Sami community members from this traditionally Sami area and researchers who have worked with the Sami in that space to offer stimulus and ideas for the broader discussion within Finland regarding *how* to increase Sami inclusion, decision-making, and resource sharing in research. Here, we explored the perspectives of Sami community members and researchers regarding *how* they could mutually conduct more community-based, participatory, and inclusive research methods, such as CBPR.

## MATERIALS AND METHODS

### Study setting

Our study had two primary research sites. The community part of our study took place in the Utsjoki region of Northern Finland. Utsjoki municipality is the only Finnish municipality with a Sami majority. There are around 1250 inhabitants, which is 0.23 person/km. Utsjoki municipality is located next to the Teno River and borders Norway, and biggest village is called Utsjoki. The Teno River is a famous salmon river and a cornerstone of Sami fishing culture in the northern parts of Finland and Norway. It should be noted that during our field work it was mentioned by our research participants that there continues to be strong cultural ties between the Sami communities in Teno River area and northern Norway that historically predate current national boundaries. There are Sami living in the village of Utsjoki as well as the community of Nuogram farther northeast of Utsjoki municipality, the Skolt Sami and Inari Sami live south of Utsjoki municipality, and there are Sami living in urban settings throughout the southern areas of Finland. Thus, it is evident that the Sami communities in Finland greatly differ from each other depending on the language, cultural, living conditions, habits and geographical regions. The researchers that

participated in our study were from the University of Oulu in Oulu, Finland. The City of Oulu is located by the Gulf of Bothnia, around 150 km south from the Arctic Circle. It is the fifth largest city in Finland with population of ~ 200,000. The University of Oulu includes eight faculties, and the Giellagas Institute that has a nation-wide responsibility to introduce, organize, and provide Sami language and cultural studies and research at the academic level in Finland.

### Sample and data collection

Purposive sampling was used to select two sets of participants for our study. One set of participants was university-based researchers who conducted research in Sami communities in Finland, responding to an open invitation from our University of Oulu Finnish research team member. The other set of participants were Sami community members in Utsjoki who in some way, whether as a research participant or as a member of a research team, had been exposed to research in their community, responding to an open invitation from our Utsjoki-based Sami research team member. The research team invited participants based on the goal of diversity across the following criteria: (1) age; (2) gender; (3) level of education; and 4) occupation. In total 19 participants were interviewed, including 8 researchers and 11 community members, 10 men and 9 women, ranging in age from mid 20 s to early 70 s. Formal western education level ranged from secondary school to terminal degrees in academics and/or medicine. Participants had a variety of occupations including professor, physician, schoolteacher, community activist, fisherman, reindeer herder and some participants were retired. The eight researchers from the University of Oulu were conducting research with the Sami in a variety of areas, including biological sciences, medicine, public health and social sciences. Of these researchers, 4 were Sami and 4 were non-Sami, with age range from 30 to early 60 s. The eleven community participants were Sami people from the Utsjoki Region of North Finland, ages 38 to 74, including 6 females and 5 males.

Three members of the research team (one Finnish, two North American) conducted the interviews over a six-month period. The interviews were conducted in either Finnish or English, lasted 1.5 to 2 h, and were audio-taped. Both the Finnish and English audio-taped interviews were transcribed at the University of Oulu, Thule Institute. The transcribed interviews were then uploaded onto a password protected secure server at Montana State University for the purpose of this analysis. All participants were asked the same set of questions in three broad topic areas regarding ethics and CBPR with Sami communities in North Finland including: (1) inclusion and partnerships; (2) ethics; and (3) trust, transparency and power (Table 1). Researchers were

**Table 1** Study interview questions

Category	Questions
Inclusion and partnerships	How do you suggest including Sami people in the research that takes place in Sami community?
	What are the historical issues researchers from outside the community need to know in order to understand the Sami people?
	What cultural issues do researchers need to understand about Sami people in order to work with the people on research projects?
	When conducting research with the Sami, how should researchers take into consideration the needs of the individual versus the needs of the collective in Sami communities?
	How can partnerships with Sami people be established to ensure that the Sami people have oversight and guidance of research projects that is conducted?
	In your opinion how should oversight of the research that is conducted with Sami communities be established and conducted?
Ethics	What values should guide research and scholarship with Sami people?
	What are the critical ethical issues in research with Sami people?
	How do you suggest going about establishing ethical guidelines for research with Sami people?
Trust, transparency, and power	How does a researcher from outside of the community develop trust with Sami people to conduct research with them?
	What is the best way for researchers conducting research to be accountable for the research they are doing with Sami people?
	What is the best way to ensure an equitable balance of power between the researcher(s) and the research participants as well as the community in which the research is taking place?
	How can partnerships between researchers and Sami communities best be developed and sustained?
	What else do you think is important for a researcher to do and know when conducting research with Sami people?

encouraged to share their experiences and perceptions of research in Sami communities and with Sami people. Similarly, the Sami community members were encouraged to share their feelings and observations about how they have experienced and seen research conducted in their communities. All participants were encouraged to express themselves in a manner that was honest, comfortable and respectful for them. The participants also confirmed comfort with either English or Finnish language. Ethical approval for this study was received from the Institutional Review Board of Montana State University.

### Analysis

The principles of grounded theory were followed to code and analyze the interview data using Atlas.ti qualitative analytic software. Grounded theory is an inductive approach to data analysis that "allows the theory to emerge from the data." (Corbin and Strauss 2008) Grounded theory honors the voices and perspectives of research participants by developing a theoretical understanding of the topic under study directly from the words and experiences of the research participants. The use of grounded theory in qualitative data analysis is particularly appropriate with Indigenous communities because it does not impose a preconceived theoretical framework 'on to' the voices or

experiences of Indigenous peoples, which may be viewed as 're-colonizing' Indigenous research participants through the research process (Sahota 2010).

The data analysis for this study consisted of three phases. First, line-by-line open coding of the interview transcripts was conducted, and axial codes were developed by identifying and linking broad analytical categories. Axial codes were in turn organized to address the overarching questions of our study. Second, once the axial codes were defined, each member of the research team reviewed the axial codes and independently generated a list of themes they thought were reflected in the study. Following this independent process, the research team then met as whole to further refine and solidify the main themes that emerged from the analytical categories generated during the earlier phases of analysis. Third, as the last phase of our data analysis, all participants were provided written summaries of our preliminary results and invited to comment and/or participate in additional review and finalization of recommendations; no participants made comments or suggested edits to the preliminary results and 8 of the 19 interviewees agreed to discuss the preliminary results in person. This group reflected participants from both the Sami community and the academic community. Through this iterative, inclusionary process over many months, the findings presented in this paper were directly validated and finalized.

## RESULTS

Five consistent themes emerged from the two sets of interviews. The themes included: (1) establishing trust; (2) research participation; (3) research comprehension; (4) research ethics; and (5) inclusion in research. Although the themes were identified and shared by both interview groups, their interpretations of the meanings of the themes were widely divergent (Table 2).

### Establishing trust

According to Sami community members' trust is gained through building relationships with the Sami.

I think actually probably the only way is that you get to know someone and the other people that they trust ... you will get people to talk quite easily... but if you would just call or knock on the door, they're like no way!

In addition, the Sami interviewees talked about trust being gained through time.

... you have quite a while to build trust with someone before you can... we get those questions so much about this, they're making research and emails all the time. Sometimes we don't even answer ... it shouldn't be that they expect we spend 2 h reading their ... research plan.

And,

... all the time you're not an insider and you probably won't get all of the feeling and you won't be able to look inside out ... it's hard to start research ... but you should still be able to come ... as an insider and slowly and slowly ... it will start .... if you have research process lasting 3–4 years then you might just start researching and see something differently, but after 3–4 years ... you find the trust.

While some researchers stated that they valued establishing trust by emphasizing transparency in the research process with Sami people and believed that it was important to communicate openly and share results with the Sami about research studies, there were other researchers that viewed the theme of trust differently. For example, researchers reported that in some instances researchers do not trust Sami to understand the results. One researcher stated,

It requires expertise ... I don't want any community to read the results ... I don't trust the end... I want the answers to stay within those researchers.

There were also concerns from the researchers that the Sami will only trust researchers they know, or if the

researchers are Sami themselves or if the researchers are trusted by another Sami. The researchers did seem aware that Sami in general may not trust researchers because of suspicion about how the results of a study will be used and whether or not the results will be supportive of the Sami people and their culture or be detrimental to their communities and way of life. As one researcher stated,

... if the person who is doing the study is Sami, or someone that someone knows is trustworthy I think then the Sami people will trust and give honest answers to them, or show something to the people who are doing the study... they may think that what are they doing? Are they going to steal something or are they going to use it against us or something like that? I think it's mostly on the elders of the Sami, but I think many younger Sami people may have these fears also.

This comment also highlights the intergeneration mistrust of researchers that has been passed down through Sami family members from great grandparents, grandparents, parents and youth.

### Research preparation

Sami community members discussed the importance of silence within their culture as part of understanding how researchers must prepare for studies in their Sami communities. Sami community members highlighted the importance of not talking if someone wants to be accepted in their community.

...the culture of silence. And the culture of if you talk you are going to be excluded from the society.

Understanding Sami culture was considered an essential component to conducting accurate research studies with Sami communities particularly in the area of understanding the ways in which Sami communicate and the underlying meaning of their communication.

... everybody should really have someone from inside telling you what did this person actually really mean. We have had so many research projects where people tell things for the researcher, what they know they want to hear, and then there has been interpreted wrongly.

And,

...maybe they are saying a lot but if you don't know the culture you don't understand how much he or she has already told you ... you don't understand everything that's inside ... the information.

**Table 2** Comparison of themes between Sami community members and researchers

Sami community members	Researchers
<i>Establishing trust</i>	<i>Establishing trust</i>
Relationship building is foundational to establishing trust	Lack of trust in Sami community members' honesty when participating in research with researchers outside of the community
Relationships are built over time	Awareness of intergenerational mistrust for researchers
<i>Research preparation</i>	<i>Research preparation</i>
Outside researchers must be silent and pay attention in order to be accepted	Enculturation of researchers in Sami communities was not necessary
Awareness and understanding of Sami culture and its impact on the how Sami view the world and live their lives	Involvement in Sami culture as a means to facilitate the preparation of research in Sami communities was viewed as only minimally important
Researchers must be prepared in their basic understanding of Sami culture when they come to Sami communities to do research	
<i>Research comprehension</i>	<i>Research comprehension</i>
Research must be relatable and understandable to Sami people	Valued making research accessible to Sami communities
Understand that silence from a Sami community member means disagreement, not agreement	Valued the use of Sami language and culture in providing the results of research conducted in Sami communities
<i>Research ethics</i>	<i>Research ethics</i>
Felt unformed about the research taking place in their communities and the results of the research	Limit autonomy of Sami people in research taking place in their communities
Weary of outside researchers	Sami are biased and not neutral about research in their communities
Believed Sami communities should have decision-making control of the types of research taking place in their communities	
<i>Inclusion in research</i>	<i>Inclusion in research</i>
Include Sami people in all phases of the research process	Limit inclusion of Sami people in research to data collection
Include Sami organizations in the decisions about research in Sami communities particularly research that involves fishing and reindeer herding	

Sami community members frustrated by researchers coming to their communities not aware of some of the basic foundations of Sami culture stated that researchers should do their homework before considering a research study in their communities and definitely before actually arriving in the community.

... do your homework before you come to research anything. If you are going to research for example reindeer herders, that you have to have the right clothes with you and ...know where are you going, what you are doing and why ... the season is also very important when people are here and you are very busy with fishing you are not going to sit with the researcher drinking coffee and thinking about health issues or whatever!

In contrast, the researchers spoke little about the importance of such preparation for conducting research. While they acknowledged the need to understand culture and linguistics, they did not mention the value of enculturating themselves in Sami society to better understand their own work and more effectively interpret the results. Some

researchers stated that initial involvement with the Sami in the developing of the research may be useful; however, the researchers seemed to think that their own professional capacity was enough.

The process is okay to design the questions ... because asking questions this way or that way may encourage them to answer ... the part of reading the results... it's a research issue. They should not be involved in that part.

### Research comprehension

The Sami community members believed that the research conducted in their communities should be relatable and understandable to them. For example, outside researchers who conduct their research in Finnish or English without checking to see if that may be inappropriate to the topic may be viewed as culturally insensitive and not understanding of the nuances of Sami language within families to describe things. There was an identified need for outside researchers to validate Sami quotes in order to truly understand what is being communicated to a researcher.

... if you are directly quoted it should be checked ...

Sami community members also highlighted the need of researchers to comprehend the use of silence in the research process, namely that silence among the Sami in North Finland usually represents disagreement.

... if you are talking to Sami ... and he or she is not saying anything, the Finnish researcher thinks that he agrees, but Sami knows that she or he doesn't agree.

The researchers also viewed research comprehension as important. In general, the researchers saw the value in addressing communication and cultural barriers when conducting research in Sami communities. Researchers stated that addressing the differences in language was absolutely necessary in research with the Sami, particularly as it relates to interpreting the research results.

They are quite different whether you speak Finnish or Sami because those people when they are talking about for example reindeer herding or relatives or family, so we have our own words for everything in the Sami language and if you are talking in Finnish you are talking about a different thing, so you don't get the same thing ... there can be misunderstandings ... if you are Sami speaking and you are interviewed in Finnish because maybe you don't understand the question, maybe you misunderstand it and you are going to answer another question than what your interviewer meant.

They also believed that there was a need to pay attention to any cultural barriers that may impact the research. As one researcher stated,

... if you are making research ... you should know the context, you should know the language ... and there would be more depth in those analysis.

### Research ethics

Sami community members reported feeling uninformed about the purpose of research studies happening in their communities and, just as importantly, they reported being uninformed about research results.

... these research projects ... I don't know what they do with the results. I have no idea ...

There was also consensus among the Sami community member interviewees that they were growing weary of being researched.

... Everybody knows that we have been researched a lot. Everyone knows somebody who has been involved with some research ... All of us know

somebody who has been pictured and researched ... And maybe we're a little bit bored of this, researching, researching and researching which never comes back.

Because of Sami concerns about the types of studies taking place in their communities and their experiences with research fatigue, suggestions to increase oversight of research in their communities were made such as establishing community tailored ethical guidelines for research. This was especially emphasized in relationship to the extraction of natural resources in Sami communities,

... in other places ... local communities have set guidelines for if you're collecting data, about our community and that includes our land... and people, then you have to have our permission. If you're collecting data you have to have our permission ... they should get access from the locals to do research ... that would be very important because it's really a big pressure now on the north area, and they research more and more now for minerals ... they are going even more after oil and the salmon industry...

The Sami community members generally believed that they have a right to ethically oversee, monitor and regulate the research conducted in their communities. In contrast, the researchers interviewed for this study generally preferred to limit the autonomy and decision-making of the Sami related to research in their communities and did not generally support the community having decision-making power regarding participation in research. As one researcher stated, participation in research is an individual decision, not a collective community decision.

I don't support that ... every person should have the choice ... if I want to participate, I don't want the community around me to say no ... It's not freedom ... in every community there must be someone who wants to say no to everything ... I don't want them to have the power.

Some researchers believed that the Sami are too biased to effectively give their input in the research process. An example of this emerged from the difference between researchers that study reindeer and the Sami reindeer herders.

... scientists are not completely unbiased but there is a categorical difference between the scientists' notes and the reindeer herders' notes.

Ethical concerns were brought up by one research interviewee who happened to be Sami regarding the purpose of research being conducted in Sami communities and the dissemination of research results to community members,



which highlights the impact of the legacy of research in Sami communities.

... samples and things like ... our heads were measured and everything and they [outside researchers] promised us ... They never told us what are they going to do with all these results and they never got to know what happened to the results and what kind research was published. Even now today I don't know.

Interestingly, amongst the researchers the biggest differences did not seem to be between Sami and non-Sami researchers, but rather between social scientists and natural or biomedical researchers. In general, social scientists seemed to be much more comfortable with participatory approaches than their natural or biomedical researcher counterparts.

### Inclusion in research

The final theme that emerged from our interviews was about inclusion of Sami in research. The Sami community members believed that relevant groups should be included in research, particularly with issues related to research design and research questions.

... Talk to people and meet first about the topics and questions ... about what should be researched ... if it's about the school you should meet with the school people about the agenda, if it's about salmon, meet with the salmon people to help decide the questions ... and what to do about the results ...

Sami community members reported that researchers did not want to include them in research.

...They don't want us to be included ... Finland doesn't want to hear what we have to say.

One Sami community member interviewee stated that he has seen many times researchers come to research the reindeer with “their list of things they want to do” and the Sami reindeer herders are not involved in determining what part of the researchers' lists are important or not important as it relates to studying the reindeer. In addition, the Sami community members talked about including Sami organizations involved in the reindeer or salmon industry as well as the Sami Parliament being involved in the development of research guidelines for these topic areas.

... research on Teno River ... we are organized here ... those who have fishing rights ... have organizations ... they should be included ... when you talk about the reindeer ... of course the reindeer associations they should be involved ... when it comes to

the Sami research the Sami Parliament that's our self-governing body so it should be somehow be involved.

The Sami community member interviewees reported being suspicious of researcher motivations to study the fishing industry, because they do not believe that they were properly informed about the fishing industry research in their communities. Sami community members also questioned the results of the fishing industry research in their communities.

... where do they [the researchers] get the answers? They still go on with their research counting how many salmon were fished per year. I think they are imagining the results ... I don't trust it. The local people here don't trust the salmon research ... It's a tradition, my father told me you shouldn't answer that research. It's not going to bring us any good. Don't tell them. My father was not trusting them, I'm not trusting the salmon research, my son is very angry and says, I'm not telling a thing to them! ... researchers should come to the community, to our villages to talk about the situation, talk about their research, probably every year coming and telling what they are researching, what they found out, how do they get their results... answer the questions people have... tell to us that yes they have been wrong, they have changed their ways...

This belief among the Sami community member interviewees that they are not included in, or trusting of the research being conducted in their communities was furthered commented on during another interview in which the Sami community member addressed the significant influence of the convergence of research and tourism as it relates to fishing in Northern Finland.

... the attitude of the researcher ... like I'm the boss and respect me... it's very annoying. For example, the tourists who are coming here in the summertime to catch salmon they are saying it aloud and it isn't so good that they're coming here. The poor people here they don't have anything, and the tourists are coming here and buying the fishing license and buying some things from the shops and we don't even like them to be here! ... the people here they don't even like the fishing tourists. We could ourselves fish the salmon! ...

Perhaps the liveliest discussions in both the Sami community member and researcher interviews were those related to the inclusion of Sami in research involving reindeer or salmon. Here Sami community members believed researchers were actively not including them in their research and were particularly not good at communicating

their research ideas, plans, and results. As one Sami community member interviewee poignantly stated,

...it's not a common practice ...

From one researcher perspective, the inclusion of Sami in research should be limited in scope, being primarily and typically confined to data collection.

...we need trust [in order] to collaborate in a way that people are willing to take the effort because they need to do something. Actually, they need to scrape some samples, some scales from the fish, put them in a small paper envelope, write down information about the size of the fish, the date, the place, fishing gear, so forth, the sex of the fish and everything. So, they actually need to do something. We are paying ... just a little ... we train them and ... We provide the measuring boards and we provide the scales and we teach them how to use them properly and that's a very close connection that we maintain over years.

This comment incorporates a common perspective from researchers related to our earlier theme of establishing trust in that the value of trust is tied to researcher ability to “get the data” with assistance from the Sami. Note that the inclusion of the Sami is limited to that of a data collector trained in a western science methodology to collect the type of data only relevant to the outside researchers. As noted by several of our respondents, this type of inclusion in research does not honor Sami Indigenous knowledge or cultural practices, nor does it incorporate local wisdom or experience into the data collection process. Another researcher stated,

You can think of reindeer herders ... where to find them ... you don't need a community-based approach ...

Here we again find a more individualist approach to involvement with research in that the researcher's statement highlights reindeer herder inclusion in research on an individual basis as opposed to using a community focus, which incorporates a more culturally attuned, communal Sami worldview. Another researcher's comments reinforced this individualist perspective,

... not very much ... some interaction but it has been based on reindeer ownerships and not any other matters ...

This comment emphasizes the rarity of the reindeer herder community inclusion in research, as well as the typical basis for research inclusion being determined by the dominant cultural view of reindeer being viewed as an individual commodity as opposed to a core collective and cultural component of Sami life. The lack of importance

placed on the inclusion of any aspect of the integral place that reindeer and salmon have within Sami society and culture pervaded the researcher interviews. As one researcher stated,

... it's about fishery perspective ... the point is not the Sami culture, the point is the fishing, the fisheries and the practices and the catches and everything. Of course, these things are very closely connected... We are assessing population size and things like that so it's not about Sami culture. It's about how the Sami are working and practicing their fisheries in relation to the fish population.

## DISCUSSION AND CONCLUSION

Our study explored the perspectives of Sami community members and researchers relating to developing ethical guidelines of research with Sami people in Finland using a CBPR framework. CBPR provides a set of principles and practices that can be used as a structure for community members and researchers to design, implement, and evaluate research studies that are equitable and mutually beneficial. Our study demonstrated that Sami community members and researchers often approach research differently based on their own experiences. These differing perspectives can have an impact on how research is conducted, what types of questions are asked, results generated, and how research results are shared and used, thereby compromising research's capacity to be rigorous, credible, and most beneficial to the Sami community and others. Recognizing the extent to which Sami community members and researchers varied in their perspectives on community engagement, participation in research, and what they perceived as ethical, we identify some primary issues to be addressed in future efforts to foster community engagement with Sami people in Finland and develop ethical guidelines for research with the Finnish Sami.

First, developing and maintaining trust between community members and researchers is a necessary component of conducting ethical research with the Sami. The need to establish trust between Indigenous communities and outside researchers and the necessary strategies to do so is well established in the CBPR literature. Furthermore, a trust relationship dynamic between Indigenous peoples to which the research relates to and the researchers conducting the research has been established in the research literature as a foundational principle in research with Indigenous communities (Christopher et al. 2008; Tondu et al. 2014; Tunon et al. 2016). Indigenous communities in New Zealand, Australia, Canada, and the USA have developed policies and guidelines for not only honoring

individual human rights, traditional knowledge, and use of natural resources among their peoples, but also what is required of researchers to create equitable balances of power between community members and researchers in order to support and promote trusting and equitable relationships. In this arena, the Nordic countries in which Sami people live seem to be behind. This situation is somewhat of a paradox in that there is a great amount of understandable national pride in countries such as Norway, Sweden, and Finland regarding post World War II policies that aim to treat all members of society equally. However, when people are treated as equals, they may not be treated fairly or equitably because different people have different histories, past, and current experiences of relevant power dynamics and trauma, and diverse cultural expectations and needs. The failure to acknowledge and address these historical, personal, and epistemological differences erodes trust. When such differences are not honored and peoples' unique experiences and/or perspectives are not integrated in the research process, mistrust can flourish, and scientific validity can be threatened. Therefore, establishing specific ethical guidelines in Finland, such as those recently established by the Sami Parliament in Norway, that clearly delineate the importance of trust and strategies for establishing trust with Finnish Sami community members, and the need for tailoring the research to the history and the context in which the research is taking place is warranted.

Second, related to the lack of trust that was present in our interviews, was the perception that both Sami community members and researchers were biased. Our Sami interviewees believed that the researchers were biased for a variety of reasons related to the type of research they were doing, who was funding the research, and what kind of administrative oversight and potential benefit the Finnish government might have in the research being conducted. In particular, our Sami interviewees talked about the extreme bias they saw in salmon and reindeer research conducted in Northern Finland. Our Sami interviews portrayed a belief that even though the Finnish government would like everyone to have the same rights to fishing and herding reindeer, from a Sami perspective, this is not possible. The impossibility of equal fishing and herding reindeer rights is directly connected to a Sami world view which is grounded in the belief that connection to land, place and animals is, in part, what makes one Sami. In Finland, what and who is Sami is a political issue of much debate. Thus, when policy makers categorize and regulate access to fishing and reindeer herding using only the dominant Finnish cultural lens, and they attach government funding to the research that is conducted on and about fish and reindeer, they are creating a potential research bias that diminishes and negates part of the very core of what it means to be Sami. Our researcher interviews also addressed bias from the perspective that

they felt Sami community members were biased and not able to provide objective viewpoints on research topics that pertained to them. The researchers perspective may in fact be due to the manner in which the vast majority of western scientists are trained in deductive reasoning strategies. In much western science, to be neutral and detached from the research subject under observation are strengths and a cornerstone of reliable and valid science. From a Sami perspective, this is a disadvantage because in their worldview, being detached and neutral prevents the research from being connected to the people, the place, and the animals that the research is about; in their view, such cultural knowledge is essential to asking and answering meaningful questions. This issue of perceived bias highlights the difference in Sami culture and the academic culture that will need to be integrated into future ethical protocols for research with the Sami as well as bridged into future research efforts that are beneficial to both Sami communities and researchers in Finland.

Third, because of the differences in perspectives voiced in our interviews between Sami community members and researchers as it relates to community participation in research, there is a need to educate researchers in participatory methods and how to engage community members in research. In addition, academic training in Finnish institutions would benefit from integration of interdisciplinary collaborative, community-based methods in their coursework in order to train future generations of researchers in participatory research methods such as CBPR. Different types of academic disciplines warrant different types of education. So too does conducting research either in or with an Indigenous community, as Indigenous communities present a unique set of historical, cultural, and social issues that impact research dynamics and outcomes. For example, it is important for researchers working with Sami communities to understand that their culture and the place where they live and the history of their people in a particular place cannot be separated from a particular research topic, regardless of what the research topic is. Researchers must also understand that in some instances the extent of the historical trauma experienced by the Sami at the hands of outsiders, whether they be the Finnish government or researchers, has resulted in some situations in which Sami will withhold speaking with a researcher truthfully as a means to protect themselves and the knowledge that they carry. This level of suspicion can be mitigated by addressing our above point related to researchers taking the necessary steps to establish and maintain trust in and with Sami communities.

There are limitations to our study. First, as can be the case with qualitative studies, our sample size was small and is suggestive, but not fully representative of Sami community members and researchers that work with the Sami

in Northern Finland. Second, selection bias may have been a factor in our study as we specifically recruited and interviewed individuals who were Sami and had experience in some way with a research study and who were researchers who worked with the Sami. Third, the interviews were conducted in either English or Finnish, which could have hindered some of the Sami speaking interviewees from expressing themselves in a way that felt right for them in their native Sami language. This issue was explicitly discussed with the Sami interviewees who noted for this particular topic, English or Finnish language was generally appropriate. Fourth, our study specifically involved Sami who lived in Finland, and, therefore, may not be applicable to Sami who live in Norway, Sweden, or Russia, who may have their own unique set of histories, life experiences, and cultural beliefs and practices that must be taken into consideration as part of a research study. Finally, we recognize that Sami communities and histories are complex and borders are fluid, particularly in the context of our study site in north Finland, where Sami people living in the Utsjoki region may have more in common with Northern Sami in Norway than with Skolt Sami, Inari Sami, or urban Sami living in Finland and elsewhere. Thus, our findings and recommendations may be more suggestive and most useful in a pan-arctic rural Sami context.

Overall, our study had several strengths. We contribute to the significant and growing body of post-colonial critique of unexamined assumptions within seemingly routine research practices that take place between the Sami in Finland and researchers from academic institutions. Our findings add support and additional breadth to those who highlight the complexity of culture, the value of situated knowledge, and the importance of being a reflective practitioner of any research method (Benhabib 2002; Haraway 2013; Said 2020). While it is important to note that not *all* research relevant to Sami people must adhere to all principles of CBPR, we believe that the quality, credibility, impact, and reputation of research in general would be significantly enhanced if adherence to CBPR principles and practices increased in research conducted in the region. Our study recommendations build upon those of earlier initiatives, such as those of the Sami Parliament of Norway and the Nordic Sami Institute, now the Sami University of Applied Science, and support other ongoing efforts to increase Sami voice and agency in research priorities and decisions. Also, the Sami people of northern Finland, like Indigenous people in many places, have experienced both the culture-crushing forces of colonization and the hopeful and resilient aspects of cultural reclamation and re-birth. In recent years, Sami artists and authors have described and further explored these vital aspects of the ever-evolving Sami culture, and anyone trying to apply lessons from our

own work would do well to keep this complexity and fluidity in mind (Valkeapaa 1983; Aikio 1994; Paltto 2009).

To our knowledge, our study is among the first to explore Sami community member and researcher perspectives on *how* to conduct research with and about Sami people in Finland. We used an iterative and inclusive process for the development of the research questions, data collection and analysis, which increased the validity and credibility of the results to diverse stakeholders (Wallerstein et al. 2018). Preliminary findings have been presented to Sami Parliament leadership in Finland and to other Arctic researchers for additional feedback and discussion, and the response has been generally positive, with several noting the timeliness and importance of the findings. Currently the Finnish National Board on Research Integrity has produced the document, *The ethical principles of research with human participants and ethical review in the human sciences in Finland*, in which section 3-1b states “... Sami, as an Indigenous people ... have the right to maintain and develop their own language and culture.” (p. 50) (2019). While this ethical principle clearly supports the culture and language of Sami people in Finland in the context of human subjects research, it lacks the inclusion of Sami as equal partners in the development, design, implementation, assessment and dissemination of research in their communities. Although there are not, as yet, specific ethical guidelines for how to conduct community-engaged research with Sami people in Finland, in 2019 the University of Lapland established a working group of Sami professors and organizations to formulate ethical guidelines for research with the Finnish Sami in order to help researchers work in a sustainable way and enhance the self-determination of Sami people in Finland (University of Lapland 2020). The Finnish National Board of Research Integrity also continues to address the development of ethical guidelines for research with the Sami in Finland through meetings with Sami and non-Sami scholars in Finland (Finnish National Board of Research Integrity 2020).

Based on our research findings, we encourage the development of ethical guidelines for community-engaged research with Sami people in Finland that includes (1) the importance of establishing trust in the community academic research dynamic; (2) participation of Sami community members in the development and implementation of research that takes place in the spaces in which they live and work; (3) a commitment to ensure the research is relevant and pertinent to Sami people and respectful and attuned to their language and cultural beliefs; (4) a research philosophy that supports Sami-led decision-making regarding the types of research being conducted in their communities and access to the results of research

conducted in their communities; and (5) the inclusion of Sami people in all phases of a research study including the conceptualization, design, methods, implementation, analysis, and dissemination of results. Our study fills an important gap in the literature related to the growing need for ethical guidelines for Indigenous peoples in the North and the inclusion of their Indigenous and Traditional Knowledge, community-focused perspectives, and decision-making in all phases of research. As noted earlier, national borders were artificially imposed across existing Sami cultural ties between what is now Norway, Sweden, Finland, and Russia. Any proposed solutions regarding research with and about Sami people should reflect awareness of these multiple borders and cross-country connections as well as the diversity of cultural, linguistic, political, and environmental within Sami communities across the North. Given this multi-dimensional context, those entities involved in the development of ethical guidelines for research with the Sami in Finland may benefit from examination of how the highly diverse Indigenous communities in North America, including Native American, Alaskan Natives, and First Nations, have established ethical guidelines and protocols to ensure community engagement, decision-making, and resource-power sharing related to research conducted with and in their communities. Our work enhances the evolving Nordic conversation about how best to conduct useful and impactful community-based participatory research methods with and about Sami communities, particularly but not exclusively around the human-environmental interface in Finland.

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