



A toolkit for Community Based Participatory Research in Greenland

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Award # 1319651 to Elizabeth Rink, Ph.D., M.S.W at Montana State University, Bozeman,
Montana and Gitte Alder Reimer, Ph.D. at Ilisimatursarfik, Nuuk, Greenland.**

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Section 1. Introduction and Background

A brief overview of Community Based Participatory Research and relevance for Greenland

1. Introduction to the toolkit: Why is it written and who it is written for

This toolkit is written as a guide for communities and researchers who would like to conduct research in Greenland through a collaborative and equitable partnership. It is also a resource for anyone conducting research projects in Greenland to educate them on the relationship between research that takes place in Greenland and its impact on communities. Additionally, this toolkit is a guide for Greenlanders who want to gather more information about research and how research partnerships may benefit their communities.

2. What is Community Based Participatory Research (CBPR)? Overview of CBPR and Key Principles

What is CBPR?

“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change...” ~ (WK Kellogg Foundation)

CBPR was developed as an action-oriented strategy for conducting research studies that lead to social change and relevant policy recommendations. CBPR is rooted in social justice, and the concepts of procedural and distributive justice, distributive justice meaning fairness in how the burdens (such as environmental pollution) and resources (such as a clean water supplies) of a society are allocated between groups and procedural justice meaning that isolated communities, people of color, non-dominant or otherwise marginalized groups have an equal voice in decision-making and policy creation (Kuehn, 2000 and Minkler et al. 2012).

Overview

Community based participatory research is driven by the expressed interest and the specific needs of a community. Community based participatory research studies are designed to create a positive social change surrounding the topic expressed as pertinent. In a CBPR study, researchers and local partners work together to meet the goals of the community, making decisions together to define research questions, collect data, interpret research findings and use results to create meaningful change in their communities.

Key Principles of CBPR

- CBPR recognizes community as a unit of identity
- CBPR builds on strengths and resources within a community
- CBPR facilitates collaborative, equitable partnerships in all phases of research
- CBPR promotes co-learning, and capacity building between partners
- CBPR emphasizes local relevance of public health problems
- CBPR shares knowledge and research findings with all partners, and involves all partners in disseminating the project results
- CBPR is a long-term process and commitment

(Source: Hartwig et al., 2006)

3. Why CBPR is a good fit for the Greenlandic context

a. Connection to place and holistic worldview

A key element of CBPR is that it designs research with the needs of a specific community in mind. CBPR is built on an ecological approach, meaning it functions with the understanding that research studies, social change and policy solutions will be different between communities depending on the environment, culture and social structure of that community. Because communities, rather than researchers with a specific expertise, drive the development of research, CBPR is a strategy that can be used across topical areas.

Across Greenland, though mostly in its small settlements and towns, many Greenlanders still live lifestyles that are centered on the natural environment. Often families rely on hunting and fishing for both food and income. Flexibility and adapting to changing weather and fluctuating animal harvests is part of everyday life. The Greenlandic mindset is very focused on the present moment, rather than on planning for the future. Though cities and some other parts of Greenland have become more modernized, a holistic worldview and belief that everything is connected is a pervasive belief throughout Greenlandic culture. Through this lens, research variables are not something that Greenlanders will examine separately from everything else in their lives. This contrasts with many Western research styles which have a linear focus and often dissect topics into a few specific variables. The CBPR approach does not force this type of linear model and, instead works to use a more flexible approach that gathers information about the community using a more holistic interconnected view. CBPR is an iterative research process. This makes CBPR stand out as a practical approach for research in Greenland.

c. CBPR and The United Nations Declaration on Rights of Indigenous Peoples

The United Nations Declaration on the Rights of Indigenous Peoples, adopted in 2007, was a major

b. Shifting systemic power imbalance

In contrast to some Western research approaches, CBPR recognizes that research studies designed in one community do not translate to other communities without adjusting for community context; and that knowledge produced without understanding how a community works, thinks and interacts may not translate into successful interventions, social change or policy changes. To create lasting change, CBPR works with communities to understand not only the topic area, but the values, knowledge and belief systems within each community.

Until 1987, Greenland did not have a university to train researchers, so the majority of scientific inquiry in Greenland has been conducted by researchers who are connected to institutions outside of Greenland resulting in data that is used and stored apart from context in which it was collected. Along with the ethical issues this presents, an outsider approach (where Greenlanders are not involved in the research agenda) can leave research questions that need to be investigated for community well-being or environmental safety unanswered, while less pertinent topics that are not relevant to the community are addressed. This also creates a dynamic where knowledge about a community is held away from the community, which can take power and ownership away from community members. In contrast, CBPR creates local ownership over research topics and data, with communities working in partnership with researchers to set research agendas. This works to balance unequal power systems and minimize the risk of research doing harm or being irrelevant to community interests.



step in recognizing and protecting the rights of indigenous groups around the world. This declaration emphasizes removing mechanisms that have led to systemic discrimination of indigenous peoples and recognizes the distinct identities and cultural integrity of indigenous peoples (OHCHR, 2013). Despite this declaration and indigenous populations recently becoming more visible in decision making spaces and media across the world, indigenous groups are still too often left out of decision making processes and marginalized by profit and production driven systems. In line with the goals of the UN Declaration, CBPR is focused on restorative justice, removing power imbalances and de-colonizing systems and structures that have led to discrimination and subjugation of indigenous peoples. CBPR uses methods that work to build autonomy, and that value local knowledge. CBPR is community driven and honors traditions, beliefs and relationships to place that are central to cultural identity, using these unique strengths to elevate indigenous voices.



4. How can CBPR benefit Greenlandic communities?

Many social issues in Greenland have been developed using a framework that has been modeled after Danish systems and not sufficiently adapted for Greenlandic communities. CBPR projects that center on local voices can initiate systemic changes that benefit and serve the needs of Greenlandic communities.

- Communities can prioritize issues they view as most important by setting research priorities
- CBPR uses local voices to communicate about topics, and empowers community members to be leaders
- CBPR leverages local knowledge to shape policy making
- CBPR has an emphasis on local decision making, and local control of resources
- CBPR builds capacity, such as new skills, new relationships, strategies for decision making, communication strategies, technological expertise and experience working with outsiders
- CBPR can contextualize data and provide deeper understanding of specific issues

Section 2. Step-by-Step guide for conducting community based participatory research



5. The Process: Steps to conducting CBPR in Greenland

a. Developing partnerships

Community based participatory research projects are usually developed through a relationship between a community and a researcher or team of researchers. As a researcher, it is important to spend time in the community as relationships with community members grow. The role of each partner in the project partnership can vary based on project needs, goals, skills, and access to resources. In the beginning, CBPR focuses on developing relationships, learning how the community operates, and identifying key people who can be a bridge in the community-researcher partnership. Furthermore, key principles in CBPR include: 1) learning from and listening to community needs; 2) focusing on community strengths; 3) taking time to be reflective of how the research is being conducted in a community and who is conducting the research

Ideally a project will be developed with input from involved:

- members of the population of focus for the study, for example, if fisherman are the population of the study, they should be part of the research partnership
- community members who will represent the culture and values of the specific community, for example a trusted elder
- community leaders who know how to mobilize community members
- Decision makers in the community
- researchers with training to conduct rigorous studies and who have the desire to learn from the community
- community members, key stakeholders and any potential research collaborators must be involved in the proposal development and proposal application.

It is important to identify a person or people who can serve as liaisons to the community and

can help navigate the challenges of working in the culture and environment of Greenland. This may often be community leaders, business people or school teachers who have experience working with people from outside of the community.

Defining the community

The population of Greenland is roughly 90% Greenlandic and 8% Danish, with other racial/ethnic groups comprising the rest of the population (World Factbook, 2018). In Greenland it is important to note that there are many viewpoints on who is a Greenlander. Greenlanders may be Inuit or of Inuit descent. Greenlanders may also be mixed with Inuit and Danish or other European ancestry. People may also consider themselves a Greenlander if they have lived in Greenland for the majority of their lives but are not of Inuit descent. Despite these differences in view points, the overwhelming majority of the population are of Inuit or mixed Inuit-Danish descent. In Greenland, Greenlanders and Danish citizens hold many professional and leadership roles in Greenland. As CBPR methodology works to de-colonize systems and balance power it is essential that researchers and community partners are clear about the difference between indigenous members of Greenlandic communities and Danish members of the community. This means being intentional in the engagement of Greenlandic community members as community advisory board members, tailoring research protocols to Greenlandic worldviews and belief systems, and gaining the Greenlandic perspective. This does not mean exclusion of Danish community members, or Greenlanders who are both Danish and Greenlandic, rather it requires commitment to building on the voices and identity of the indigenous Greenlanders. As many Danish and Greenlandic/Danish hold leadership or professional roles in Greenland, with education from outside of Greenland, they may be more connected to the western world

and may be easier to relate to for research teams because of culture and language differences. Yet, it is important for outside researchers to build and foster relationships that are representative of the indigenous majority.

Community advisory board

A community advisory board is a key piece for conducting CBPR. Not everyone that is involved in initiating the partnership will be on a community advisory board. The community advisory board is a formalized role, and community advisory board members are usually paid a per diem and/or given some kind of incentive to consistently contribute to the project. Ideally, a community advisory board is developed at the start of the research study and before research protocols are finalized. The community advisory board is made up of community members who are trusted members of the community, and who are willing to represent the project in the community and spend time collaborating with researchers. The community advisory board will work with the research team to develop research questions, make decisions about how to collect data in the community and how to then share that information. The number of members on a community advisory board can range based on the project but is often between 3-6.



b. Building trust, creating vision statements, and developing project principles

Building trust

Trust is an important piece of community based participatory research. Trust allows relationships to grow and must be established so that reciprocal learning can happen between all members of the research team, and so that the research participants can be honest and forthright about the topic with the understanding that the design of the project and motives of research team are to bring positive changes to the participant community. In research studies that do not directly engage community members as study participants, it is still essential to build trust and establish local relationships. The relationship to the natural world is central to Greenlandic life and studies in the natural sciences must engage with communities with respect for that relationship and the local and traditional knowledge of Greenlanders about their natural world.

This trust building process takes time and is an ongoing. Researchers who have worked with Indigenous communities in the US conducting CBPR have developed the following recommendations for building trust:

1. acknowledge personal, communal and institutional histories
2. understand the historical context of research
3. researchers who are from outside the community should be present in the community and listen to community members
4. expertise and knowledge of all partners should be acknowledged
5. partners should be clear and upfront about intentions and expectations (Christopher et al., 2008)

Vision statement

The community advisory board and research partners must work together to develop a shared vision statement. The vision statement clearly states the purpose of the research and goals for its impact on the community.

Examples:

- The purpose of this project is to gather information about food availability in town ____.
- The goal of gathering this information is so that researchers and project partners can explain and communicate specific needs for food availability in town ____.
- Objectives for this project will be to increase capacity to influence policy change, to establish a community voice in food policy and to build relationships.

Project principles

It is helpful for projects partners to create a written list of guiding principles for working together. These principles should be created as a group and will be unique to the community and needs of the project.

These questions can be used to guide the process of creating project principles:

- How will the proposed project build on the strengths of the community and strengthen its capacity?
- How will the partners, their local histories, and where the partnerships are centered influence the direction of the work being proposed?
- What benefits will the community receive?
- How will the proposed project simultaneously conduct research while also addressing long-term systems change (i.e. poverty, imbalance of power between communities and institutions, etc.)?
- What kind of influence will community members have on direction and activities of the project? Who will make decisions?
- How will the community be involved in the project objectives, implementation, evaluation, shared ownership of data, interpretation and dissemination of research findings?

The project principles and vision statement should be written out and kept by each partner to guide interactions and decision making as the research is conducted.



c. Setting research priorities, study design and data collection

Research priorities and the study design must be created based on the level of collaboration decided upon in the project principles. It is important to ensure both academic and community partners are honest and open about their priorities and outcomes for research.

Research priorities

Research priorities must build on strengths, skills and resources available. Research topics must be something the community is already addressing or hoping to address. Projects must build upon the local expertise on the topic area and seek out and highlight local knowledge on the topic. If a topic area is not on the communities mind it is probably not an appropriate topic to address using CBPR. Partners must assess the feasibility of making a change on the research topic, and how conducting research on the topic will impact both participants and the community as a whole. The topic studied must have benefits

that impact the study participants, and the community as a whole as well.

Partners must also address how the study will be funded, what research activities are financially supported, and the duration of funding. The plan for managing and distributing funds must be made clear to all partners. It is important for the CBPR process that funds are dispersed to the community and not held only by researchers and the institutions sponsoring research. Often community members are paid to be on the community advisory board or to work on the research project. Sharing resources and finances is a key piece of maintaining a balance of power.

Developing a study design through collaboration

The level of involvement of community partners in the study design must be based on the project principles. It is not essential that the community advisory board be directly involved in creating all of the research questions and planning the designing. However, the community advisory board must go over the protocol before data collection begins, and the research team and community advisory board must go over the research protocol together to ensure there are no misunderstandings.

The community advisory board must work with researchers to create a research plan and data collection strategy that is culturally appropriate and realistic for Greenland's weather, environment, and time of year. This means the research design must be written with unexpected challenges in mind, such as unexpected travel delays, community events, seasonal community activities or other special circumstances that may delay the research process.

CBPR projects can utilize qualitative, quantitative or a mixed methods design for collecting data. This will depend on the research question and variables being investigated.

- Qualitative methods are appropriate for studies that want to explore or understand a topic further. An example of qualitative data collection could be conducting in-depth interviews and focus groups to explore local attitudes and beliefs surrounding possible adaptations to changing weather patterns.
- Quantitative data collection is appropriate for projects want to describe or explain a specific variable or topic, and to look for cause and effect relationships. For example, a quantitative study could collect data about changes in family income after a new policy that changes a fishing quota.

Using a mixed methods research design is also an option for CBPR, with quantitative collected to describe the research variables, and qualitative data collected to get an understanding of the context surrounding the research variables. An example of this could be a study about a community food environment and could include quantitative surveys to describe what specific foods are available, combined with qualitative interviews to understand local food preferences and eating habits.

Conducting data collection in partnership with community

If it is possible and appropriate community members should be trained to collect data, or to facilitate data collection. Training community members is a good way to build community, strengthen skills, and increase capacity of the community to engage in research and the research topic.

Depending on the nature of the research, community members may not be appropriate for collecting data, for example if there are issues of safety or confidentiality.



d. Interpreting findings within community context

Research findings are shared with participants and community with the community in a structured way. Meeting in small groups with a facilitator is a good way to share initial findings with a community. Depending on the research project, and who the participants are, findings may be shared first with participants in one setting and to the community in a different setting after participants have contributed further contextualization of the findings. The research team must refer to the project confidentiality agreement and use discretion about the level of sharing that is appropriate for the topic area.

CBPR emphasizes that study results are spoken about, written about and presented within the context of the place the research took place and within the social and cultural norms of that place. It is good to use the voices of community members if possible to deepen the connection of the research to the people it is impacting.

Along with the specific context and circumstances of the communities involved in the research study. It is important to keep in mind the political history of Greenland to understand how its systems have been shaped.

Greenland was originally invaded by the Norse in the 10th century, it was later colonized by the Danish in the 18th century. In 1953, Greenland

was 'de-colonized' under Denmark's constitution, but it did not achieve a home rule government until 1979 and Self-Government until 2009. Today, Greenland is self-governing with a parliamentary democracy. However, it is still a part of the Kingdom of Denmark, and Denmark still has control over its foreign relations, national defense and some finances (World Factbook, 2018).

Greenlanders have Danish citizenship and can access services and education in Denmark. However, for some, the differences between Indigenous culture and Danish culture may create barriers for moving between the two cultures. For example, Danish culture is education driven, and Danish youth are encouraged to travel and become independent early on. Greenlandic Inuit culture is focused on family, close ties and living closely to the land and environment where they reside. The geographic separation also means movement back and forth requires substantial time, planning and resources.

It is important for research to address how current policies were developed through this relationship between Greenland and Denmark, and to identify strengths and gaps in how this impacts communities. As well, the fairly recent change to self-government and more local control over topics ranging from environmental restrictions to supply chain management to individual health care services highlights the need for research that is done with the intention of influencing local policy.

With this in mind, research findings that share systemic and structural mis-matches between the intent of policies and the outcome and about context along with research results will be a more powerful tool for communities to use to advocate for themselves.

e. Disseminating results

Based on the project principles, partners will decide on data ownership, and how to share

and store data. Disseminated results must focus on strengths and share the context of data, so it is not misunderstood and does not portray the community in a negative way. How communities choose to use their data will vary.

The project findings can be shared in multiple ways in order to reach a variety of audiences including community members, policy makers, health professionals, political leaders and decision makers. Data must be shared in forms that are accessible for community members. Many Greenlanders listen to the radio consistently, so sharing study activities and study findings through radio programs is a good way to reach community members.

Study findings can also be shared through policy recommendation pieces, posters, artwork, maps, handbooks, scientific journal articles, or presentations. Community partners and researchers both have a role in disseminating results. Examples of this include: presenting findings to policy makers with the research team, co-authorship of publications, or leading community focus groups about the research results.

Data findings will do the following:

- support community ownership over the research topic
- highlight community strengths
- to leverage the voice of the community to create change and shift power balances
- advance knowledge of the topic & the field
- identify further research questions
- make recommendations about policies, programs and services



f. Maintaining relationships and sustainability of partnerships

Research partners must evaluate the process of working together and give and receive feedback. Partners must discuss the strengths of the research team and of the partnership in general. Partners must also discuss the

challenges of working as a research team and provide feedback on what did and did not work in the partnership. This process is crucial to creating an ongoing relationship and identifying strengths of the team that may inform future projects.

The community- research team must also address how effectively the CBPR model and partnership impacted the research topic. Questions to ask include:

- Has there been an improvement in the way partners work together as a result of this effort?
- Does this effort help prevent problems in the community?
- Is there evidence of increased community capacity to deal with the issues involved with this activity? (Center for Civic Partnerships, 2001)

CBPR in Greenland: A case study

Population Dynamics in Greenland was a CBPR project conducted through a partnership between a community in Greenland, the University of Greenland, and Montana State University.

The Greenlandic community that partnered in the study expressed an interest in exploring health in their community surrounding the high number of births, youthful population and pregnancy and reproduction.

The research partnership was developed through a long-term researcher commitment to building relationships in Greenland. Over a 13 year period, the principle investigator developed trusting relationships with community members and Greenlandic researchers at the University of Greenland, resulting in an interdisciplinary partnership that brought together reproductive health expertise, community interest, local and traditional knowledge and researchers with specific cultural expertise.

A community advisory board was developed to guide the research process, to ensure researchers developed the study to meet the needs of the community, was relevant to a local context, and to participate and guide each phase of the research study.

The research partners made multiple trips to the community over a 4 year period to work with community members to implement the study. During the course of the study community members were interviewed by a Greenlandic member of the research team in Greenlandic to investigate the determinants of reproductive health.

In addition, the research partners collaborated with the community advisory board to design the research questions, develop the interview guides for the study, analyze the results of the data collection to determine their relevancy to the community, and identify the best way to share the results with key stakeholders and policy makers in Greenland.

Section 3. Challenges, lessons and ethical conduct for CBPR in Greenland

6. Lessons for community engagement

Process of entering and engaging with community

In the process of community engagement, it is important to always ask formal leaders for permission and to hold open community meetings for anyone to join. It is important to continue this process of asking for permission and holding open meetings even if a community does not respond, or a leader does not have any questions the first time they are approached. This process is essential to building trust and working respectfully. Following this process regardless of the level of community response will ensure projects hold the space for input and questions and conversation when and if those responses arise from leaders and the community. Along with these formal steps of engagement, it is essential to go to the community, and to be physically present. Relationships and trust building require shared physical space and getting to know the rhythms and cycles of Greenlandic life. Email, Skype and phone calls while useful, are not sufficient for building or maintaining relationships.

Presence and in person relationship building is essential regardless of the type of research work being conducted. Earth scientists and other scientists conducting research on the natural environment must also show up, build relationships and foster trust and communication even if they conduct research on non-human topics and do not involve human participants in studies.

Greenlanders have a more holistic worldview than many western scientists. Scientists engaging with the natural world have just as significant an impact as scientists engaging with community members. Continual relationship building, holding meetings with community

members and learning about Greenlandic understandings of the natural world are essential to meaningful engagement and to informed science.

Key lessons:

- Go to the community, be physically present in the community
- Ask permission from formal leadership and continue to do so
- Hold open meetings for the community- at the onset of the project and throughout
- Continuing to hold open meetings regardless of attendance

Language

The use of Greenlandic rather than Danish or English is crucial to engaging with local communities. Often community members who speak English or Danish will represent a life experience that is different than the majority of their Greenlandic community and may not be in line with the experiences of the Greenlanders' voices that may be less prominent. The use of the Greenlandic language in communication and research activities supports a respect for identity and is essential for acknowledging the value and importance of local knowledge.

Research fatigue

Engaging with and working on with academic or research partner's takes time, energy and effort from community members. Research fatigue can be taxing on communities and diminish the quality of research projects and partnerships. With awareness of the possibility of research fatigue, the process of CBPR can include steps to reduce it. Gatekeepers, or community members who may speak multiple languages or have the capacity to facilitate the ability of

researchers to partner with communities can become fatigued and overwhelmed by the time and effort this process takes. Spreading research related tasks and responsibilities between multiple community members can be helpful for reducing research fatigue. As well, though a goal of CBPR is to develop lasting and sustainable partnerships, realistic timelines and breaks between projects within communities to allow for normal life activities and community functions is a part of this sustainability. Researchers need to be careful to manage their own expectations of relationships and not burden community partners.

Incentives

It is necessary for research participants to receive incentives in acknowledgment of their time and contribution to research studies. If research involves individual participants, this may be something like a gift card. However planning for more substantial incentives may be more appropriate in some cases. For example, if the research includes hunters giving up valuable hours of time hunting to participate, it is important that this contribution be recognized and that the incentive truly represent the value of the contribution from that hunter, accounting for the cost to their livelihoods from participating.

In some cases it may be most appropriate to plan for a larger and community focused incentive, rather than small individual incentives. Contributions from research projects to community schools or gathering places, such as adding a school library, or contributing supplies for an art program are examples of incentives that can have a longer lasting impact on the overall community. In other cases, communities may decide building interpersonal relationships is more important and appropriate. Rather than a material incentive, a research team could volunteer time teaching in the school or providing services at the health center. This will depend on the focus of the study, needs of the community and skill set of the study team.

Incentives and contributions to the community are important in all types of research and are not limited to human centered studies. For example, in a hydrology study that impacts a community it is still important to acknowledge engagement of the community even if there are no individuals participating as subjects in the study.



Potential Challenges

- CBPR highlights local voices and values local knowledge. It can be a challenge to effectively communicate these findings with community outsiders, government officials and policy makers who can be more receptive to scientific knowledge and quantitative data, than to indigenous knowledge and data collected using qualitative methods.
- Danish influence has shaped systems and maintained leadership in many decision-making structures in Greenland, this has benefits and detriments to local communities, explaining this tactfully and initiating change within the dispersion of power in Greenland can be a challenge.
- Geographic distances can make building and maintaining partnerships more challenging and can be a barrier to conducting fieldwork successfully (Rink, 2016). Yet, excluding the most remote communities from CBPR partnerships can perpetuate gaps in research about health issues in isolated communities and further health disparities (Ritchie et al., 2013).
- Academic partners and community partners may have different expectations about sticking to research timelines and completing tasks for the project. It is important to address project commitments, budgets and resource allocation and expectations for fieldwork with honest, open and clear communication.
- Weather and transportation in Greenland are unpredictable which can strain research timetables and budgets. It is important to plan for the unexpected.



CBPR compared to Western research methods and community engaged research methods.

Table 1.

	Western Research	Community-Engaged Research	CBPR
Research Objective	Based on data and funding priorities	Community input in identifying locally relevant issues	Full participation of community in identifying issues of greatest importance
Study Design	Design based entirely on scientific rigor and feasibility	Researchers work with community to ensure study design is culturally acceptable	Community closely involved with study design
Recruitment	Based on scientific issues & “best guesses” regarding how to best reach community members	Researchers consult with community representatives on recruitment & retention strategies	Community representatives provide guidance on recruitment & retention strategies and aid in recruitment
Data Collection	Conducted by academic researchers or individuals with no connection to the community	Community members involved in some aspects of data collection	Community members collect data to the extent possible based on available skill sets. Focus is on capacity building.
Analysis & Interpretation	Academic researchers own the data, conduct analysis & interpret the findings	Academic researchers share results of analysis with community members for comments & interpretation	Data is shared; community members & academic researchers work together to interpret results
Dissemination	Results published in Peer-reviewed academic journals	Results disseminated in community venues as well as peer-reviewed journals.	Community members and academic researchers work together to share results (public meetings, radio, bulletin, presentations etc.) Results also published in peer-reviewed journals.

Table 1. adapted from:

Hartwig K, Calleson D, Wallace M. Unit 1: Community-Based Participatory Research: Getting Grounded. In: Developing and Sustaining Community-Based Participatory Research Partnerships: A Skill-Building Curriculum. 2006. www.cbprcurriculum.info

7. Conducting CBPR with Greenlandic communities on sensitive topics

Conducting research on topics like sexual health, suicide, sexual violence and trauma in small close-knit communities can create community turmoil in small, sparsely populated countries such as Greenland. Researchers must be sensitive to confidentiality and aware of participant safety. Researchers must also be aware of their role in the research process and how their presence in the research as either a Greenlander or non-Greenlander may influence the implementation of the research study. Depending on how the research study is designed and who is conducting the data collection, community members may be hesitant or very forthright about experiences with sensitive topics.

Issues community members and researchers partnering together to conduct research on sensitive topics may consider:

- Researchers must be aware of current circumstances of recent and long-term histories of trauma and traumatic events within a community as it may be necessary to adjust research timeframes or protocols to allow communities to process recent traumas.
- Participating in a research study may be a healing and therapeutic process of the research participants. For example; research participants who are able to share their stories or life narratives within the context of an interview and/or a group discussion may experience a relief from stress or empowered because they feel that their voice has been heard.
- Developing research protocols including human subjects consent forms and identifying how data will be stored and who will have access to the data requires working closely with a study's community advisory board and an ethical review board. Community input on appropriate ways to collect data on sensitive topics, who and

how the data is best collected will assist in ensuring that research on sensitive topics is handled culturally and ethically appropriately.

Appropriate referral protocols must be outlined in the research protocols for addressing any distress that may arise from participation in a research study. Outlining this referral process is particularly necessary in the small, isolated towns and settlements in Greenland that are outside the larger urban communities in Greenland.



8. CBPR lessons for the natural science research

Greenland gets a lot of attention from earth science and environmental researchers because of melting ice, sea rise and the availability of natural resources. It is important that these researchers and groups acknowledge the local people, their lifestyles and the impact of their studies on community life.

Things to keep in mind:

- Some communities in Greenland are not familiar with outsiders. Researchers must take the time to explain what they are doing and be present for interaction with the community.
- Greenlandic communities do not separate themselves from the natural world, rather they view themselves as a part of the natural world.
- Even if projects do not involve community members directly, the research that takes place in the environment and landscape of a community influences the flow of community life and can be disruptive.
- The Greenlandic lifestyle is dependent on the plants, animals and nature. Local fishermen and hunters observe the environment year-round and over decades, while many scientists are present for short and sporadic time periods. Still, local knowledge is often left out of policy making, while scientific recommendations are utilized. Researchers can take an active role in shifting this system by including community involvement in study design.
- Bringing local voices into resource management gives ownership and decision making to those who are most affected.
- Involving community members as appropriate in a research study increases local acceptability of the study and increases the reliability and validity of the research results.



9. Institutional Review Boards (IRB), informed consent and biological sampling

Institutional Review Boards

Institutional review boards are a way for funders and institutions that are sponsoring research to ensure study protocols are ethical and designed to maximize benefit and minimize risk to all participants.

Different institutions, agencies and governing entities often have their own Institutional review board and process. In Greenland research goes through an ethical review process through the Commission for Scientific Investigation, and for health research through a Greenlandic Health ethical review board.

For IRB or ethical review, study protocols need to include the following information for reviewers:

- Background, purpose and objectives of the study
- Research methods the study will use and a rationale for choosing them
- Population or research participants
- The plan for recruitment of participants
- Risks and benefits involved for participants

- Plan for ensuring privacy and confidentiality for participants
- Compensation -how study will provide incentives or compensation for participants
- Conflicts of interest
- Informed consent process- documentation of consent from participants

Informed Consent

It is important for research studies to obtain informed consent from all research participants. This is to ensure project participants are aware of the objective of the study, what their participation in it means, and how their privacy will be protected. Informed consent is usually a document that participants sign which outlines these key points about the study and ensures participants understand benefits and hazards of participating in the study.

Biological Sampling

Due to its unique environment, there has been an interest in biological sampling in Greenland.

Biological sampling in order to advance scientific knowledge without consent and transparency, can be and has been a violation of autonomy in Indigenous communities around the world. To remove the possibility of this violation, transparency and disclosure between researchers, medical professionals and community members is important. As well,

researchers and medical staff who wish to further their specific studies must build hypotheses that are of relevance to communities, presenting their ideas and research goals to the community with utility for that community in mind.

Biological sampling without consent and without a clear and planned relevance that serves those from who the sample was taken can contribute to the subjugation of indigenous Greenlanders and perpetuate systems that are based on a top-down, colonial framework. While some biological sampling may be mutually beneficial to community members, scientists and a global body of knowledge, this is a very sensitive area and researchers must be careful and clear with intention and planned benefit for the community and must proceed with understanding of different interpretations between western science and local belief systems. Historical misconduct surrounding indigenous biological samples must be acknowledged. Ethical considerations with full protection for freedom and autonomy must be taken. Without full transparency, informed choices and true mutual benefit, biological sampling can be counter-productive to community well-being and respect for the worldview of indigenous Greenlanders.

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Appendix 1.

The following checklist includes key actions to facilitate CBPR that reflects scientific rigor and meaningful collaboration.

The Project Proposal

___ the project proposal includes the latest literature regarding the topic identified and the existing barriers to change

___ the proposal exhibits a clear and up-to-date understanding of CBPR literature and principles

___ the proposal includes a realistic understanding of the potential limitations of CBPR (such as significant time requirements or subjectivity associated with community data collectors)

___ the proposal provides evidence, such as letters of support or survey results, that the health problem addressed is significant to community participants

The Research Design

___ builds on identified community strengths, such as existing organizations and networks, cultural beliefs, and political will

___ includes community input into plan for data collection approaches that is acceptable to participants and respectful of their culture, time, and resources

A Collaborative Approach

___ includes community involvement in all phases of the research effort and provides structures for shared decision making

___ includes efforts to provide research collaborators and participants with information so they can make informed choices regarding their involvement and contribution to research (e.g., training, materials written in lay language)

___ builds on the knowledge and strengths of community collaborators for research activities such as participant recruitment, intervention development, and data collection (e.g., hiring community research assistants, involving local practitioners)

___ recognizes potential limitations of CBPR approach and takes steps to address those limitations

___ reflects flexibility and rigor to implementing research methods that respect participants' interests

___ includes assessment of feasibility for long-term sustainability within the community

___ presents study results to members of the community (following rules of confidentiality) for their input regarding interpretation, presentation, and dissemination of the data

___ builds capacity that will remain with the community after the researchers are gone, for example; hiring for research jobs, leadership roles, presentation of findings, infrastructure building, proposal writing

___ disseminates research findings while respecting confidentiality

___ shares results with research participants and designs dissemination strategies involving community partners for both academic and community-level distribution (newsletters, videos, lay publications, TV, and radio)

Research Environment

___ includes a section on the community “environment” in terms of individuals that facilitate the research process and things like the availability of facilities for data collection, community advisory board meetings etc.

___ describes the political environment as either a support or challenge related to sensitive research topics such as sexual health, smoking, or domestic violence

___ describes which resources obtained for the proposal are used to enhance the research environment within the community (e.g., computers for data collection)

Budget and Timeline

___ the project includes the resources and the time needed to develop or enhance community partnerships

___ provides resources for recruitment, retention, and partnership building while respecting the cost of research to participants and community partners. (e.g., food, travel, lodging, meeting room rental, office supplies for community-based research staff, reimbursement or incentives for lay health advisors)

___ plans for the cost of training and materials to initiate efforts by the community to address policy and environmental change as a result of research findings