

# THE PRACTICAL APPLICATION OF COMMUNITY-BASED PARTICIPATORY RESEARCH IN GREENLAND: INITIAL EXPERIENCES OF THE GREENLAND SEXUAL HEALTH STUDY

Elizabeth Rink <sup>1</sup>, Dionne Gesink Law <sup>2</sup>, Ruth Montgomery-Andersen <sup>3</sup>, Gert Mulvad<sup>4</sup>, Anders Koch <sup>5</sup>

<sup>1</sup> Montana State University, Department of Health and Human Development, Bozeman, Montana, USA

<sup>2</sup> University of Toronto, Dalla Lana School of Public Health, Toronto, Canada

<sup>3</sup> NAPA, Information Consultant, Nuuk, Greenland

<sup>4</sup> Center of Primary Health Care, Nuuk, Greenland

<sup>5</sup> Statens Serum Institut, Department of Epidemiology Research, Copenhagen, Denmark

Received 16 September 2008; Accepted 25 May 2009

## ABSTRACT

Increasingly, community-based participatory research (CBPR), with its emphasis on engaging communities as full and equal partners in all phases of the research process is being promoted to address the health needs of peoples living in the North American Arctic. However, the CBPR approach is not without its challenges in Arctic countries such as Greenland, where research capacity, different languages, distance, time and cost become barriers to remaining true to the purest form of CBPR. In this paper, we describe the practical application of CBPR principles and methodologies to a sexual health project investigating sexually transmitted infections in Greenland. We present the initial challenges encountered in the early stages of the pilot CBPR sexual health study, and solutions to these challenges. We also provide recommendations for expanding the capacity in Greenland to conduct CBPR projects.

*(Int J Circumpolar Health 2009; 68(4):405–413)*

**Keywords:** Community-based participatory research, challenges, sexually transmitted infections, Greenland

## INTRODUCTION

In the 1980s, Greenland implemented a highly successful gonorrhea intervention project that resulted in a substantial drop in the country's gonorrhea rate. Despite this accomplishment of the Greenlandic health care system, the rates of sexually transmitted infections (STIs) are again high in Greenland. From 2003 to 2006, Greenland reported chlamydial infection rates 10 times higher and gonorrhea rates 100 times higher than the rates reported for Denmark. These are the highest STI rates in the North American Arctic (1). Thus, further research exploring the range of individual, familial, social, cultural and environmental factors contributing to the country's disparately high STI rates is warranted.

Community consultation has been used to improve health studies conducted in Greenland in the past (2). However, community-based participatory research (CBPR), where the community members are involved in the development, design, implementation, analysis, interpretation and dissemination of results, as well as knowledge transmission of the study results, has not been practised in Greenland. In Canada and the United States, CBPR has been identified as an effective method for conducting research in Inuit, American Indian, First Nations and Métis communities, especially in the North because of its emphasis on community-academic partnerships to build mutual ownership of a research project, and its ability to empower communities or groups to address their health disparities in a socially, culturally and environmentally appropriate manner (3,4). In particular, CBPR has been used effectively

to design and conduct research on complex sexual health topics such as STIs and HIV (5,6). CBPR is also beneficial from a scientific perspective because it joins the knowledge, skills and broad experience of researchers with the , knowledge, skills and local experience of the community, thereby enhancing the ability to successfully conduct meaningful research that may improve health (1). Increasingly, health research in the North American Arctic that incorporates a CBPR framework involves non-academic, non-health services community partners, and are longer-term research projects that include community-based interventions. These are promoted as addressing the health needs considered to be most relevant to the communities living in the North American Arctic (7,8). Therefore, the purpose of this paper is to describe our initial experiences with the practical application of CBPR research methodologies in Greenland with the Greenland Sexual Health Study.

## BACKGROUND

The Greenland Sexual Health Study is an international, interdisciplinary collaborative scientific study involving the University of Toronto in Canada, the Office of the Chief Medical Officer and the PAARISA (Office of Health and Preventive Measures) in Greenland, along with the Center for Primary Care in Nuuk. Local health partners in Greenland, the Statens Serum Institut in Denmark, and Montana State University in the United States are also participants. The goals of the Greenland Sexual Health Study were: (1) to quantify the prevalence of different STIs

(chlamydia, gonorrhea, mycoplasma genitalium, trichomonas and bacterial vaginosis) in Greenland; and (2) to identify individual, familial, social, cultural and environmental factors contributing to Greenland's high STI rates. Through this project, we are also able to explore the possibility of using CBPR principles and methodologies to conduct sexual health research in Greenland.

The Greenland Sexual Health Study's partnership began in 2006 with preliminary correspondence between Gert Mulvad of the Primary Care Clinic in Nuuk and the Chief Medical Officer of Greenland. In the spring of 2007 at the Arctic Human Health Initiative Meeting in Banff, Canada, an invitation from Greenlandic and Danish researchers was extended to Canadian and American scholars to come to Greenland, to help build the foundation for a research study on STIs in Greenland using a CBPR framework. Endorsement for the Greenland Sexual Health Study was also received from the International Polar Year in spring 2007. In the fall of 2007, the Canadian and American researchers involved in the project went to Greenland to attend NunaMed in Nuuk, where they presented their initial findings of STI rates in Greenland, met with key stakeholders in Greenland's health care system and proposed CBPR principals and practices as a framework for conducting an STI research study in Greenland. Subsequently, in July 2008 the Greenland Sexual Health Study pilot tested the study's survey instrumentation using cognitive interviewing strategies. In-depth interviews and biologic sampling (self-collected urine and vaginal swabs) from 150 men and women aged 15 to 65 and older living in Nuuk, Greenland,

was conducted through the late summer and fall of 2008, using purposive sampling techniques and locally trained Greenlandic research assistants. Biologic samples were used to check for infection with chlamydia, gonorrhea, mycoplasma genitalium, bacterial vaginosis and trichomoniasis. The initial research project took place in Nuuk, with the intention of expanding the project to Sisimuit, Tasiilaq and other parts of Greenland. The research protocols for the Greenland Sexual Health Project received ethical approval from the University of Toronto in Canada and the Commission for Scientific Studies in Greenland (Kommissionen for Videnskabelige Undersogelser I Grønland, KVUG).

#### **Challenges of using CBPR in Greenland**

Implementing a CBPR project in Greenland poses several challenges. The vast majority of the health research conducted in the country is dominated by partnerships between medical professionals working in the Greenlandic health care system and researchers outside Greenland, where knowledge of CBPR methodologies is low; accessing communities is difficult because of language barriers, geographic distance, cost and time limitations; the concept of community is elusive; and the health care system is the gatekeeper to the community. The specific challenges encountered in the initial stages of the Greenland Sexual Health Study included: (1) community consulting; (2) data collection; (3) financial; (4) accessing the community; and (5) concepts of community.

*Community Consulting.* Consulting with community members on the STI project who were not representatives of the Greenland health care system was one of the first chal-

allenges encountered by the researchers. Historically, health research in Greenland has been driven by researchers whose primary experiences have been in Greenlandic Health Care Services, which has described and analysed the epidemiology of chronic and infectious diseases since the mid-twentieth century (2). This approach to conducting health studies, which involves surveillance, requires the assessment and control of health services, and has provided Greenland's Home Rule Government and the country's health care system with the information necessary to address the healthcare needs of the people living in Greenland. However, this approach has the tendency to minimize the importance of social and cultural knowledge and behaviours. Since there are few Greenlandic-based researchers and research facilities, the tradition of conducting research in Greenland has created a dependency on outside researchers (9). Thus, research in Greenland has been mainly *community-placed* not *community-based* (10).

In the case of the Greenland Sexual Health Study, applying CBPR principles to a study of STIs in Greenland was initiated by the 4 founding partners (University of Toronto, Office of the Chief Medical Officer, Statens Serum Institut, and Montana State University), through discussions and presentations at national and international meetings in Canada, Greenland and Denmark. This was followed by conversations and presentations to key leaders and health care providers from different communities throughout Greenland in order to develop support, collaboration and consensus on using CBPR strategies to conduct the study. Although this formative assessment strategy is considered important

to improving the relevance and effectiveness of a community-based participatory research project, it remains investigator-driven and reliant on expert, rather than community knowledge (11). While it made practical sense to establish a collaborative relationship with the entities in Greenland and Denmark who had the most expertise in conducting research in Greenland, the process did not include gaining the perspective and knowledge of community members. This lack of community-based involvement minimizes the importance of community input, and perpetuates the divide between researchers and community members. The next step for the Greenland Sexual Health Study is to establish community advisory boards at each of the study sites, to ensure that the research is guided by the community and that the community has ownership of the project, as opposed to the research just happening in it (10).

*Data Collection.* To date, the Greenland Sexual Health Study has collected data in Nuuk by conducting in-depth interviews with research participants, as well as collecting vaginal swabs and urine samples to test for chlamydia, gonorrhea, mycoplasma genitalium, bacterial vaginosis and trichomoniasis. These 2 areas of data collection deviated from a traditional CBPR approach, in which community members are involved in the design of the data collection process. Unlike traditional CBPR projects, the researchers generated the research questions and designed the initial survey instruments. However, in order to elicit community members input into the research design (as would be expected in a traditional CBPR approach), in-depth consultations employing

cognitive interviewing techniques were conducted with Nuuk residents. The cognitive interviews lasted anywhere from 1 to 3 hours and served as a means to generate a conversation between the respondents and the researchers on how to encourage community participation in the project, how to word and ask questions in ways that would be appropriate for research participants who identify themselves as either Greenlandic, Danish, or both and how to provide feedback to the community on the study results.

With respect to the biological samples collected in the study, biological samples taken from Greenlanders have been handled in accordance with scientific ethics regulations, and have been sent to Denmark for analysis and, in some cases, bio-banking. This goes against a CBPR framework, in which the results of the biological sampling are owned by the community and the community makes decisions about the use, interpretation and dissemination of those data. A pure CBPR approach would foster the capacity of individual communities in Greenland to maintain their own bank of biological samples, determine the means of analysis and make their own decision about how the biological samples can be used. It became apparent that a research code of ethics (i.e., a data-sharing agreement) was needed to clarify partner roles and use of the data gathered by the project. Upon request from the Greenlandic partners of the project, the other research partners agreed that no identifying information would leave Greenland (consent forms or otherwise), surveys and all other forms would be stored in Greenland, and once biological samples were analysed and the study completed, the biological samples would be destroyed rather than

bio-banked. Because incorporating biological sampling into a CBPR framework is new in Greenland, it will become important for the members of the research team involved in the Greenland Sexual Health Study to communicate to the communities the status of the bio-banking process. This must be done in order to strengthen the relationship between the researchers and the communities, and to build trust and understanding of a research process that involves collecting biological samples (12).

*Financial.* Grant monies acquired for CBPR projects in Canada and the United States call for the funding to be split equitably between the academic partners and the community partners (10). In Greenland there is no precedent for an equal division of financial resources between academic and community partners. For example, in the Greenland Sexual Health Study, research participants were not compensated for their participation in the project. In countries like Canada and the United States it is standard practice to compensate participants for their time with gas cards, gift cards or cash. However, in Greenland in the past, research participants have not been offered any kind of incentive, as participation in scientific studies is meant to be completely voluntary. While this may appear as a monetary savings for the research project, it does not adhere to CBPR practices. In Canada and the United States, CBPR projects rarely succeed if the projects have relied on volunteerism from community members (13). Additionally, in the course of conducting the initial study in Nuuk, some of the research participants stated that they would not participate in the in-depth interviews unless they received some compensation for their time.

*Challenges accessing the communities.* A core philosophy of CBPR is the inclusion and recognition of a community's current knowledge, historical wisdom and insights into a research project. In order to partner successfully with a community and its members within a CBPR context, researchers must spend a significant amount of time with community members, participating in community events and getting to know the community members. In this respect, Greenland presents unique environmental and geographic considerations. The current population of Greenland is 56,000, with the majority of the population living in the southwestern areas of the country. Towns and settlements in Greenland have anywhere from 50 to 6,000 inhabitants (14). Nuuk has 16,000 residents and is the capital of the country. Travel to Greenland is costly (both in terms of time and money), with a minimum of 3 flights through Denmark or Iceland to Kangerlussuaq, and then to other communities in Greenland. If weather permits, the fastest one can get to Greenland from the United States or Canada via Denmark or Iceland is 2 days, but it can take longer if delays are experienced, which is common. Consequently, a minimum 2-week commitment is necessary for research trips to Greenland. This prevents frequent travel to the communities. Travel within Greenland is also expensive and must be by plane, helicopter or boat as there are no roads linking one community to another. Thus, conducting CBPR related projects in Greenland is expensive, and CBPR researchers cannot simply come and go from Greenland, or travel in and around Greenland on a short-term basis to develop research ideas and work on study design and methods with

communities. Rather, CBPR researchers in Greenland must stay in the country over long periods of time to interact with the communities and establish relationships with community members, which takes time and financial resources not only for supporting the research itself but also to sustain the researchers, since they require housing, food and transportation. Frequent and lengthy stays may also be particularly challenging for researchers with families. These findings are consistent with experiences reported by CBPR projects with the Center for Alaska Native Health Research and support the position that application of CBPR principles and methods in Arctic regions of North America, which in many ways resemble Greenland, are tremendously time-consuming and costly, and require long-term commitments by the researchers, the communities and the agencies funding CBPR projects in the Arctic (15).

Due to the above-mentioned issues, the implementation of the Greenland Sexual Health Study began in Nuuk because of logistical ease of transportation to and from the city and because the key partners who were involved with the work of moving the project forward live and work in Nuuk. Nuuk also provides ease of access to multilingual community members representing a cross-section of people living in Greenland who consider themselves to be either Greenlandic only, Danish only or both Greenlandic and Danish. Also, in keeping with a true CBPR approach that utilizes members of the community to implement a project, as opposed to outsiders coming in to conduct the data collection, the Greenland Sexual Health Study hired and trained Greenlandic research

assistants to implement the initial study in Nuuk. These research assistants were not only practical participants in the project but also were members of the community, thus creating a link that strengthened the CBPR approach of the study. Furthermore, 2 of the 3 were interested in research as a career field and understood the importance of insuring that all parts of the process were well documented, including the challenges that were met throughout the process. The limitation to starting a research project in Nuuk is that it is considered Greenland's most cosmopolitan city, with the highest standard of living and may not adequately reflect the entire population of Greenland, their beliefs or cultural practices as a whole.

There have also been challenges related to differences in philosophies among the members of the research team, which has influenced community access. During the planning and implementation phase of the Greenland Sexual Health Study the Canadian, American, Danish and Greenlandic members of the research team needed to candidly discuss how to involve community members in the project, how the data were going to be collected, what kinds of research questions to ask, how the data were going to be stored and who had ownership of the data, who was going to assist in the interpretation of the results and how the data would be shared with the community. It became clear through this process that the members of the research team had different philosophical approaches to the research process. For example, the Canadian and American researchers are accustomed to community involvement, input and decision-making in all phases of a research project, in contrast

to the Danish and Greenlandic members of the research team, who are accustomed to a conventional, epidemiological approach to research that does not include the application of CBPR methodologies. Recognizing the expertise that each member of the research team brings to the project was necessary. Thus, the Greenlandic and Danish researchers involved in the project who work in the Greenland health care system have been the most qualified in getting the project up and running in Greenland by providing access to individuals who can participate in the study, and the Canadian and American researchers have been the most qualified to help the Greenlandic and Danish researchers learn how to implement CBPR projects.

*Concept of community.* A final and important challenge in the initial stages of the implementation of the Greenland Sexual Health Study has been deciding on the concept of community. The Inuit were the original inhabitants of Greenland. However, over the last 3 centuries, the Danish and Christian influence in Greenland has resulted in substantial social, cultural and genetic mixing between persons of Inuit and Danish ancestry. Greenland is politically divided into 18 municipalities (as of 2009, it has 4 municipalities), each with a number of towns and settlements with anywhere from 50 to 6,000 inhabitants (14). Relatively more Danes live in the larger towns. The highest relative number of Danes in Greenland live in the capital, Nuuk. The municipalities are each led by a council and a mayor. All members of council are elected politicians. Consequently, traditional Inuit community structures are not transparent and can be hard to access, especially in Nuuk, and cognitive interviews with residents of

Nuuk suggest that both the identity and the relationship between Danes/Denmark and Inuit/Greenland are very complex. These issues raise uncertainty about what constitutes a community in Greenland, as some individuals may identify their community as a geographic location in Greenland, whereas others define it by the language they speak, where they grew up, how long they have lived in Greenland or what kinds of activities they participate in. The increased heterogeneity in Greenlandic communities and the inherent differing viewpoints on what constitutes community and defines its members adds another layer of complexity to conducting CBPR projects in Greenland. It can be difficult to determine who can speak for the community on its behalf and who should be included as a partner in the project. This issue of what constitutes a community in Greenland has influenced how the research team has approached implementing the project, in that we have continued to rely on members of the Greenlandic health care system to assist in working with the community. It was also necessary for research documents to be translated into Greenlandic, Danish and English in order to be inclusive of all individuals involved in the study, and although the project was initiated in Nuuk, it will be expanded to other communities in Greenland in order to provide a broad representation of the individual, familial, cultural and environmental factors contributing to Greenland's high STI rates.

#### **Future directions for CBPR in Greenland**

The Greenland Sexual Health Study has identified some areas of concern for using CBPR in Greenland that are primarily

grounded in the historical difference of the way research has been conducted here. CBPR is a new approach to research in Greenland that does not negate the conventional model of conducting investigator-driven, epidemiological research, but it provides a different method of investigation. However, if a CBPR research approach is to be advantageous in Greenland, a number of factors need to be considered. First, to lay the foundation for CBPR research from being community-placed to community-based, researchers who conduct studies in Greenland must begin to recognize the value of involving the community actively in research. Additionally, the training of medical professionals working in Greenland, as well as the employment of the Greenlandic University's professors and Ph.D. students will speed up the process of educating young Greenlandic scientists. This, along with workshops with relevant community representatives offering courses to students at the University of Greenland's School of Anthropology, Health Education and School of Sociology are needed to provide education on CBPR principles and methodologies in order to build the capacity for local expertise in conducting its own CBPR research and intervention projects. Second, allocation of funding and policies must be adequate to support CBPR projects. Third, community advisory boards comprised of academic and non-academic, health care workers and regular community members must be established to provide oversight, guidance and a community voice to CBPR projects in Greenland. In the years to come, the Greenland Sexual Health study will show to what extent the CBPR approach is feasible and advantageous in Greenland.

## REFERENCES

1. Gesink Law D, Rink E, Mulvad G, Koch A. Sexual health and sexually transmitted infections in the North American Arctic. *Emerg Infect Dis* 2008;14:4–9.
2. Bjerregaard P, Mulvad G, Olsen J. Studying health in Greenland: obligations and challenges. *Int J Circumpolar Health* 2003;62:5–16.
3. Holkup PA, Tripp-Reimer T, Salois EM, Weinert C. Community-based participatory research: an approach to intervention research with a Native American community. *Adv Nurs Sci* 2004;27(3):162–175.
4. Mail P, Conner J, Conner C. New collaborations with Native Americans in the conduct of community research. *Health Educ Behav* 2006;33(2):148–153.
5. Hampton M, McNabb-McKay K, Jeffery B, et al. Building research partnerships to strengthen sexual health of Aboriginal youth in Canada. *Aus Comm Psychol* 2007;19(1):28–38.
6. Reece M, Dodge B. A study in sexual health applying the principles of community-based participatory research. *Arch Sex Behav* 2004;33:235–247.
7. Lightfoot N, Strasser R, Maar M, Jacklin K. Challenges and rewards of health research in northern, rural and remote communities. *Ann Epidemiol* 2008;18:507–514.
8. Smith H, Bjerregaard P, Chan H, Corriveau A, Ebbesson SO, Etzel RA, et al. Research with Arctic peoples: unique research opportunities in heart, lung, blood and sleep disorders. *Int J Circumpolar Health* 2006;65(1):79–90.
9. Teufel-Shone N, Siyuja T, Watahomigie H, Irwin S. Community-based participatory research: conducting a formative assessment of factors that influence youth wellness in the Hualapai community. *Am J Public Health* 2006;96:1623–1628.
10. Isreal B, Schulz A, Parker EA, Becker AB. Community-campus partnerships for health. Community based participatory research: policy recommendations for promoting a partnership approach in health research. *Education for Health* 2001;14(2):182–197.
11. Merzel C, D’Afflitti J. Reconsidering community based health promotion: promise, performance, and potential. *Am J Public Health* 2003;93(3):557–574.
12. Boyer B, Mohatt G, Pasker R, Drew E, Drew EM, McGlone KK, et al. Sharing results from complex disease genetics studies: a community based participatory research approach. *Int J Circumpolar Health* 2007;66(1):19–30.
13. Burhansstipanov L, Christopher S, Schumacher A. Lessons learned from community-based participatory research in Indian country. *Cancer Control* 2005;11:70–76.
14. Kjeldsen A. Health and society in Greenland. *Int J Circumpolar Health* 2005;64(3):257–259.
15. Boyer B, Mohatt G, Lardon C, Plaetke R, Luick BR, Hutchison SH, et al. Building a community-based participatory research center to investigate obesity and diabetes in Alaska natives. *Int J Circumpolar Health* 2005;64(3):281–290.

*Dr. Elizabeth Rink  
 Department of Health and Human Development  
 Montana State University  
 318 Herrick Hall, Bozeman  
 MT 59717-3540  
 USA  
 Email: elizabeth.rink@montana.edu*