DEVELOPING A CULTURALLY COMPETENT AND
SOCIALLY RELEVANT SEXUAL HEALTH SURVEY
WITH AN URBAN ARCTIC COMMUNITY

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ABSTRACT

Objectives. To develop a culturally competent and socially relevant sexual health survey for people living in Nuuk, Greenland, aged 15 years and older.

Study Design. Qualitative study with interviews.

Methods. Community and research informants (n=10) were interviewed informally to identify survey topics. A sexual health survey was constructed combining local knowledge from informants with a review of sexual health literature for the Arctic and other Indigenous locations. The draft survey was distributed to community partners for commentary and revision. After translation into Danish and Greenlandic, cognitive interviews were conducted with 11 Nuuk residents, identified through snowball sampling, to both pilot test the survey and exchange social and cultural knowledge relevant to sexual health in Nuuk. The utility of this process was evaluated against implementation of the final survey to Nuuk residents enrolled in Inuulluataarneq (n=149).

Results. Theme saturation was reached by the ninth interview. STI risk and self-efficacy, co-occurrence of alcohol use and sex and STI knowledge were identified as most relevant. Questions about community efficacy, culture/community involvement and identity were most sensitive. Upon implementation of the final survey, 146 of 149 participants answered all survey questions. Two Elder participants refused to answer questions about sex. Some questions had low response variability but still added to our contextual understanding and helped to build rapport with participants.

Conclusions. Combining an iterative process with community-based participatory research principles and cognitive interview techniques was an effective method for developing a sexual health survey with Nuuk residents.

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Keywords: Aboriginal health, cultural competency, knowledge translation, sexual health, survey methods
INTRODUCTION

Greenland’s medical and public health system has several success stories on preventing the spread of human immunodeficiency virus (HIV) and reducing the burden of other sexually transmitted infections (STIs), like gonorrhea (1–6). Despite these accomplishments, Greenland still reports the highest STI rates in the Arctic (Greenland reports Chlamydia rates ten times higher than Denmark, seven times higher than Alaska and twice as high as northern Canada (7)). Access to STI health care services, timely diagnosis and treatment of infections and active contact tracing of sexual partners has helped lessen the STI disparity between Greenland and the rest of the world; however, it was hypothesized that other strategies may be warranted to eliminate the disparity. It was further hypothesized that these strategies may need to focus on the social, cultural and environmental factors influencing sexual health and STIs. To address these hypotheses, Inuullutaarneq (the Greenland Sexual Health Project) was initiated.

The goal of Inuullutaarneq was to take a community-based participatory research approach to investigate the factors influencing sexual health and STIs in Greenland by (1) surveying Greenlanders 15 years old and older about their sexual health and (2) testing participants for STIs. Consequently, we needed to develop and test a sexual health survey relevant to the social and cultural context of Greenland before administering it to the broader population. Many sexual health surveys and psychometric instruments have been developed, tested and validated for communities outside of Greenland; however, these instruments may not be directly applicable to the Greenlandic context (8) and needed to be validated cross-culturally.

Our objective is to describe the process we used to develop a culturally competent and socially relevant sexual health survey for people living in Nuuk, Greenland, aged 15 years and older, who are predominantly Greenlandic (Inuit) and Danish.

MATERIALS AND METHODS

Study setting
Geographically, Greenland, the largest island in the world, straddles the Arctic Circle in the Atlantic Ocean and is part of the North American continent. Politically, Greenland was colonized by Denmark in 1721, granted Home Rule in 1979 and became self-governing on 21 June 2009, making it the first Indigenous population to be autonomous in modern times. The population of Greenland (2007 population=56,648) is still predominantly Inuit or of Inuit descent (more than 80%), though there is also a significant foreign-born population (approximately 11%) that is predominantly Danish (Statistics Greenland, 2007). Inuit in Greenland prefer to be identified as Greenlandic. Both the Greenlandic and Danish cultures are influential in defining the Greenlandic identity. Our investigation was conducted in Nuuk, the capital of Greenland and the largest town (population approximately 15,000). We kept a wider age demographic because even though the prevalence of Chlamydia infections are highest for youth (under 25), gonorrhea, syphilis and HIV typically afflict an older demographic (7). HIV in Greenland is highest among, and almost limited to, Greenlanders over the age of 50 (9). We were also interested in the social and cultural factors influencing STI transmission, so it was important to get an understanding of the attitudes,
perceptions, beliefs and practices of the adult generation since they are teachers, mediators and models for the younger generation.

**Process**

We combined an iterative process with community-based participatory research principles and cognitive interview techniques to develop the sexual health survey (Fig. 1). First, local sexual health knowledge was gained by conducting informal interviews with key community and research informants. Next, local and global knowledge were integrated using community informant discussions and a review of the sexual health literature for Greenland and other Indigenous and Arctic communities to develop survey topic areas. Standard survey instruments for these topics were identified when possible. A draft of the survey was distributed to the research partners for commentary and revision.

After translation (and further revision) into Greenlandic and Danish, cognitive interviews were conducted with Nuuk residents to both pilot test the survey and exchange social and cultural contextual knowledge relevant to studying sexual health and STIs in Nuuk. Here, we use the term cognitive interview to mean the method used to investigate (1) the mental process respondents use to answer survey questions, including how they comprehend questions and directions, recall information, make decisions and judgements, formulate answers and verbalize responses (10), and (2) the cultural competence and social relevance of survey questions, including identification of

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**Figure 1.** Diagrammatic representation of the iterative process used to develop a culturally competent and socially relevant sexual health survey for Greenlanders 15 years of age and older.
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taboo topics, cultural sensitivities and how to ask sensitive questions, culturally appropriate wording, social norms and socially acceptable behaviours as they pertain to sex and relationships, any gaps in knowledge around STI transmission in Nuuk, and which questions were relevant to the Nuuk context.

Finally, we evaluated the effectiveness of our process against the implementation and responses to the final survey both in terms of completeness and variability in survey responses. This study was approved as ethical by both the Kommissionen for Videnskabelige Undersøgelser i Grønland and the University of Toronto.

RESULTS

Step I: Local sexual health knowledge
We conducted informal interviews with 7 community informants from Greenland and 3 Danish researchers who were conducting health studies in Greenland; to date, Danish practitioners and researchers have predominantly provided health care and led health studies conducted in Greenland. Community informants included physicians, nurses and midwives working in Nuuk (n=5) and other parts of Greenland (n=2). Most of these interviews were conducted during the Greenlandic health system’s NunaMed conference, held in Nuuk, September 2007. Interviews with Danish researchers were held in Copenhagen, Denmark, at the Statens Serum Institut and the National Institute of Public Health in November 2007. These are the 2 institutions out of which the bulk of Greenlandic health research has been conducted. Community and research informants were asked four questions: (1) what they knew about sexual health and STIs in Greenland, (2) why they thought STI rates were so high, (3) how we should go about studying STIs in Greenland, and (4) what topic areas to focus on if we were to develop a survey.

Step II: Integration of local and global sexual health knowledge
Decisions about sexual health process scales and topics to focus on for the survey were informed by both interviews with community and research informants in Greenland, and previous sexual health studies conducted in Greenland (2,6,9,11,12), the Canadian Arctic (13-15) and in American Indian communities in the United States (16–19). We hypothesized that individual, family and social (partners, peers and community) factors were influencing sexual health and STIs in Greenland (Fig. 2). Based on our conceptual model, the original survey included questions on (1) family, peers and community norms, (2) sex, susceptibility for a sexually transmitted infection and partners, (3) sexual partners and condom use, (4) mental health and wellness, (5) efficacy and social support, and (6) identity and culture. When possible, standard psychometric instruments were used to measure the characteristics and behaviours hypothesized to be associated with STIs in Greenland (12,17,20–25).

Step III: Translation
A thorough translation process improves the validity of survey results. Four trilingual Greenlandic translators (fluent in English, Danish and Greenlandic) were hired to translate the sexual health survey from English into Greenlandic and Danish. The survey was translated and back-translated in 2 rounds. The first round of translations was for cognitive
Step IV: Cognitive interviews
Cognitive interview techniques (10) were used both to test the quantitative sexual health survey and to exchange social and cultural knowledge relevant to studying sexual health and STIs in Nuuk.

Study sample
In 2007, Nuuk had a population of 15,047; 16% of Nuuk residents were 15 to 24 years of age and 60% were 25 to 65 years of age (26). A sample of participants reflecting the study population (Greenland residents 15 years old and older) were identified using a snowball sampling strategy, stratified on age (youth, adult), gender (male, female) and ethnicity (Greenlandic, Danish or both). Key informants were used to identify initial potential respondents. Snowball sampling was used to identify the rest of the respondents through word of mouth. Subsequently, 11 Nuuk residents were identified and contacted either face-to-face or by phone and asked to participate in the study.
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Cognitive interviews
Cognitive interviews were conducted in Nuuk by the principal investigators at a private and secure location agreed upon by both the investigators and the participant. Interviews started with the consent process, after which the sexual health survey was administered and timed. Verbal parental consent was also obtained for participants under 18 years of age. Consent forms and the sexual health survey were available in Greenlandic, Danish and English, and participants could choose which printed language they wanted to use. Cognitive interview questions were open-ended and in English only. A translator was available to assist with interviews.

Upon completion of the survey, the primary interviewer proceeded to administer cognitive interview questions, beginning with questions about the survey overall, then individual questions specifically. Cognitive interviews were conversational and questions were open ended to facilitate a more open and free exchange of sexual health knowledge between the local participant and the interviewers. Participants could “think aloud” (10) in response to cognitive interview questions and interviewers used verbal probing techniques to elicit more detailed information on the context and nature of problems, as well as alternatives and potential solutions, when problems were identified. Interviews took between one and a half and three hours to complete.

Cognition questions about the survey overall were developed to assess the length and emotional impact of the survey, explore ease of transitioning between survey sections, gain insight into overall relevance and importance of survey questions, including whether the questions would actually assist in determining what factors were driving sexual infections in Nuuk, and facilitate sexual health knowledge exchange. Example cognitive questions about the survey overall included:

- How difficult was it to transition between sections of the survey?
- How would you structure this survey?
- How relevant are the questions?
- Which are the three most important questions?
- Which three questions would you remove?
- What questions are missing?

Cognitive questions for individual survey questions were developed to determine the social and cultural relevance of specific questions; evaluate how the study population might understand, mentally process, and respond to the survey; and find sources of error (10), including wording or instruction difficulty for interviewers, instructions for participants, clarity of the questions (cultural or linguistic considerations, reading or comprehension level, vagueness, dependent responses, clarity of intention, understanding), assumptions (asking more than 1 question, consistency of behaviours), knowledge, sensitivity and bias (cultural appropriateness and competency, social acceptability, traumatizing questions), structure and response categories (open vs. closed, insufficient category options, ordering) and variability in responses (Table I; complete cognitive interview questions available upon request).

Content analysis was conducted to look for common themes around problems, missing questions, sensitivities and suggested solutions (Table I). If 1 or more persons identified a problem with the same question, the question was re-examined and revised. The structure of, and questions included in, the sexual health survey were revised to accurately reflect decisions made in response to the knowledge gained (Table I).
| Original survey question | Cognitive questions | Sample of responses | Revision to survey |
|--------------------------|---------------------|---------------------|-------------------|
| How much do/did you trust your most recent sexual partner? (Totally trust, Mostly trusted, Suspicious, No trust) | • What does “trust” mean to you here?  
• What were you thinking when I asked you about trusting your partner?  
• How well does this question apply to you?  
• Would you say your trust stays the same or does it vary or depend? | • If he’s gonna behave alright and be honest about having an STI – behave meaning talk a lot to other people about me  
• Good question because you don’t always trust your partner  
• Well, I guess  
• Depends on whether serious boyfriend or just some guy you met at a party | Unchanged |
| How safe do/did you feel with your most recent sexual partner? (Completely safe, Somewhat safe, Unsafe) | • What does “safe” mean to you here?  
• What were you thinking when I asked you about feeling safe with your partner?  
• How well does this question apply to you?  
• Would you say feeling safe stays the same or does it vary or depend? | • You don’t get STI or get talked bad about, same as trust  
• Good question  
• Well  
• Depends  

Follow-up Probe:  
How does this question compare to the trust question?  
Feels like almost the same question | Removed |
| How often do you have sex under the influence of alcohol or drugs? (Never, Sometimes, Often, Always) | • How did you come up with your answer?  
• Do all the possible answers here seem okay or did it seem like there was a right answer?  
• How would you ask this question on a survey to people your age? | • Sometimes I hook up at a party when I was drunk, but lot of times I was sober so not a lot of times, know it will happen again  
• No right answer  
• Have you ever drank and had sex? Then this question: Over the past three months, as a percentage, how often did you get drunk and have sex? | • How often do you drink and have sex? (Never, Sometimes, Often, Always)  
• How often does alcohol affect your ability to make good sexual decisions? (Never, Sometimes, Often, Always)  
• Over the past three months, as a percentage, how often did you get drunk and have sex? | Heavily changed |
Results: Cognitive interviews (Step IV)

Cognitive interviews were conducted with 11 Nuuk residents ranging in age from 16 to 45 years (5 under 20 years; 6 25-to-45-year-olds; 5 males; 6 females; 4 were Greenlandic; 2 were Danish; 5 were Greenlandic and Danish). All participants had lived in Greenland for at least 2 years and spoke English. Language was not a barrier for identifying survey problems or solutions. Theme saturation was reached by the ninth interview, so we conducted 2 more interviews to ensure we would not gain more information by interviewing more people (27). Minimal new information was gained so cognitive interviews were stopped after 11 participants.

Sexual health survey overall

Generally, participants felt most of the survey questions were relevant. One participant stated,

“They are really relevant because they make you think about how you are living.”

The structure, flow and clarity of the questions needed improvement. It was suggested that identity questions remain at the end of the survey because, if asked at the beginning, participants would think we were trying to compare Greenlanders with Danes and would affect their responses. Several participants also indicated that questions about community efficacy (how well the community, both Greenlandic and Danish, works together to overcome challenges) and community involvement (types of activities an individual participates in as a community member) were sensitive enough that some participants could become quite upset, again possibly affecting their responses to the rest of the questions in the survey.

STI risk and self-efficacy, co-occurrence of alcohol use and sex, and STI knowledge were most frequently identified as the most important questions in the survey. Partner trust was also identified as an important factor influencing sexual decision-making.

When probed about what questions were missing, 4 themes emerged: demographics, capturing identity, communication, and high-risk activities. Some participants felt our survey was missing several sensitive questions about being in a high-risk environment; namely, that we should ask about sexual abuse and “partying.” Several participants noted that sexual abuse was highly prevalent in Greenland and one participant noted that; “sexual behaviours when you are older are influenced by sexual abuse when you are younger.”

Sexual health survey questions specifically

Community efficacy questions that touched on the relationship between Denmark and Greenland sparked the greatest reaction. We hypothesize that this sensitivity is part of the complex social, cultural and political tensions between Greenland and Denmark as the decolonization and self-governance process continues.

Questions about traditional activities were sometimes perceived as testing just how Greenlandic one was, and several respondents said these questions were about old Greenland, not modern Greenland. There was evidence of research fatigue around questions pertaining to traditional activities and many did not see any influence of traditional identity or activities on sex or STIs.

The issue of how one self-identifies versus how society identifies an individual was raised. One participant explained, “In Green-
land, I am viewed as Danish, and in Denmark, I am viewed as Greenlandic,” and, as such, the participant felt he/she was not really recognized as belonging to either community. Several participants shared this experience. It was suggested that to measure identity correctly, 2 questions should be asked: (1) Which language does the participant wish to use, or which language does the participant use to speak, read and write? and (2) Where did the participant grow up (Denmark, Greenland, both, elsewhere)?

Participants felt that identity was an important consideration when it came to sex and that differences exist between Greenlanders and Danes when it comes to sex; however, the nature of this difference remains unclear. Greenlanders were perceived as being more open about having sex. One participant remarked, “Greenlanders are very sexually active. People have never been shy or taboo about sex. Abstinence is not something any parent in Greenland would say. [People are] active from a young age.”

This is in line with earlier studies’ findings that Greenlandic youth have an early onset of sexual activity (28,29).

In contrast, Danes were perceived as more open to talking about sex, especially within families, a phenomenon said to seldom occur in Greenlandic families. While some participants identified openness to talking about sex as a cultural difference between Danes and Greenlanders, others suggested that this openness was more a function of education. Open communication within the family was identified as important in preventing the spread of STIs. It was suggested that the survey include questions about how sex is talked about within the family and whether the participant has trouble talking about sex.

Lack of taboos around sex may explain why respondents, regardless of ethnicity, struggled with the abstinence question on the survey. When we asked respondents to repeat the abstinence question in their own words, they were able, but most respondents laughed and many qualified their response by saying “…but I don’t believe in it” or that the question was “old fashioned.” As one participant explained, “I don’t want to go there because sex is important; of course we have sex.” One participant likened abstinence to “…my Dad’s bad jokes.”

Four different participants described a language distinction between how questions are asked in Greenlandic versus Danish. We were told that careful attention needed to be placed on negative wording. To repeat a particularly clear example:

“In Danish, you might ask ‘Wouldn’t you like to go to the movies with us tonight?’ and the Danish response would be ‘Yes,’ meaning ‘Yes, I would like to go to the movies with you’; but the correct response in Greenlandic would be ‘No,’ because ‘No, I would not not like to go to the movies with you.’

This distinction helped explain the difficulty Greenlandic respondents had with several of our negatively worded questions. It also became apparent that if participants felt they could see why we were asking a question, they were much more open, trusting and candid with their responses. It was recommended that indirect questions be asked more directly.

Two common themes emerged regarding sex and alcohol, sex and drugs and transac-
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Tional sex (exchanging sex for money, alcohol/drugs or food) in Nuuk: (1) alcohol use is related to sex, and cannabis is the only drug in Greenland and its use is not related to sex; and (2) there is no commercial sex work in Nuuk. A police officer verified that the only drug in Greenland was cannabis and that commercial sex work did not exist (Officer J. Brant, personal communication, June 2008). However, during our interviews it became clear that there was a lot of sex being traded for alcohol and that no one perceived this as transactional sex. It was also suggested that sex was sometimes traded for a safe place to sleep.

Sexual health survey revisions: We restructured the survey so that it started with non-sex questions about demographics and mental health, then gradually introduced more personal questions about sex, including:
- Exposure to STI information and testing
- STI knowledge
- Perception, behaviour and intention questions about STI risk
- Condom use, behaviours and intentions
- Number of sexual partners
- Relationships and partnership dynamics
- STIs and accessing STI health care services

We ended the survey with non-sex questions about community, social support and identity.

Some participants identified exposure to high-risk environments as an important factor influencing STI transmission in Nuuk. We hypothesized that built environments could influence STI rates indirectly in one of two ways. First, built environments have been associated with depression (30,31), and depression with increased risk for STIs (32). Second, poor built environments have been associated with elevated alcohol use (33), and alcohol use with increased risk for STIs (34,35). Depression is known to be high in Greenland (36), and we found evidence of the co-occurrence of alcohol use and sex in Nuuk (data not shown). Consequently, we added questions about built and natural environments.

Limitations
We had a good cross-section of participants representing the study population; however, we did miss some important groups during cognitive interviewing. We did not have any respondents in the 20-to-24-year-old age group, and all our participants were well educated, so we did not end up testing our survey on young adults or undereducated Greenlanders.

Step V: Sexual health survey evaluation
Upon implementation of the final revised survey in Nuuk as part of the larger ongoing sexual health investigation and intervention in Greenland, 146 of 149 participants answered all survey questions. Two Elders refused to answer questions about sex, and a third participant, over 40 years of age, did not answer 3 questions on condom use with different types of partners.

Generally, variability in survey responses has been good; however, in Nuuk, there has been little variability in response to social support (98% had someone they could depend on if they needed help, 2% did not), or comfort with their sexual experiences (91% comfortable, 9% not comfortable).
DISCUSSION

We found that combining the iterative process with community-based participatory research principles and cognitive interview techniques was an effective way of developing a culturally competent and socially relevant sexual health survey for people living in Nuuk, Greenland.

Guidelines on how best to ask sensitive questions about sex and STIs have been well documented in the literature (37–41). However, often, these guidelines have been developed in the context of individualistic societies and have not been applied in collective or Indigenous societies, like Greenland. We found it was best to ask all questions directly, rather than circling the question of interest with a series of indirect questions. Indirectly asking questions raised suspicion in respondents, eroded rapport and hindered candid responses. Participants were much more candid and honest if they knew the motive behind the questions, which was achieved by asking questions directly. This directness and literalness needed to be taken into account when wording and translating questions as well.

Asking Elders about personal sexual health using a survey format was not effective. We also found that some of the questions we identified as important or that were added during cognitive interviews lacked variability in responses. Despite low variability, however, the results to these questions did lend insight into the contextual setting in Nuuk and helped build rapport with participants.

We found a slight bias for questions that touched upon conflict. Historically, conflict avoidance would have been vital for survival in the North because it would have been extremely difficult for an individual to survive the environment without the group or collective. When we asked questions about the community and its ability to come together to solve problems (community efficacy questions), if a Greenlander was responding and did not want to disagree with a statement involving cooperation between Greenland and Denmark, he/she would tend to say “I don’t know” rather than “I disagree,” while a Danish respondent would disagree directly. As well, we were instructed to place questions with an element of social conflict — for instance the community efficacy, community involvement and identity questions — at the end of the survey, as these were the most sensitive questions.

We noticed also that questions assigning emotions did not perform well. Originally, we included the question, “When I think about my sexual experiences I feel sad” (25); however, this question caused problems for several respondents. One respondent said, “I would tend to disagree even if it was not true”; another said, “[I feel] a bit glad because I was reminded how life could suck”; and a third said, “When I think about my sexual experiences ‘I feel sad’ makes me think about sexual abuse. This is a very difficult question because it will be hard for some people. The last two questions are difficult for Greenlanders. It needs an ‘I don’t want to answer’ category.” We did not want to ask about sexual abuse at this point in the survey, and were concerned that if respondents started dwelling on sexual abuse, it might influence the rest of their responses. However, we did want to get a sense of how “at peace” or comfortable participants were with their sexual history, so we reworded the question to read “I am comfortable with my sexual experiences” and included “agree,” “disagree” and “don’t know” as response categories.
A survey section devoted to sexual diversity (i.e., lesbian, gay, bisexual, transgender/sexual and questioning, or LGBTQ) was not explicitly included in the survey, because we did not hypothesize that it was contributing to STI transmission in Greenland. Community informants told us that being LGBTQ was not socially acceptable so most LGBTQ individuals left Greenland for Copenhagen as soon as they were old enough. Our own observations suggested that this was true, that a hidden LGBTQ population would be very small, and that responses to questions about sexual diversity would be unreliable as LGBTQ individuals would not be willing to self-identify to local interviewers, even if confidentiality was assured. That having been said, we did word our sex and relationship questions to be gender neutral and not to assume heterosexual partnering so that LGBTQ individuals could easily respond to all questions. We also asked respondents to quantify both male and female sexual partners, with the option to self-administer that question so we could try to get some sense of the proportion of same sex partnering for each gender.

Community review and input helped translate standard instruments into more culturally competent and socially relevant tools. We recommend using a similar process that integrates local and global sexual health knowledge in future research with Arctic communities. This would better ensure that data collection strategies are congruent with how people living in isolated northern settings receive and process information related to their sexual health.

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