



## Health Research Ethics Workshop and Community Consultation

Rankin Inlet, NU

November 13–15, 2007

### Summary Notes

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In a workshop held in November 2007, participants from around Nunavut gathered to discuss health research, ethics, and health research priorities for Nunavut. The participants were from Iqaluit, Gjoa Haven, Rankin Inlet, Cambridge Bay, Kugaaruk, Clyde River and Ottawa, ON.

#### **I) INUIT AND COMMUNITY PERSPECTIVES ON ETHICS AND HEALTH RESEARCH**

##### Ethics

Participants were given a short presentation on ethics in research and learned about five principles of ethical research:

- beneficence (doing good, ensuring the research will have a benefit,
- non-maleficence (doing no harm)
- autonomy (the right to refuse participation)
- dignity (treating participants with dignity)
- truthfulness and honesty (about the nature of the research)

Participants also received short fact sheets developed by Qaujigiartiit/AHRN-NU on the CIHR Guidelines for the Conduct of Health Research with Aboriginal Peoples.

During discussions, 'Inuit ethics' were discussed by participants and it is important to note that participants requested more dialogue with elders in future discussions about ethics in Nunavut.

The information participants shared in this meeting will be used to inform the development of a Qaujigiartiit/AHRN-NU Ethics Checklist for communities to use when reviewing health research proposals.

##### Recommendations for researchers:

The participants at this workshop added the following recommendations for researchers coming to Nunavut:

- Researchers should consult with the community (about research questions, health topics, finding assistants, etc.), and especially elders when there is an opportunity
- Researchers should provide training opportunities when they are in communities, by:
  - o Including community members in the research through consultation with local knowledge holders or hiring local research assistants
  - o Holding open forums and presentations in the community and/or visiting and speaking in schools.
- Results should be returned to the community in a format that is useful and understandable, such as through community radio, through community presentations, posters and informative pamphlets if appropriate, etc..

#### Inuit-related research

Participants would like information, results, and published studies that pertain to Inuit health gathered to one central location where it can be accessed by any who needs it, as the information could be used by community and territorial organizations in Nunavut.

#### Information about research processes in Nunavut

- People in communities need more information about the research process, particularly:
  - o How projects are licensed
  - o Who in the communities and in the territory are consulted during the development of the research project and during licensing
  - o How to increase community involvement in the research process from start to finish

## **II) CRITERIA AND PRIORITIES**

Participants in the workshop identified priorities for health and criteria for the conduct of health research in Nunavut, through a series of group exercises.

### **Health (research) priorities**

- A. Mental Health and Well-being
  - Cultural identity; cultural continuity; language loss; Rapid change and victimization
  - Addictions: drugs, alcohol, & gambling

- Emotional health; depression; self esteem; peer pressure; jealousy; anger; inferiority; emotional support for family caregivers and front-line workers
- Healthy relationships: with family, partner, & community
- Suicide and suicide prevention
- Elder abuse
- Sexual abuse
- Spirituality
- Role models: people in communities who are thriving

## B. Physical Well-being

- Nutrition: country foods (and healthy preparation); store bought foods; reading food labels; nutrition education; portion and balance
- Healthy pregnancy; prenatal care; breastfeeding
- Dental health
- Obesity and diabetes
- Cancer
- Heart health
- Hand washing: germs, illnesses, & communicable diseases
- Lack of physical activity (and land activities)
- Overcrowding
- Smoking and 2<sup>nd</sup> hand smoke
- Environmental health; pollution; contaminants; sewage treatment
- Food sanitation
- Early childhood development

## C. Healthy Family Life

- Healthy relationships: family, partner, & community
- Elder Abuse
- Overcrowding
- Suicide
- Addictions: drugs, alcohol, & gambling
- Abuse: emotional, physical, child abuse
- Teenage pregnancy; 'Kids having kids'; lack of parenting skills; communication in families
- Care for the chronically ill and disabled; long term care for the elderly
- Adoption
- Financial management
- Self esteem
- Healthy role models

**D. Traditional and Spiritual Values**

- Traditional parenting skills
- Inuit medicine incorporated with contemporary/western medicine
- Traditional midwifery
- Need for Inuit health professionals
- Healthy pregnancy: it takes a community to support a pregnant woman
- Suicide and suicide prevention
- Healthy eating and traditional food preparation
- Supporting and promoting food sharing
- Language loss (in relation to identity)
- Lifestyle: traditional and modern, the feeling of being trapped between 2 worlds, particularly for young people
- Incorporating traditional knowledge into in-school curriculum

**E. Prevention, Education, Support and Livelihood**

- Prevention through education
  - Many illnesses or health states can be prevented through education, such as: abortion, ear infections, communicable diseases, dental problems, tobacco-related illnesses and sexually transmitted infections
- Education and Support
  - Support initiatives that encourage community members to teach each other
  - Encouraging and supporting good role models
- In-school Education
  - A Nunavut-based in-school curriculum that is relevant to northern students, meets the standards for schooling expected across Canada, and incorporates traditional knowledge.
- Employment and Livelihood
  - Making positive contributions to the community and feeling useful
  - Poor retention and support of health staff has an impact on the health of communities

**Criteria for Research in Nunavut**

Participants identified important criteria for what they would like see included as a part of their vision for health research in Nunavut.

- A. Equality
  - Community research assistants receiving credit for their contributions
  - Equal treatment of researchers and community knowledge holders
  
- B. Trust
  - Consultation with communities *before* the start of projects
  
- C. Results and knowledge sharing
  - Research results shared with and presented back to community members in a format that is visible and understandable
    - plain language reports;
    - in-school presentations;
    - talks on the radio, etc.
  
- D. Ethics
  - Territorial-level ethics review that incorporates Inuit ethics
  
- E. Community comes first
  - Researching a topic of importance to the community
  - Community members conducting the research
  - Researchers and community members sharing worldviews and getting to know each other
  - Working in partnership with the community to relieve stress for both the researchers and the community
  
- F. Participatory Action Research (PAR)
  - Research method that promotes
    - Equality in relationships
    - The sharing of personal stories
    - Pride in and ownership of what is learned/discovered

## II) STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS

Strengths and weaknesses are the things that participants felt we have control over and are assets for improving the health of our communities and furthering research. Opportunities and Threats are the things that participants felt we do not have control over. Strengths are Opportunities are the assets, skills, and resources that we can use to move community-driven research forward in Nunavut; Weaknesses and Threats are the

obstacles and barriers that we must work on and overcome in order to develop the health research environment that participants would like to see in Nunavut.

<b>Strengths</b>	<b>Opportunities</b>
<ul style="list-style-type: none"> <li>- Community: community desire for healthy families and community members; and community involvement (hamlet, youth, sports, schools, wellness centre, heritage centre); understanding that the community works together, have similar goals, want to share ideas, concerns, complaints; many community-based programs such as Great Kids; our community supports, such as the people we work with and our strong family ties to loved ones</li> <li>- Assets: good prenatal care; some motivated front-line workers; traditional medicine; good local country food; good water; telehealth; our own knowledge, tradition and cultural practices (passed on through experience)</li> <li>- Skills such as interpretation, communication, presentation-making and the ability to educate by sharing knowledge</li> <li>- Resources, such as the internet; terminology; our languages; materials in Inuktitut and Inuinnaqtun; willingness to try new things or old ways</li> <li>- Knowledgeable people in our communities, such as elders, Community Health Representatives, health staff, and out-spoken motivated people with a passion</li> <li>- Knowledge of community history</li> <li>- Awareness of what needs to be addressed</li> <li>- *Some* funding</li> <li>- Patience and Perseverance</li> </ul>	<ul style="list-style-type: none"> <li>- Funding</li> <li>- Work for graduate students</li> <li>- Workshops</li> <li>- Nurses</li> <li>- International Polar Year</li> <li>- Ecosocialism</li> <li>- Furthering education; education opportunities for young and old</li> <li>- Hope, resilience and optimism</li> <li>- New research to expand on existing traditional knowledge</li> <li>- New government-initiated programs</li> <li>- Internet and information sharing</li> <li>- Training opportunities that are located in the North</li> <li>- National recognition of Aboriginal rights</li> <li>- Access to advanced health care</li> <li>- Consultations with Inuit communities to promote Inuit control over lives/health/decisions</li> <li>- National and Territorial health promotion campaigns</li> <li>- Workshops including elders</li> <li>- Mining and job opportunities</li> </ul>
<b>Weaknesses</b>	<b>Threats</b>
<ul style="list-style-type: none"> <li>- Funding</li> <li>- Local human resources: lack of local and Inuit health professionals; not enough Inuit in decision-making positions; people stretched too thin; lack of reliable staff; poor retention of health care professionals; not enough Inuit trained researchers</li> <li>- Infrastructure: lack of Federal</li> </ul>	<ul style="list-style-type: none"> <li>- Addictions (drugs and alcohol)</li> <li>- Federal government funding cuts to important programs and policies</li> <li>- Pollution and climate change</li> <li>- High school drop out rate</li> <li>- Unsupportive resource people</li> <li>- Weather</li> <li>- Isolation (from each other, from</li> </ul>

<p>support/money for front line workers; infrastructure failures (buildings in poor condition, power outages, internet); not enough resources for community presentations (materials)</p> <ul style="list-style-type: none"> <li>- What we teach our young people: young people need places to go; more young people need to get involved with elders; young people need motivation</li> <li>- Personal health and well-being: losing loved ones; poor communication; families moving away; addictions (smoking, drinking, gambling); procrastination and laziness; selfishness; discrimination; pride; self esteem; mental health; family abuse, domestic family affairs</li> <li>- Resources and training: lack of training for proposal writing; lack of training for care workers at elders facility</li> <li>- Communication: not enough sharing of best practices</li> <li>- Low voter turnout - political participation, community participation in decision-making</li> <li>compliance (with teachings or treatments)</li> <li>- Lack of empowerment</li> <li>- Language barriers</li> <li>- Education: lack of formal education, low levels of education, high school dropouts</li> <li>- Lack of accessibility to affordable healthy foods</li> <li>- Lack of communication between organizations</li> </ul>	<p>communities, from decision-makers, from territorial and federal governments)</p> <ul style="list-style-type: none"> <li>- American hegemony</li> <li>- Threat of nuclear war</li> <li>- Lack of northern education opportunities</li> <li>- Time</li> <li>- Community members not wanting to participate in healthy lifestyles</li> <li>- Misinformation from malicious sources (pharmaceutical companies, etc.)</li> </ul>
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#### IV) PUBLIC HEALTH OPEN HOUSE

On the last day of the meeting, a Public Health Open House was held at the Siniktarvik Hotel and Conference Centre. The Open House was open to the public and special invitations were extended to high school students.

Rankin Inlet Public Health put up posters and displays and nurses and a Community Health Representative were available to answer questions and share information about a variety of health topics. In addition, they offered flu shots throughout the day.

A series of presentations were delivered throughout the day on:

- diabetes

- hand-washing and germ transmission
- sexual health
- healthy eating, nutrition, and reading food labels
- public health strategy for Nunavu



**This report was prepared by:**

Gwen Healey  
Executive Director, Qaujigiartiit/Arctic Health Research Network (Nunavut)  
Iqaluit, NU  
[Ahrn.nunavut@gmail.com](mailto:Ahrn.nunavut@gmail.com)  
T: 867 975 5933  
F: 867 975 5940

**ARCTIC HEALTH RESEARCH NETWORK**

AHRN is a community driven, northern lead, health and wellness research network that facilitates the identification of health research priorities in the three Canadian territories.

The goal of AHRN is to enable health research to be conducted locally, by northerners, and with communities in a supportive, safe, culturally-sensitive and ethical environment, as well as promote the inclusion of both traditional knowledge and western sciences in addressing health concerns, creating healthy environments, and improving the health of Nunavummiut.

AHRN ensures best practices in health research through participation in health research activities, data management, dissemination of findings, training of health researchers, and knowledge translation to ensure transfer of findings to policy, practice and community programming.

Representatives from Nunavut Tunngavik Inc., the Nunavut Research Institute, the Nunavut Association of Municipalities, and the Dept. of Health and Social Services, community members, and youth are currently involved in the initiative in Nunavut.

[www.arctichealth.ca](http://www.arctichealth.ca)

