Research in Greenland – ethical aspects

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Why am I here

- I have been head of the Regional Research Ethics Committee and member of the National Research Ethics Committee in Denmark
- I am an advisor in Greenland on viral hepatitis and occasionally questions of research ethics in genome sequencing
- I am doing research on hepatitis B in Greenland together with my phd student Karsten Rex
WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects

Adopted by the 18th WMA General Assembly, Helsinki, Finland, June 1964
and amended by the:
29th WMA General Assembly, Tokyo, Japan, October 1975
35th WMA General Assembly, Venice, Italy, October 1983
41st WMA General Assembly, Hong Kong, September 1989
48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996
52nd WMA General Assembly, Edinburgh, Scotland, October 2000
53rd WMA General Assembly, Washington DC, USA, October 2002 (Note of Clarification added)
55th WMA General Assembly, Tokyo, Japan, October 2004 (Note of Clarification added)
59th WMA General Assembly, Seoul, Republic of Korea, October 2008
64th WMA General Assembly, Fortaleza, Brazil, October 2013
Helsinki Declaration
Vulnerable Groups and Individuals

19. Some groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm. All vulnerable groups and individuals should receive specifically considered protection.

20. Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices or interventions that result from the research.
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Indigenous Peoples

There is no internationally accepted definition of “Indigenous Peoples”

Four criteria are often used in international law:

- Residing within or associated with a specific geographic area, the ancestral territory and natural resources in these areas

- Maintenance of cultural and social identity, and social, economic, cultural and political institutions separate from mainstream or the dominant society and culture

- Descendants from population groups present in a given area

- Self-identification as being part of a distinct indigenous culture, and the desire to preserve the culture
Is research in Inuit in Greenland different from research in other Indigenous People?

- Inuit constitute 80% of the population in Greenland. In comparison, Aboriginal and Torres Strait Islander Peoples constitute less than 2% of the population in Australia.
- Greenland has its own Government.
- Among others, autonomy over the health care system.
- Although there is resentment against Denmark, the cooperation between both peoples and governments work fine.
Indigenous health life expectancy at birth or inequality in health

- If you belong to the Baka tribe in Cameroon, you can expect to live to the age of 35 years, 12 years less than the non-indigenous population in the same area.

- In Greenland you can expect to live to the age of 73 years, compared to 82 years in the general Danish population.

Lancet, 2016; 388: 104
Ethics in biomedical research in Greenland

- The Research Ethics Committee for Health Science Research in Greenland
- Greenland's Health Science Research Council
- The Board of Health and Prevention
- Greenland Medical Society - Good research practice in Greenland - a guideline
The Research Ethics Committee for Health Science Research in Greenland

- National Physician’s Office Secretariat
- Board of Health and Research
- Lay persons (2)
- M.D.s (2)

Aalborg Universitetshospital
Region Nordjylland
The Research Ethics Committee for Health Science Research in Greenland

Tasks:

- To carry out a scientific ethical assessment of biomedical research projects planned to be conducted in Greenland according to the guidelines set out in the Danish law of Research Ethics

- To follow as much as possible the practice implemented in the scientific ethics committee system in Denmark

- Follow developments in biomedical research and work for the dissemination of knowledge of the related ethical issues
Greenland's Health Science Research Council

Purpose

- To discuss general aspects of research on Greenlandic health conditions
- To present a priority of health science research in Greenland for the Home Rule Government member for health
- To promote the establishment and strengthening of research networks
- To set aside funds from the Ministry of Health to Naalakkersuisoq for Health
- To participate in the public debate on research in Greenland
1. The implications of societal change on the disease pattern including research on mental health and illness

2. Children in Greenland, Greenland for children, including the family's social behavior and health

3. Social and geographical inequalities in health, including health conditions in the settlements

4. Health services research and prevention research, including intervention research

5. Human biological research
Greenland Medical Society
Good research practice in Greenland - a guideline

• Ensure optimal relations between researchers and the population in Greenland

• Requirements and advice

• Includes all health related research, incl. Register and questionnaire surveys

• Explains about cultural differences incl. difference in the way of saying "no thanks" to participation

• Ensure cooperation agreements that will make the project possible - must be reported to the Board of Health and Prevention
Why do research in Greenland?

- Diseases or conditions where the researcher has special insight and can contribute to society (Greenland)
- Society (Greenland) has particular interest and funding is available
- Non-Inuit researchers find research involving Inuit population exotic or romantic
- Desire for adventure
- A little of everything
- Focus on the core task –

More health for the people of Greenland
Focus on the core task –
More health for the people of Greenland

- Will the Greenlandic people get better health
- Is there an improvement in the self-perceived health
- How to ensure the Greenlandic population direct influence on research
- How can we ensure that the Greenlandic "preconception" / insight comes in at the design stage of research projects
If Greenland’s Health Scientific Research Council took the lead

Made a law on research ethics in Greenland

Planned large overall research projects/areas and invited teams to bid

Collected all Danish research groups "under one umbrella"

Established an ambitious national Greenlandic biobank

Kept biological material (blood, tissue etc.) and bioinformatic data in Greenland

Established "User Groups" to discuss research projects, for example young people to discuss research in STDs

then Greenland could get a better overview, more synergy and perhaps better research - and “more health” for the people of Greenland
Ilulissat – the Icefjord