



# Health research - collaboration, presentation and implementation

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# HEADINGS

- 1) A story that changed life's
- 2) Health research in Greenland
- 3) Research ethics
- 4) Comments and recommendations



# CHOLESTASIS FAMILIARIS GROENLANDICA (CFG)

- **In 1990:** Pediatrician Inge Merete Nielsen in East Greenland did see children with icterus, bad thieve, itching, and malabsorption – starting within the first month after birth. The children often died before 12 years of age.
- **1990'es:** Start exploring family trees revealing the possibility of a monogen recisively enherited disease.
- **2000:** Together with experts the disease is located to kromosom 18q21 and 15-27% og the population in East and 1-6% i West Greenland was found to be carriers.
- **1990-2000:** Another monogene disease (Propionacidæmi) caused by lack of the enzyme propionyl CoA-carboxylase (PCC) was found In 6 Inuit children. App. 2-7% of the population were found to carry the gene.
- **1. January 2006:** Screening are offered all pregnant women. The partner is investigated if the woman is tested positive.



# WHY WAS THIS PROJECT SPECIAL?

It had all the elements of a success!

- A local need
- Economic attractive
- Local organization in place - included in prenatal care
- Intensive collaboration between researchers, the health care system, and the government on the implementation



# HEALTH RESEARCH

- We need research
- Major driver = interest (opportunity and funding) – not altruism
- Publications unevenly distributed (arctic, children in Greenland, worldwide)
- Solution: Cooperation needed to close the gaps and change the bias.



# MAKE DATA COMPERABLE AND COOPERATE

- Projects often initiated from the outside –different methods or questions on same items
- Disadvantage: Comparison impossible – no trends.
- Divide locations and subjects
- Research fatigue is beginning to show
- Solution: Cooperate.



# THE IMPORTANCE OF CONTEXT AND CULTURE

- Public health problems similar – local differences in social, economic, and political conditions. Context is everything to solutions.
- Remember your own cultural context
- Consider your prepositions.



# RESEARCH ETICS

- Is “fly out fly in” completely gone?
- WHO and CINE (2003):
  - Cooperation
  - Organized, designed and performed in accordance to culture
  - Based on mutual respect and benefits for both parties.





# RESPECT OUR RIGHT TO GOVERN

- Tempting to propose solutions
- “For a man with a hammer everything looks like a nail”  
(Mark Twain)
- We have to look at the maximal “benefit for the investment” and might already have been there
- If you want it implemented – get in touch.  
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THANK YOU – SEE YOU IN  
GREENLAND

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