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# Towards a Nordic Data Sharing Framework

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## Members of the group

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Mikael Fogelholm, University of Helsinki (Chair)

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- “NORIA-net” is a NordForsk preparatory action for the national and Nordic research funding agencies and policy makers
- NORIA-net on Registers was initiated by the NordForsk Board in 2011/2012
- Targets both social and health registers (including biobanks)
- This particular NORIA-net should give strategic advice to the NordForsk board on how to increase Nordic cooperation on register-based research
- Final report available early 2014

- **Overall aim: to enhance the joint use of Nordic registers for research**
  - If the national registers were combined into real Nordic data sets:
    - Population of 25+ Million
    - Increased quality of research
    - Used for evidence-based decisions
    - Attract international attention
- In order to create this unique asset:
- Need of harmonisation of practices
  - Need to overcome existing hindrances (e.g. ethical, technical)
  - This presupposes long-term commitment (co-funding) from national funders and policy makers

- Publication: «Reinforced Nordic collaboration on data resources» (Marie Sandberg, CSC, 2012)



Nature of barriers:

- **ethical (social trust, role of Ethical Boards)**
- **legal (access to personal data; authorities; EU)**
- **technical (interoperability of data)**
- political (priorities)
- financial (lack of pooled Nordic funding)
- organizational (scattered data sources, etc.)

## **Nordic expert meeting: "Responsible Data Sharing Across Borders" Rosenbad, Stockholm, March 2013**

- Analysis of current legal situation with regard to sharing data across borders in the Nordic countries (Draft report)
- Proposal for a Nordic data sharing framework (Draft report)
- Report from the seminar available on [www.nordforsk.org](http://www.nordforsk.org)

The NORIA-Net Registries Working Group proposed that the Nordic countries would adopt the following measures in order to set up a **Nordic Data Sharing Framework**:

- 1) Applicable Nordic laws relating to data sharing would have to be synchronized to the extent that it would make it possible to share and combine data within a research project across registers and across borders (data protection, ethical review, statistics, biobank etc.)
- 2) Ethical permissions would be mutually recognized as valid through-out the Nordic countries

- 3) Only one prior authorization of the data protection supervisor would be required for each research project
  
- 4) Each country would ensure that research data gets properly anonymised or pseudonymised according to the latest technical standards by the register hosting organization itself or other competent body

Pseudonymisation would mean two way encryption of data; key with a trusted organization to be determined at the national level;



## LINKING OF DATA BY BUREAUS OF STATISTICS

- 5) If statistical micro data needs to be linked with other register based data or other data and across borders, the Statistics Authority of the country of the research organization to which the Principal Investigator is affiliated is in charge of the anonymisation or pseudonymisation of the data.
- 6) After anonymisation/pseudonymisation of the data, the Statistics Authority will deliver the data to the Principal Investigator to be utilized in the research project.

- 7) The Principal Investigator may deliver the key-coded data sets to other researchers, including to those residing in other Nordic countries, but shall be liable on behalf of the research project for the compliance with the data protection and other legal requirements.
  
- 8) NordForsk could facilitate and coordinate the launching of the Nordic Data Sharing Framework

# What would change from today?



- Only one ethics board would grant the research permission which would be valid for all the Nordic countries;
- Only one Statistics Authority would combine the data sets from all other statistics authorities and register hosting organizations;
- Statistics Authorities would recognise that the level of protection in the Nordic countries is equivalent to their own

# Outcome of the NCM conference, March 2013



- In general, the **Bureaus of Statistics** are able to receive data from another country, but it is unclear whether data for research purposes could be sent to another country

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- The Bureaus of Statistics have established a task force that is discussing ways to achieve the pan-Nordic register-based research collaboration

A dialogue on **ethics** was initiated:

- Could it be possible that an evaluation by one ethics committee would suffice in all of the Nordic countries making ethical permissions valid across borders?

>>> This would require approximation of national laws, in particular in Sweden, as well as shared understanding of relevant ethical principles.

**Data Inspection Authority** perspective:

- The group follows developments with regard to the European Data Protection Regulation closely

# Future plans

- Final report available early 2014

“Announce Nordic pilots in order to practice research based on joint Nordic register data”

- BBMRI Nordic Pilot as a model
- Initially focused on the health and welfare area
- be used as show cases
- start (or test) harmonization work
  
- 30 MNOK
- Funded in competition/peer review
- Tentatively run over 3 years

# Future plans cont.



## Conclusions from the “Joint Nordic Focus on Research Infrastructures” Conference in Stockholm 27-28 Nov. 2013

*The following seven **Action Points** were the outcome of the workshop on health and welfare:*

- Simplify Nordic research support operations carried out by the Nordic Bureaus of Statistics, national health register institutes and other register hosting bodies.
- Set up procedures of mutual recognition for ethical review permissions between the Nordic countries.
- Support approximation of Nordic legislation and practices for using personal data in cross-border research

# Future plans, cont.

- Support the development of technical solutions enabling secure transfer, storage and access to research data across borders, possibly through the Nordic e-Infrastructure Collaboration (NeIC).
- Investigate possibilities to create a unified data sharing facility in each country for example such as the Danish solution on health data
- Launch funding schemes for research pilots and training programs aimed at using joint Nordic data sources.
- Set up a Nordic Initiative to support, monitor and develop register-based research



## Examples of registers

Social: education, labour market, migration, etc

Health: patient registers, prescription registers, cancer, etc

## Researchable questions

- Youth unemployment and its connection to education, migration, health...
- Underlying causes for the increasing incidence of mental unhealth

# Vision



Nordic Centre for Register-based Research??



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**Thank you for your attention!**

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