NordForsk

Joint Nordic registers and biobanks

a goldmine for health and welfare research

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Outline

Presentation of work carried out by:

The NordForsk working group «NORIA-net on Registers and Biobanks»

Joint Committee of the Nordic Medical Research Councils (NOS-M)

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- **NordForsk is a *platform* for joint Nordic research and research policy development** in the Nordic countries

- It was **established by the Nordic Council of Ministers in 2005**

- Headquarters in Oslo

- The aim of the organisation is to *facilitate* cooperation in all fields of research when this ***adds value* to work being conducted nationally**

- Basic funding is provided by the Nordic Council of Ministers and additional funding by stakeholders especially the Research Councils in the different Nordic countries ("The 2/3 principle")

Strategic priorities for 2015-2018

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Nordic cross-border research cooperation

Strengthening integrated cross-sectorial research with the aim to tackle societal challenges and ensure sustainable development

- Nordic Programme on Health and Welfare (one example)

Nordic research infrastructure cooperation

Increasing cross-border access to and joint use of existing research infrastructures in the Nordic region and globally

Supporting the establishment of new Nordic research infrastructure cooperation

- Nordic Trial Alliance, Nordic Biobank Network
- Facilitation of Nordic register-based research
  - ethical review procedures (mutual recognition)
  - analysis of the upcoming European legal framework
  - cooperation between statistical bureaus
  - development of technical solutions for sensistive data by NeIC
  - Nordic register pilots

NORIA-net on Registers and Biobanks

- «NORIA-net on Registers and Biobanks» working group was active 2012-2014
- Targeted both socioeconomic and health registers as well as biobanks
- Mandate: give strategic advice to the NordForsk board on how to **strengthen Nordic cooperation on register-based research**
- Work tasks included identification of existing hindrances impeding Nordic research and proposing ways to overcome these

NORIA-net Members

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Erland Hjelmquist, former Secretery General, FORTE (Chair)
Mikael Fogelholm, University of Helsinki (Chair)

Ilmo Keskimäki, National Institute for Health and Welfare, Finland
Jan-Eric Litton, BBMRI-Nordic
Salvör Nordal, Nordic Committee on Bioethics
Jørn Olsen, Institute of Public Health, Aarhus University
Juni Palmgren, Swedish Research Council
Elisabeth Rynning, Medical Law, Uppsala University*
Stig Slørdahl, NOS-M and NTNU
Eskil Wadensjö, Swedish Institute for Social Research
Marjut Salokannel, Finland, Docent, LL D

*left the group in 2012 following her appointment to the Swedish Supreme Administrative Court

Goal: Joint Nordic Registers

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Overall aim: to enchance the joint use of Nordic registers in research

If the national registers were combined into real Nordic data sets:

- *Population of 26 Million*
- *Increased quality of research*
- *Used for evidence-based decisions*
- *Attract international attention*

In order to create this unique asset:

- *Need of harmonisation*
- *Need to overcome existing hindrances (e.g. ethical, technical, organisational)*
- *This pre-supposes long-term commitment (co-funding) from national funders and policy makers*

The nature of barriers

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- The nature of barriers had been identified

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

- **The NORIA-net focussed on the ones in bold**

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

www.norden.org/publications

Recommendations from the NORIA-net (1)

1. NordForsk should provide a cooperation platform for the Nordic bureaus of statistics, national health register institutes and other register-hosting bodies. This platform should facilitate research support operations in order to increase joint Nordic research. Discussion platforms for different stakeholders should also be supported, when relevant.

2. NordForsk should investigate possibilities for developing procedures for mutual recognition of ethical review permissions between the Nordic countries, including models for informed consent. This will require political consideration and should be carried out in dialogue with the Nordic Council of Ministers.

3. NordForsk should actively follow, and, if necessary, influence the ongoing revision of European legislation targeting data protection, clinical trials and copyright legislation, in particular in relation to data sharing and with a view to drawing the full benefit of new research technologies, such as text and data mining. This may require political consideration and follow-up by the Nordic Council of Ministers.

Recommendations from the NORIA-net(2)

4. NordForsk should establish a small strategic expert group responsible for these processes, initially for the 2014–2016 period. The group should possess the relevant expertise and have the support of relevant Nordic stakeholder groups. It should report to the NordForsk Board.

5. As a follow-up to recommendations one to three, NordForsk should establish a research programme to pilot the joint Nordic use of registers. The programme should fund Nordic pilot projects using joint Nordic register data sources within the field of health and wellbeing.

6. Future vision: Nordic Centre for Register-based research

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Follow up of recommendations

Nordic Expert Meetings arranged

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1. ”Responsible Data Sharing Across Borders”, Stockholm March 2013

- Analysis of current legal situation with regard to sharing data across borders in the Nordic countries. Proposal for a Nordic data sharing framework discussed.

- Panel discussions (Representatives from Nordic 1) Ethics committees; 2) Bureaus of Statistics; and 3) Data protection auuthorities)

2. Nordic conference on RI cooperation, Stockholm November 2013

- Nordic Action Plan for for registers, biobanks and interventional research proposed

Joint Nordic Focus on Research Infrastructures

A Nordic metadata pilot

- The **Nordic bureaus of Statistics** appointed a **task force group** as a direct follow-up of NORIA-net on Registers expert meeting on Nordic data sharing in March 2014

- The group was mandated to do a feasibility study: Investigate possibilities of **improving joint Nordic access to microdata** for research

- Presented to and supported by the **Nordic Chief Statisticians** (Director Generals) in September 2014

- The feasibility study recommends the development of adequate common Nordic social metadata describing the precise content of registers and variables including changes over time series

- A proposal for the **development of a Nordic metadata framework for social data** was submitted to NordForsk autumn 2014

- **NordForsk board** decided to **support the proposal March 2015 with 14 MNOK**. Relevant metadata expertise and research expertise should be involved

- Calls within the **Nordic Programme on Health and Welfare** targeting **register utilisation and establishment** announced in 2014

  - Call for research projects on «Distribution of health and welfare» (5 projects funded)

  - Call for construction of joint Nordic register infrastructures by combining social and health register data (decision in June)

- Calls within the **Nordic Trial Alliance** Framework 2014

  - Nordic Clinical Research projects utilising registers and biobanks

www.nordforsk.org and nta.nordforsk.org

- Ongoing work targeting **mutual recognition** within the Nordic Trial Alliance

    - Focus of NTA Annual Stakeholders Meeting 2015

- Ongoing **legal analysis** of Nordic cooperation possibilities under the European legal frameworks and monitoring of its development

- Support of development of technical solutions enabling secure transfer, storage and access to research data across borders, through the **Nordic e-Infrastructure Collaboration**

- Interest for cooperation activities for the **national quality register** secretariats

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NOS-M White Papers

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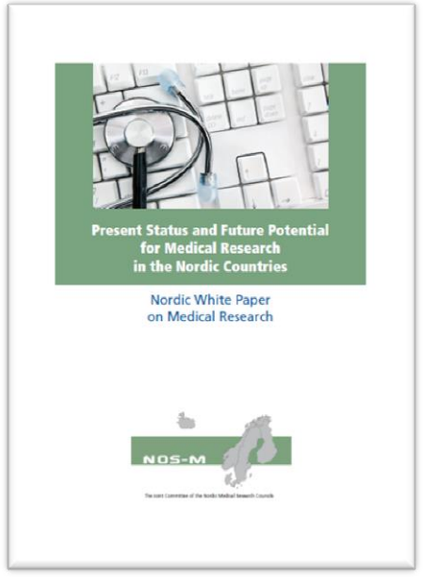
NOS-M White Paper 2011: ”Present Status and Future Potential for Medical Research in the Nordic Countries”

Better incentives for Nordic cooperation are needed
Innovations require good basic research
Clinical research requires increased attention



NOS-M White Paper 2014: ”Nordic Potential in Medical Research – Cooperation for Success”

Biobanks and Registers
Personalised Medicine
Gender Equality

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Thank you for your attention!