The Nordic conference on Registry Epidemiology in Iceland 15-16 June 2011

The Task Force suggested that registry data sharing should be focused at the Nordic conference on registry epidemiology, arranged in Reykjavik on 15-16 June 2011. Partly as a result of this, the theme of the conference was set as “Nordic Population-based Registries: Strengths and opportunities for collaborative research and co-ordinated infrastructure”.

In order to receive input on how to facilitate Nordic collaboration on the registry-based research within health and welfare as described above, the Task force organized a workshop on this theme. Six speakers with extensive experience of Nordic collaborative research within the health sciences were invited. The speakers were asked to describe examples of collaboration and to answer the following questions:

Describe very briefly what the collaboration was about. Then, instead of describing the project, focus on answering these questions:

What were the main reasons for the success of the collaboration?

What were the main obstacles/difficulties for the collaboration?

What would be the most important improvements for future Nordic collaboration?

a. Legal changes? Which?

b. Technical development? Which?

c. Organizational development, (e.g. create a Nordic organizational unit or network for collaboration?) Which changes/developments are needed?

d. Setting up common principles and procedures for Nordic access to national repositories? Which?

e. Working towards political agreements on datasharing?

f. Nordic funding for collaborative projects (model example: Nordic Cancer Union). Through NordForsk or other ways of collaboration?

g. Other suggestions?

The themes of the presentations were as follows:

1. “The scientists' right to simple access to registry data” (Anders Ahlbom)

2. “A successful Nordic registry based research activity on cancer, present and future challenges” (Hans Storm)
Sharing Registry Data for Health Research in the Nordic Countries
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3. “Nordic collaboration in sickness absence research - quo vadis?” (Ellenor Mittendorfer-Rutz)

4. “Has the time come to combine Nordic registers and how may these registers work with existing and ad hoc cohort studies? Experience from Nordforsk Longitudinal Epidemiology” (Jørn Olsen)

5. “Nordic Occupational Cancer (NOCCA) study, a unique register-based Nordic study network with huge dimensions” (Eero Pukkala)

6. “The Nordic collaboration on SSRIs and Birth Outcomes” (Unnur Valdimarsdottir)

Output from the conference

The general benefits of register research were strongly emphasized by conference speakers, as were additional benefits of collaboration. Several obstacles that hamper the efficacy of collaboration projects, and may discourage researchers from future collaborations, were also highlighted. A summary of the central themes is given below.

Benefits
A number of major benefits were described.

First, increased collaboration would most likely promote collaborations and exchange of ideas across the borders, and create a “critical mass” of active researcher within the diverse braches of registry research. This might particularly be the case within smaller or less developed research fields.

Second, differences in exposures or health policies and systems between countries could be exploited in order to identify determinants of diseases and assess intervention-effects.

Third, findings from national cohorts could be replicated. A cornerstone of medical research is replication of findings in independent samples. This is a process that often takes time, which can preclude or delay firm conclusions. The Nordic registers enable replication in large independent samples to be carried out swiftly and at a relatively low cost.

Fourth, pooling of data from the Nordic countries would increase the number of observations, which is valuable when rare exposure or rare diseases, or both, are studied.

Fifth, the Nordic collaboration can provide recommendations to national governments on the proper handling of sensitive information in a way that will maximize the accessibility of data for research while protecting personal integrity.

Obstacles
The main obstacle described by the researchers concerns lack of coordination. Too many contacts at too many levels are needed, including data providers, ethical committees and funding agencies. It is difficult to obtain information about data sources, and competing work is carried out at both registry and collaborator level. It is difficult to keep track of ongoing or planned projects. Due to insufficient
coordination, time consuming data cleaning of the same data sets is conducted simultaneously at different sites. Further, the lack of cross-border contact forums for researchers within this field can hinder potential collaborations from being realized. At present, the success of collaborations often rest on personal contacts.

Problems related to access to data in general were highlighted by the speakers. The principle of data sharing and open access was described as fundamental to justify large investments in building register data. Better access to clinical records and better possibilities to locate available data (e.g. biosamples) were requested. Harmonization and coordination of ethical approvals nationally (between different agencies) and internationally was also called for, and frustration with the delays caused by lack of such coordination was listed as a major problem.

It was also stressed that efforts should be made to set standards in data management and documentation for the agencies holding the registers, and to establish datasets with similar data structure, coding of variables etc. to limit time for subsequent harmonization of the data. Common principles for data storage and data security were also requested, as were time-limits for delivery and equal opportunities for data access.

An overarching improvement suggested by the researchers is to establish a support-centre for Nordic Register Based Research. Such a centre could be responsible for dissemination of information on data sources held in the different countries, documentation of ongoing projects, data documentation, validity studies, and quality control procedures. Training and learning options and web-based documentation open to the world could be available, and the centre could market the registers also outside the Nordic countries. It was further suggested that the centre should provide a common network for “match making” for Nordic collaborations and for sharing of information (e.g. on data cleaning).

The general lack of funding for Nordic collaboration was also put forward as a major hurdle. The researchers also felt that funding agencies often has limited understanding of the costs involved in collecting and preparing international datasets. Joint publications, with one PI responsible for all the data, and with joint Nordic funding would avoid delays and guarantee that applications intended for cross-national studies do not fail due to the lack of funding in some countries.

An example of a model for Nordic funding is available through the Nordic Cancer Union (NCU), which has contributed to substantial Nordic collaboration in the cancer research area. Similar approaches in other subject matter areas, or alternatively, general purpose Nordic grants that do not target specific areas of research would be desirable. Nordic funding for registry research would enable funding in areas not directly prioritized by the EU.