

Possibilities for joint Nordic research projects within register-based research

Mika Gissler

Nordic School of Public Health, Gothenburg, Sweden &
THL National Institute for Health and Welfare, Helsinki, Finland

Why good possibilities to register-based studies?

- Traditions: population statistics have been collected more than 250 years and health statistics more than 150 years in the Nordic countries.
- First real registers were started in the 1940-1950s, when improved computers were available: health care personnel, cancer register.
- Personal identification numbers since 1960s.
- Several data quality studies have shown the high quality of routinely collected registers.
- Data protection allows research use of register data.



The most used health registers in the Nordic countries

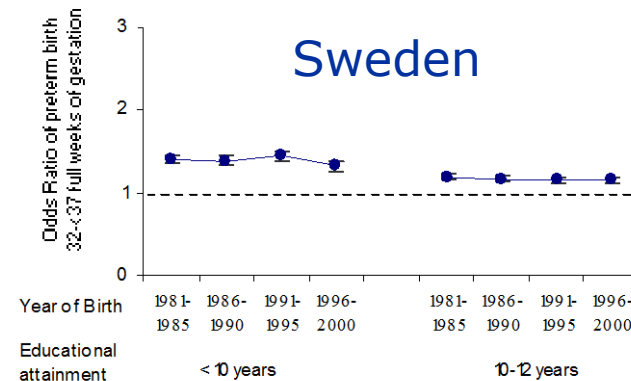
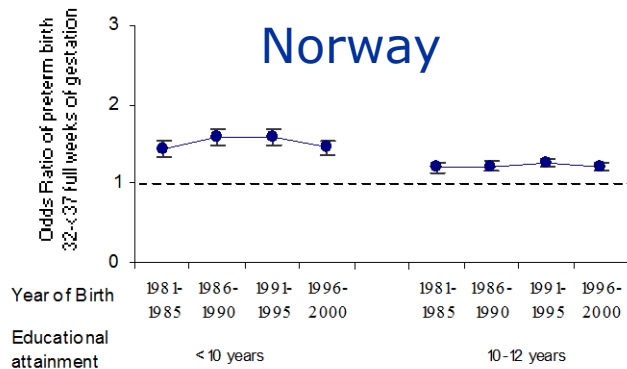
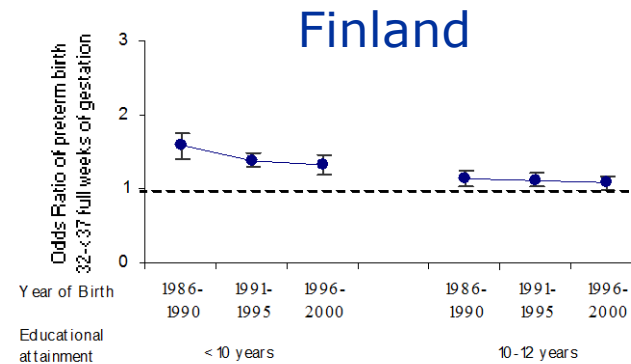
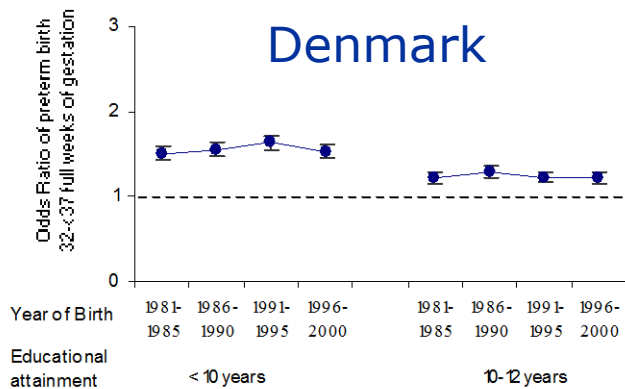
- Mortality and morbidity:
 - causes-of-death, cancers, infectious diseases, perinatal health and congenital anomalies etc.
- Use of health services:
 - hospital inpatient care, hospital outpatient visits, prescribed medicine etc.
- Health care quality registers
- Background information: Census data on socio-demographic background, family relations etc.
- Possibilities to link to medical records, biobanks etc.

Three recent examples

- **NorCHASE: Nordic Collaborative project on Health And Social inequalities in Early life**
 - Funded by NordForsk: Programme for longitudinal epidemiology
- **Nordic Academy for Mental Health: Life expectancies among patients with mental disorders.**
 - Funded by Nordic Council of Ministers
- **MART: Monitoring of Assisted Reproductive Technology in the Nordic countries**
 - Funded by ESHRE, NFOG etc.

NorCHASE:

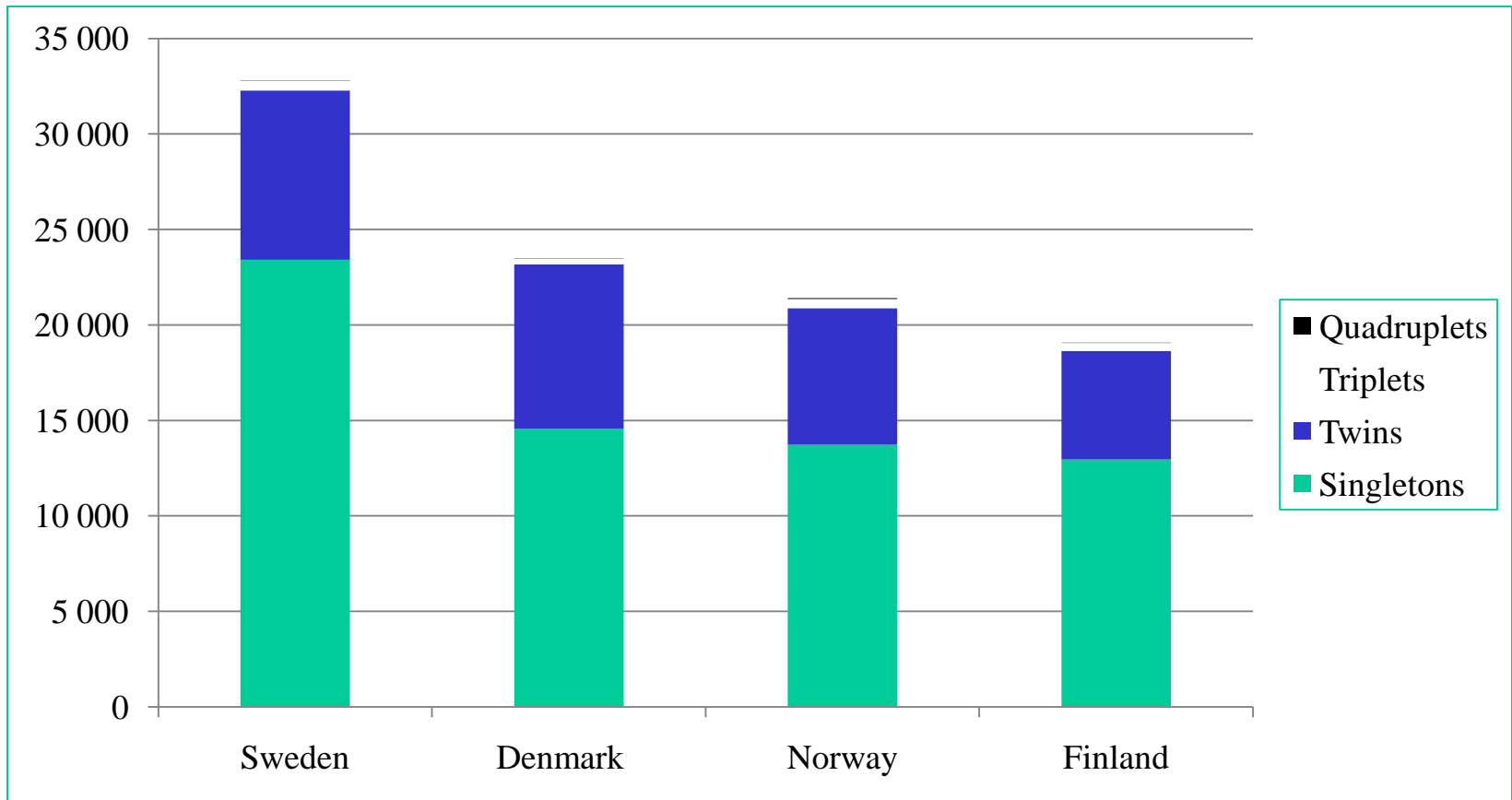
Educational inequalities in preterm birth



Life expectancy among general population and psychiatric patients



Information on 100 000 children born after ART in the Nordic countries



Nordic collaboration is not always easy - a warning example

- A study with data from 6 countries, of which 4 were Nordic countries, financing from a seventh country.
- Open questions
 - Who has the access to data?
 - Where to keep the data?
 - More ideas than anyone can apply for permissions.
 - Changing study ideas and study setting (especially controls)
- A permanent register must not be built for research purposes.



Problems related to Nordic register research

- Time to get permission may be long.
- Time to get data may even be longer.
- Data protection rules may vary from country to country
 - E.g. Statistics Finland does not give total data on all registered.
- High data costs
 - E.g. Population Register Centre in Finland charges 95 000 € for basic information on all Finnish citizens.
- Sometimes researchers cannot choose between pooled datasets and aggregated analyses.
- Nordic countries are in different phases in creating online-solutions for register-based research.

Funding of Nordic register research

- Limited funding in some Nordic countries
- More funding available elsewhere:
 - EU
 - Non European research funds
- Pharmaceutical companies and other private industries
 - Problems may occur in ownership of data and results
 - On the other hand Catch 22 –problem:
 - Drug administration requires the industry to prove drug safety, but register keepers do not give the existing data for the industry.

Conclusions

- Nordic collaboration is often required for larger datasets.
- Good research collaboration already exists e.g. between cancer registers, health care registers and birth registers.
- Are common Nordic efforts for infrastructure needed?
 - Metadata
 - Solutions for complicated linkages
 - Hub for linked datasets

Finally

- Register-based studies are feasible.
- In the future, there will be even more studies combining register data with data from other sources, such as medical records, questionnaires and even biobank material.
- The lack of information from primary health care will be solved after the national electronic patient journal system is in use.
- It is important that register-based research will never be seen as a threat for confidentiality and privacy.

Promotion of register research

- Denmark: National Centre for Register-based Research, Århus Universitet <http://www.ncrr.dk/>
- Finland: Finnish Information Centre for Register Research <http://www.rekisteritutkimus.fi/>
- Special issue on register-based research in Norsk Epidemiologi 14 (1): 2004.
- Olsen J, Brønnum-Hansen H, Gissler M, Hakama M, Hjern A, Kamper-Jørgensen F, Rafnsson V, Tell GS, Thaulow I, Thygesen LC: High-throughput epidemiology: Combining existing data from the Nordic countries in health-related collaborative research. Scandinavian Journal of Public Health 38 (7): 777-9, 2010.