Les registres de morbidité à l’étranger: Nordic view on health registers

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Questions

• What is health information system?
• Why to have register-based information system? Experiences from Finland and other Nordic countries.
• Does the EU data protection legislation allow data collection on individual level?
• How to keep sustainable register-based information systems on morbidity?

→ Options for France
Health Information System (HIS)

- Health Information System (HIS) has a central function in the health system.
- HIS allows all professional and lay users to use, interpret and share information in order to transform it into knowledge.
- Reliable and timely information is necessary at facility, local, regional and national levels to respond to rapidly-evolving health needs, to design and monitor policies and health reforms, to evaluate the impact of services, and to define budget priorities.

Data → Information → Knowledge → Wisdom
Health Information System (HIS)

- HIS can be defined as a dynamic and flexible infrastructure for the monitoring of health activities and population health outcomes (morbidity).
- HIS includes the collection, analysis, storage, transmission, display, dissemination, and further utilisation of data and information from complementary sources.
- HIS encompasses the persons, values, legislation, inter-institutional relationships, technology and standards which contribute to the different stages of the data processing.
Health Information System (HIS)

• Population-based information systems
  – Census (population count)
  – Civil registration (births, deaths, migration etc.)
  – Health monitoring (registers, statistics, surveys)

• Institution-based information systems
  – Individual records at facility level
  – Service records (statistics, registers)
  – Resource records (statistics, registers)
Measurement for health information systems

Health determinants
- Socioeconomic and demographic factors
- Environmental and behavioural risk factors

Health status
- Mortality
- Morbidity/disability
- Well-being

Health systems
Inputs
- Policy
- Financing
- Human resources
- Organization and management

Outputs
- Information
- Service quality and availability

Outcomes
- Service coverage
- Utilisation
Some historical milestones on data collection

- **Census**
  - Before Christ: the Bible, China, Roman Empire
  - Iceland 1703
- **Population statistics**
  - Denmark and Sweden 1750
- **Health registers and studies**
  - Leprosy (Norway) 1856, Blind people (Britain) 1911, Cancer (Massachusetts) 1927
Examples why registers are collected?

- Planning, administration and organisation of services
- Distribution of benefits
- Evaluation of health care services and its activities
- Control functions
- Data collection: population-based data, trends, clusters…
- Identification of cases and controls
- Calculation of denominator
- General overview of some health problem
- Protection of individuals
- Statistical purposes
- Research
Nordic countries: Denmark, Iceland, Finland, Norway, Sweden
Important registers in the Nordic countries

- Cancer register 1940s
- Registers on infectious diseases 1950s
- Hospital discharge registers 1960s
- Cause-of-death registers 1960s
- Birth and malformation registers 1960s
- Register-based Census 1990s
  - Education, income, socioeconomic position
  - Family background, relatives etc.
- Health care quality registers 1990s
- Prescription registers 1990s
Infant deaths per 1000 live births in Finland – the first 200 years

(Note: logarithmic scale)
Maternal mortality ratio in Finland

- Historical development can easily be seen in the trend figure.
- Also changes in data collection can be seen (1936).
Why good possibilities in the Nordic countries?

• Traditions: population statistics have been collected more than 250 years and health statistics also more than 150 years.

• First real registers in the 1940-50s, when improved computers were available: health care personnel, cancer register.

• Personal identification number in the 1960s.

• Several data quality studies have shown the high quality of routinely collected registers.

• Data protection allows the collection of register and their use in research.
Finnish health registers

- Cancers 1953
- Health care personnel 1955
- Tuberculosis and STIs 1958
- Congenital anomalies 1963
- Occupational diseases 1964
- Special medication 1964
- Adverse drug reactions 1966
- Hospital discharges 1967
- Cancer screenings 1968
- Causes-of-death 1969
- Abortions and sterilisations 1977
- Exposure to cancer-hazardous material 1979
- Endoprostheses 1980
- Drugs (surveillance) 1982
- Visual impairments 1983
- Births 1987
- Infectious diseases 1989
- Dental implants 1994
- Prescribed drugs 1994
- Outpatient visits in public hospitals 1998
- Outpatient visits in health care centres 2011

All these registers include personal identification number
Other important registers

Social welfare registers

- Pensions 1962
- Social Benefits (Social Insurance Institution) 1964
- Social assistance 1985
- Children taken into custody 1991
- Institutionalised care at social institutions 1994

Background data updated continuously by Statistics Finland

- Education
- Income
- Socioeconomic status
- Country of birth / language
- Citizenship
- Marriages and divorces
- Emigrations and immigration
- Link between parents and children/siblings

All these registers include personal identification number
Hospital discharge reporting system at THL
National Institute for Health and Welfare

- 1956: tuberculosis sanatoriums
- 1957: psychiatric hospitals
- 1960: general hospitals
- 1967: all public and private hospitals
- 1994: the majority of social welfare institutions
- 1994: special data on psychiatric and cardiac patients
- 1996: day surgery
- 1998: outpatient visits in public hospitals
- 2011: outpatient visits in health care centers
Problems related to register-based health information systems

• Several data collection institutions
  – Time to get permission to use the data may be long.
  – Time to get data may even be longer.
  – No possibility to combine registers for other the research purposes, for example building up a permanent quality register.
  – Data linkage processes may be complicated.
  – The costs may be (very) high.

• The interpretation of data protection vary by institution
  – E.g. Statistics Finland does not give total data on all registered.

• Sometimes researchers cannot select the best methods.

• Register data remains unutilised.
Legislation

- Nordic countries have special legislation, which allows collection of certain national registers without informed consent.
- All public and private health care institutions and health care personnel have to report to the national registers.
- Authorities have to inform all citizens which kind of personal data is collected and stored.
- The data must not be used in decision-making for a single registered person.
EU legislation

• Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data
  – There are several different interpretations of this legislation: In the Nordic countries, the possibility to collect registers by a special legislation.

• The Directive will be replaced by a mandatory regulation in the future.
  – The content remains currently unknown.
Citizens’ rights

- Citizens have the right to check their personal data either in local level (hospitals) or national level (register keeper).
- People have no right to remove their own data from national registers.
  - In Sweden, people have the right to get their complete personal identification number removed.
- Strict data protection rules applies for secondary use of data, e.g. in research.
The percentage of people who trust that health institutions protect your personal information, %

Eurobarometer 2011
The percentage of people who trust that public authorities protect your personal information, %

Eurobarometer 2011
Future directions?

Jari Haukka: Rekisteritutkimuksen tukikeskus
Future of register-based health information system?

• Can collection of register continue in the future?
• More registers will be collected since data needs are increasing.
  – More data on primary health care, e.g. in Finland from 2011
  – Can electronic patient journal data be used e.g. in collecting morbidity statistics or in research?
• More register-based research and easier access to data.
• More international collaboration in keeping registers and using them in research.
General prerequisites for good register-based information systems

1. Legislation allowing collection of individual level data (without informed consent).
2. Good infrastructure for registers, including funding.
3. Evaluate and validate the data, update the register.
4. Systematic use of unique identifiers increases the completeness of data and increases the data quality.
5. The possibility to use register information in scientific research increases the data usefulness and quality.
7. The data providers (clinicians) have to be interested in the data.