

Register-based health information systems in the Nordic countries

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Content of the lecture

- What is health information system?
- Why to have register-based information system? Experiences from Finland and other Nordic countries.
- Data protection legislation in the EU
- How to keep sustainable register-based information systems?

→ Options for Estonia

Health Information System (HIS)

- Health Information System (HIS) has a central function in the health system. It 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.
- HIS includes the collection, analysis, storage, transmission, display, dissemination, and further utilisation of data and information from complementary sources.
- It encompasses the persons, values, legislation, inter-institutional relationships, technology and standards which contribute to the different stages of the data processing.

Information needs and tools

(WHO Health Metrics Network)

| Level | Quantity | Needs | Tools |
|-----------|----------|---|-----------------------------------|
| Global | --- | Global reporting | Summary reports |
| National | -- | National planning, resource allocating | National reports and registers |
| District | - | Regional planning, resource allocating | Regional reports and registers |
| Facility | + | Management | Facility reports and registers |
| Patient | ++ | Patient care | Patient records |
| Community | +++ | Burden of disease, risk monitoring | Surveys, census |

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

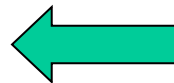
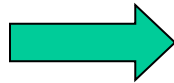
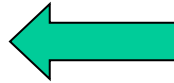
Health determinants

- 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

Register terms

- Register = Catalogue or list
 - the Middle-Age Latin expression *registrum*, from the verb *regerere* (re-enter to the books).
A register = A list or catalogue containing data on individuals
 - Register = a record in which periodic entry is made of details of any kind important enough to be noted exactly.
 - Registry = the organisation or the process involved in the support and maintenance of a register.
- Statistics = Aggregated data

Some historical milestones

- Census
 - Before Christ: the Bible, China, Roman Empire
 - South America 16th century, Québec 1666
 - Iceland 1703, Denmark and Sweden 1750
- Health registers and studies
 - William Farr (General Register Office, Britain) and his mortality studies 1840s
 - 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

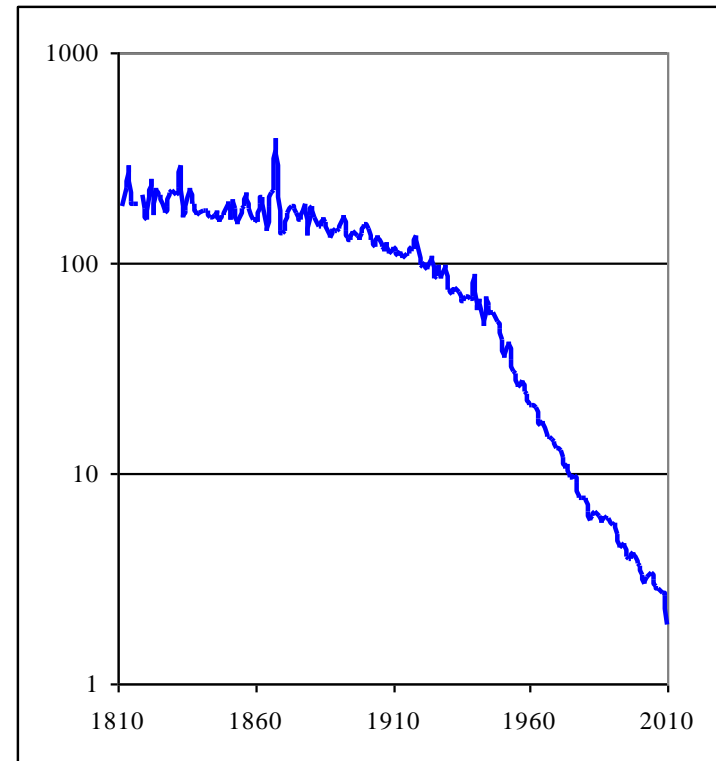
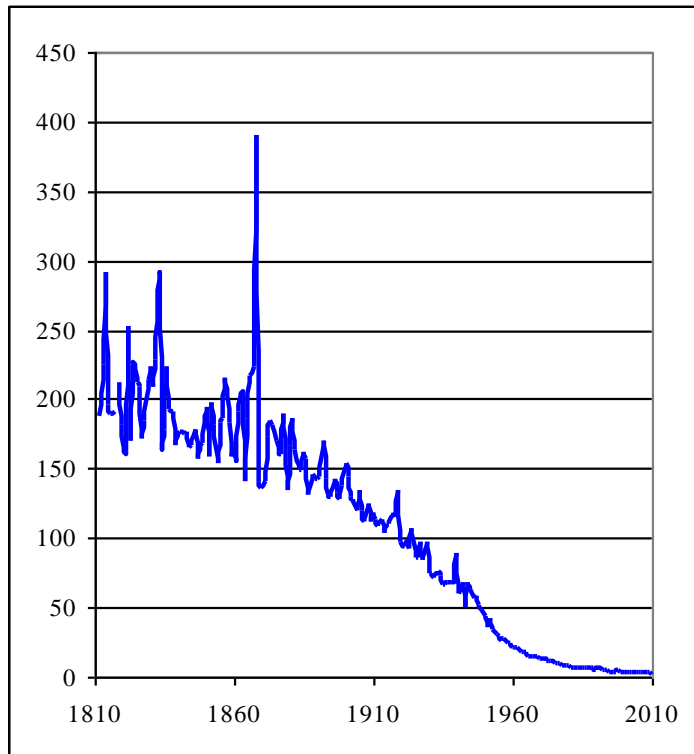


Nordic countries:
Denmark
Iceland
Finland
Norway
Sweden

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

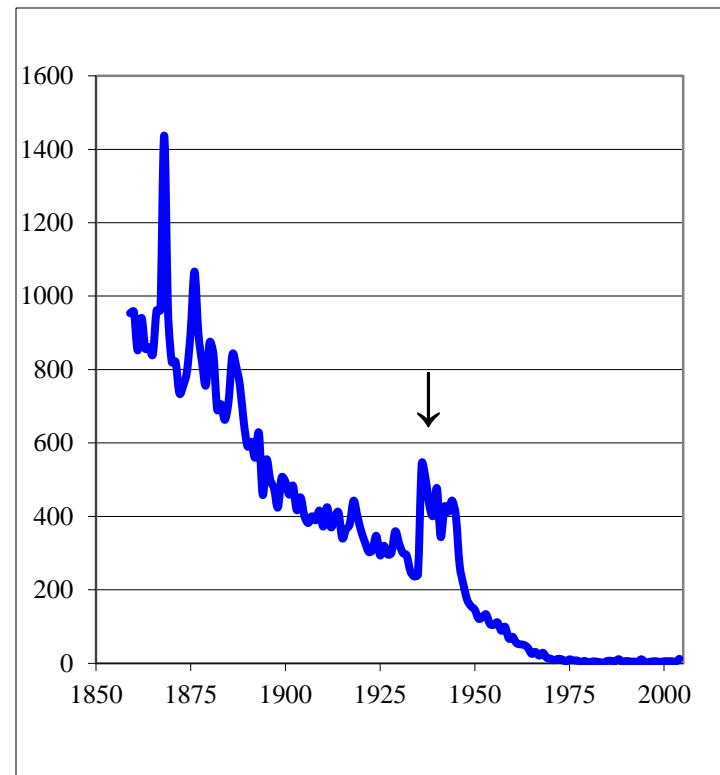
Infant deaths per 1000 live births in Finland – the first 200 years



(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).



Maternal mortality per 100 000 live
births

Unique registers and data in the Nordic countries

- IVF (in vitro fertilization) register, Denmark and Sweden
- Register on induced abortions and sterilisations, Finland
- Register on visual impairments, Finland
- Register on cancer screening, Finland
- Multiple generation register, Sweden
- Multiple generation studies in the Norwegian Medical Birth Register
- Biobanks in all Nordic countries + possibilities to link them to other registers.



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.

Long tradition to collect register data in Finland

- First registers in the 1940-1950s:
 - Register on health care personnel, Cancer register, Register on infectious diseases (Tuberculosis, STIs)
- New registers in the 1960s:
 - Register on Congenital Anomalies, Hospital Discharge Register, Register on Cancer Screening
- Personal identification numbers for all in 1964-1968.
- Data protection allows the collection of national, population-based data without informed consent.
- Registers can be used in scientific 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
- Mass 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
- 1996: day surgery
- 1998: outpatient visits in public hospitals
- 2011: outpatient visits in health care centers

Health information system at Social Insurance Institution

- Special reimbursements of medicine since 1964
- Sickness allowances and reimbursed visits in private health care services since 1971
- Rehabilitation since 1978
- Family allowances and child care subsidies since 1993
- Maternal grants since 1994
- Prescribed medicine and reimbursed interventions in private health care services since 1996

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
- Euroopa Parlamendi ja nõukogu direktiiv 95/46/EÜ üksikisikute kaitse kohta isikuandmete töötlemisel ja selliste andmete vaba liikumise kohta
 - Available at: <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=CELEX:31995L0046:ET:HTML>

EU legislation, article 7

Liikmesriigid sätestavad, et isikuandmeid võib töödelda ainult juhul, kui:

- a. **andmesubjekt on selleks andnud oma ühemõttelise nõusoleku**
- b. töötlemine on vajalik sellise lepingu täitmiseks, mille osapool andmesubjekt on, või lepingu sõlmimisele eelnevate meetmete võtmiseks vastavalt andmesubjekti taotlusele
- c. töötlemine on vajalik vastutava töötleja seadusjärgse kohustuse täitmiseks
- d. töötlemine on vajalik andmesubjekti eluliste huvide kaitsmiseks
- e. töötlemine on vajalik üldiste huvidega seotud ülesande täitmiseks või sellise avaliku võimu teostamiseks, mis on tehtud ülesandeks volitatud töötlejale või andmeid saavale kolmandale isikule
- f. töötlemine on vajalik vastutava töötleja või andmeid saava kolmanda isiku või kolmandate isikute õigustatud huvide elluviimiseks, kui selliseid huve ei kaalu üles artikli 1 lõike 1 kohaselt kaitstavate andmesubjekti põhiõiguste ja -vabadustega seotud huvid.

EU legislation, article 8.1

Liikmesriigid keelavad töödelda selliseid isikuandmeid, mis paljastavad rassilise või etnilise päritolu, poliitilised vaated, usulised või filosoofilised veendumused, ametiühingusse kuulumise, ning tervislikku seisundit või seksuaalelu käsitlevate andmete töötlemise.



EU legislation, article 8

3 Lõiget 1 ei kohaldata, kui andmete töötlemine on vajalik **ennetava meditsiini, meditsiinilise diagnoosi, meditsiinilise abi või ravi** võimaldamise või tervishoiuteenuste juhtimise jaoks ja kui kõnealuseid andmeid töötleb tervishoiutöötaja, kelle puhul kehtib siseriiklikus õiguses või pädevate siseriiklike ametiasutuste kehtestatud eeskirjades sätestatud ametisaladuse hoidmise kohustus, või mõni teine isik, kelle suhtes kehtib samaväärne saladuse hoidmise kohustus.

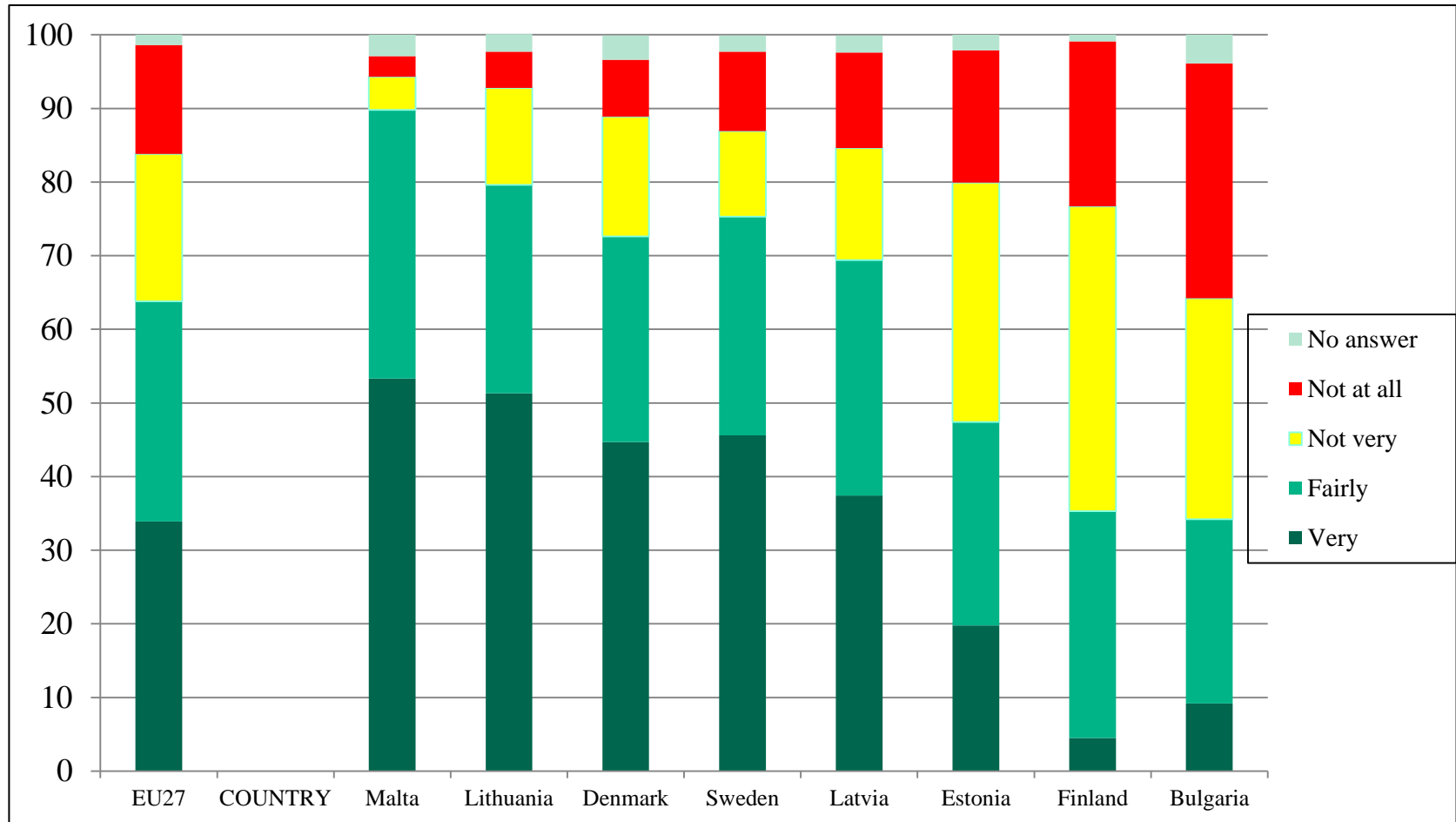
EU legislation, article 8

- 2a andmesubjekt on andnud nende andmete töötlemiseks **oma selgesõnalise nõusoleku**, välja arvatud juhul, kui liikmesriigi õigusaktides on sätestatud, et andmesubjekti nõusolek ei saa kaotada lõikes 1 osutatud keeldu.
- 4 Võttes arvesse sobivaid tagatisi, võivad liikmesriigid põhjustel, mis on seotud märkimisväärse avaliku huviga, siseriikliku õiguse või järelevalveasutuse otsusega kehtestada täiendavaid erandeid lisaks lõikega 2 ettenähtud eranditele.

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.

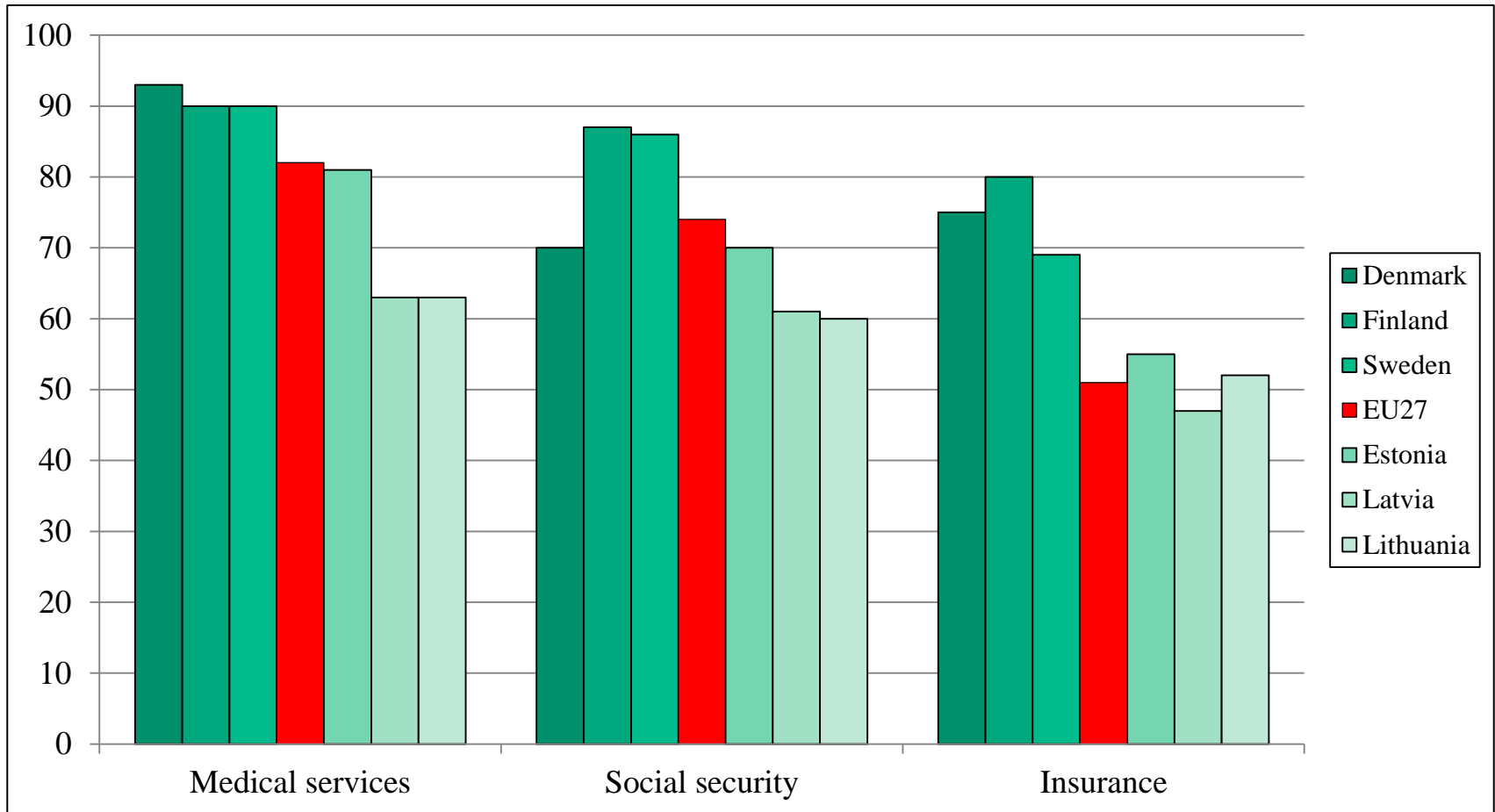
Are you concerned or not that your information is protected by public and private organizations, %



Eurobarometer 225/2008:

http://ec.europa.eu/public_opinion/flash/fl_225_en.pdf

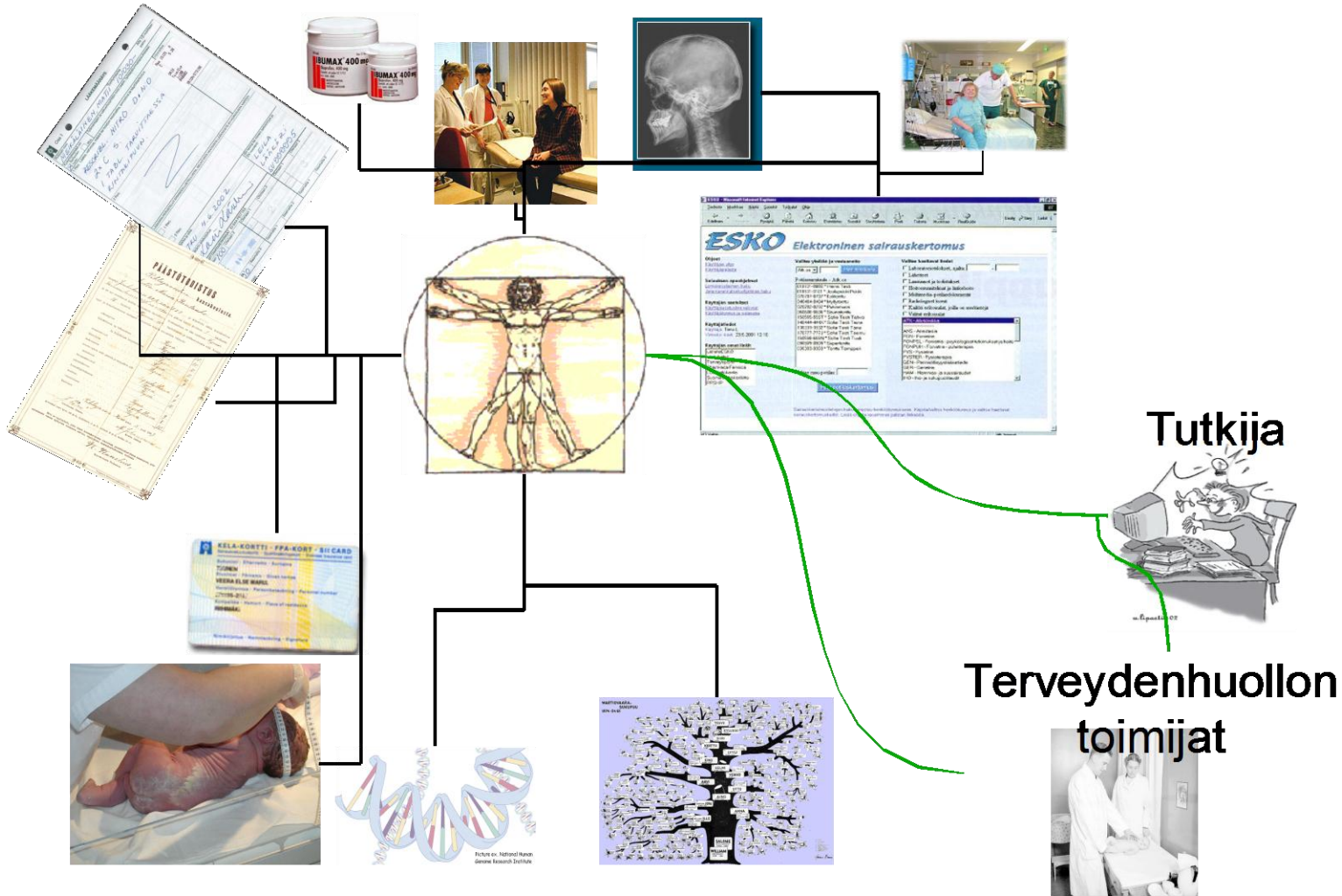
The percentage of people who are not concerned on data protection, by public and private organizations, %



Eurobarometer 225/2008:

http://ec.europa.eu/public_opinion/flash/fl_225_en.pdf

Future directions?





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 in statistics and research?
- More register-based research and easier access to data.
- More international collaboration in keeping registers and using them in research.

Questions for Estonia

- One general health register or small registers
 - The ideal solution seems to be decentralised is to have separate topic-specific registers with collaboration and possibilities for linkages.
- Can health insurance data be used and how to interpret the data?
- Can structured eHealth data be used?
- Funding possibilities:
 - Government: central, regional or local
 - Funding from data collecting and users
 - No funding

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. Wide use of unique identifiers increases the completeness of data and increases the data quality.
4. The possibility to use register information in scientific research increases the data usefulness and quality (study-specific permissions required).
5. Citizens' trust
6. The data providers (clinicians) have to be interested in the data.