

Swedish registers



Weimin YE

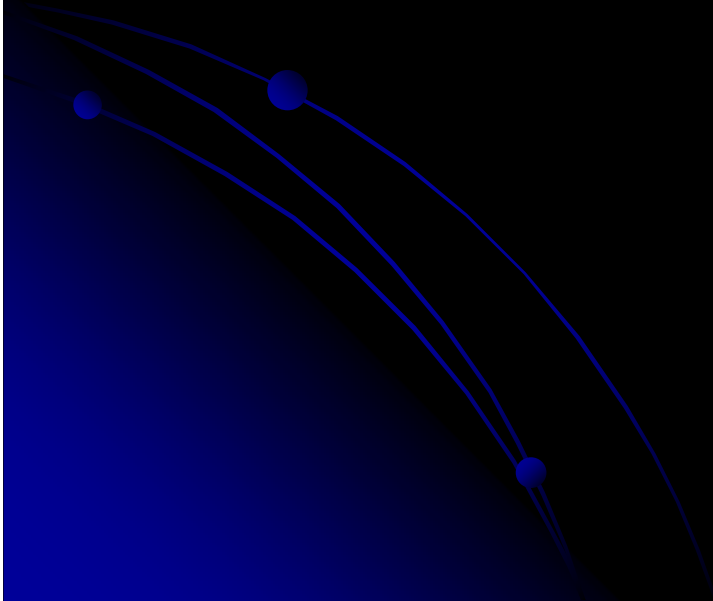
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Register overview

- Nationwide registers
- Quality registers



Overview – nationwide routines

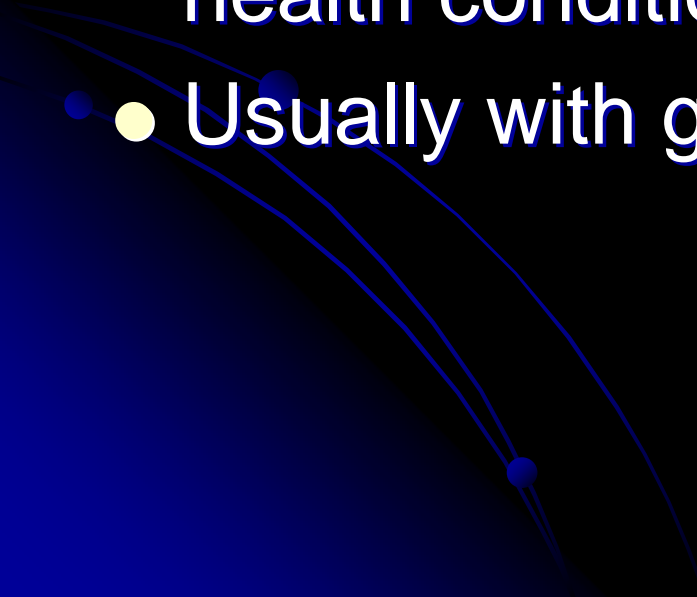
- Nationwide registers

- Total Population Register (1968-)* NRNs from 1947
- Cancer Register (1958-)
- Death Register (1952-)* earliest data from 1947, high quality data from 1961
- Inpatient Register (1964/65-)
- Multi-Generation Register (1961-)
- Register on prescribed pharmaceuticals (July 2005-)
- Migration Register
- Medical Birth Register (1973-)
- Education Register (1985-)
- Nationwide Censuses (1960, 1970, 1980, 1990)* new ones thereafter?
- etc

Overview – quality registers

- Quality registers
 - Swedish Knee Arthroplasty Register (1975-)
 - Swedish Hip Arthroplasty Register (1979-)
 - Swedish Hip Fracture Register (1988-)
 - Swedish Multiple Sclerosis Registry (1996-)
 - National Prostate Cancer Registry (1996-)
 - National Diabetes Registry (1996-)
 - National Quality Registry for Stroke (1994-)
 - Swedish Hernia Registry (1992-)
 - Etc.

Differences – nationwide registers

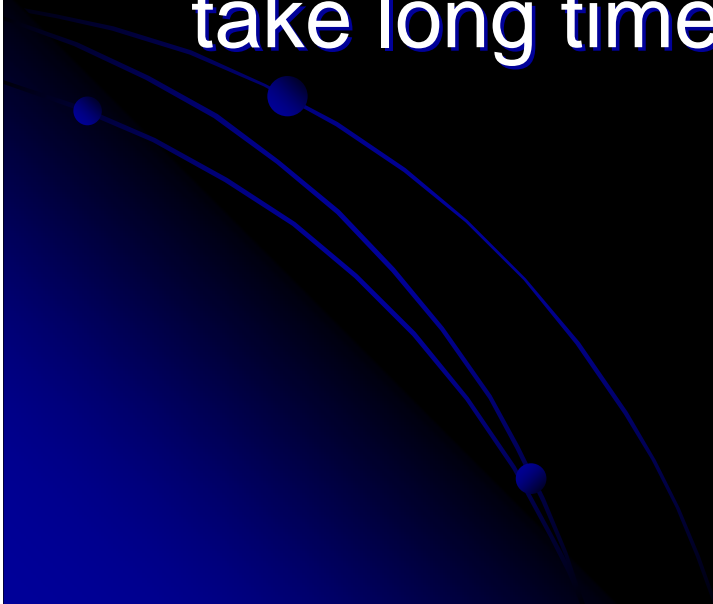
- Developed and managed by either the National Board of Health and Welfare or Statistics Sweden
 - Contain individual-based data on primary health condition
 - Usually with governmental funding
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Differences – quality registers

- Developed and managed by representatives of the professional groups who also use them.
- Contain individual-based data on problems or diagnoses, treatment interventions and outcomes, making them useful for multiple purposes.
- Usually with multiple funding.

Problems with nationwide registers

- Information is not detailed
- Quality of data is not always ensured – validation studies are needed
- Transformations of data collection formats take long time



Problems with quality registers

- Diversity – no uniform format applied
- Owner – physicians or physician-associations
- Coverage – few are nationwide complete
- Follow-up – most are young registers
- Content – either too little or too much information collected

How to select quality register?

- Coverage – better choose register approaching nationwide
- Age – better choose register with appropriate years of follow-up
- Content – better choose register with enough amount of information collected
- Format – better choose register with electronic database

Time Plan

- 2008.3-6: collect information on about 10 registers including both nationwide and quality registers, also figure out an efficient way of information collection
- 2008.7-8: collect information on another 20 registers, mainly quality registers
- 2008.8-9: summary and review work