

Health data registries a gold-mine for researchers

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Health Data Registries

- Cancer Register
- Patient register
- Medical Birth Register
- Prescribed Drug Register
- Dental Health Register

- Cause of Death Register

Objective of the Health Data Registries

- Produce health statistics
 - Follow-up, evaluation and quality assurance of health care
 - Research and epidemiological studies
- (Health Data Registries Act (1998:543))

Overall rules

- No consent
- No right to be deleted

The data are protected

- The data at EpC are strictly protected by the Official Secrets Act (9:4)
- Absolute secrecy – but there are only four exceptions to this:

Official Secrets Act chapter 9, 4 §

The four exceptions

- Statistics (official)
 - Data that in no way can be linked to an individual
 - Information about deaths to quality registers
 - Research
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- No harm



The research aim

- For release of person data – approval by research ethics committee is demanded, that is:
 - All data that can be assigned to an individual, regardless of whether there is a personal identification number.
 - Regardless of whether consent is given by the individual.
- For release of data on deceased only a research plan.

Variables

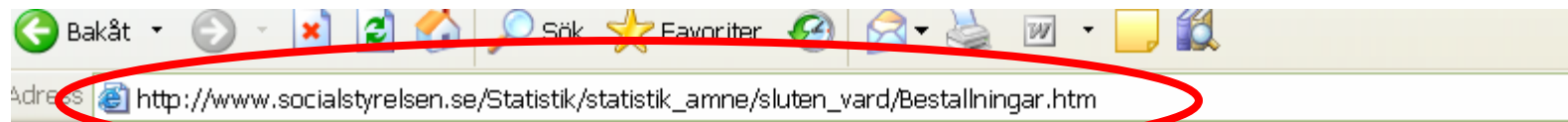
- Only information necessary to carry out the specific research project are released.
 - "The whole register" is not a well thought-out selection.

Personidentification numbers or not

- Personal identification numbers if it is necessary to carry out the research.
 - Only on specific grounds.
 - Not only because it is convenient.
- Serial numbers with a key.
- Serial number without a key is the most common way.

International Data Sharing

- In principle, the same rules apply for Swedish data inside and outside of Sweden.
- In theory - secrecy rules in the receiving country have to be similar if data is to be handed out.
- In practice - authorities are restrictive and the procedure is easier if the principal investigator resides in Sweden.



Socialstyrelsen

Statistik



- ▶ Press
- ▶ Ämnen
- ▶ Publikationer
- ▶ Statistik
- Statistik efter

Beställningar ur hälsodata- och dödsorsaksregistren

Statistikuppgifter

Uppgifter i EpC:s hälsodata- och dödsorsaksregister är

Mer information

Blankett: [Begäran om forskaruttag](#)

- [Patientregistret](#)

- [Medicinska födelserregistret](#)

The inquire

- Necessary contents:
 - The form "Begäran om forskaruttag"
 - Application to ethical board
 - Approval from ethical board
 - List of variables
 - Plan of the project

When data has been delivered...

What is the researcher allowed to do with the data?

- Only what the ethical board has given approval of.

What secrecy is applied in the information?

- The same as at the National Board of Health and Welfare (Secrecy Data Act 13 kap, 3 §)

Thank you!!