

Research Ethics in Sweden

Law and Organisation

Rune Åberg

Research Ethics in Social Sciences and Humanities before 2004

Ethics Committees at the

- Council for Humanities and Social Sciences (HSFR, subcommittee at the Scientific Council)
- Council for Social Research SFR (later Council for Working Life and Social Research, FAS)

Main principles and some recommendations

- Principle of full and adequate information
- Principle of consent
- Principle of confidentiality
- Principle of how research results will be use

The Act concerning the Ethical
Review of Research involving
Humans (2003:460, The Ethical
Review Act), valid since 2004

Reasons for legal regulations of Research Ethics

- Ethical aspects of research was regarded as a problem not only for researchers but also of public interest
- Legal regulations would clarify and specify the obligations and rights of person subject of research as well as the researcher
- However, the main reason was the ambition to broaden ethical control to comprise all research, not only research funded by HSFR or FAS

When is the law applicable?

1. When research is done on sensitive personal data, defined in the Personal Data Act (PUL 1998:204)

- Race and ethnic origin
- Political opinions
- Religious or philosophical conviction
- Union membership
- Indicators of health
- Sexual life
- Crime and penalties

and when the person subject of research has not given explicit approval.

2. If the research person will be physically affected or research is done with a method that aims at affecting the person subject of research physically or mentally

- It is illegal to do research in these cases without permission from a Regional Ethical Review Board

and

- Permission should not be given if the expected result can be achieved otherwise with less risk for the research person.

Who applies and who has the responsibility?

- The university (or some other principal) has a responsibility for controlling that their researchers do apply for permission from a Regional Ethical Board when permission is needed according to the law

Who gives permission?

1. Regional Ethical Review Boards

There are six regional Ethical Review Boards. The chairman and his/her alternate are professional judges. Among the other members are *ten* researchers and *four* are representing the public, half of them alternates. These are appointed by the government on suggestions by the Scientific Council.

2. Central Ethical Review Board

The Board is lead by a Chairman (professional judge), four researchers and two representatives of the public. This committee handles complaints over negative decisions taken by a regional Ethical Review Board.

Critical reactions

1. The Ethical Review Act gives **less** protection for persons subject to research compared to what they had before 2004.
- The law is applicable only when sensitive personal data is used **without** informed consent. In the practices that previously prevailed at HSFR and FAS, all research applications on projects working with sensitive personal data was remitted to the Ethics Committee which often gave advice about ethical matters to the researchers, sometimes as a precondition for funding.
- In a “follow up” inquiry of the Ethical Review Act it was suggested that all research projects that worked with sensitive personal data should be sent to a regional Ethical Review Board for “optional review” which means that the Board gives advice or if necessary specifies conditions that should be met before the research should take place.

2. The administration is very large, expensive and it is difficult to fill all the positions in the organisation – over 100 members in the Boards plus the administrative personnel
3. The “Register Data Problem”, actually caused by the Personal Data Act

