Chapter 4.
Handling of research material

Zhen Liao
Mikael Nissbeck
Mao Guanzhong
Malavika Ramesh
Ioana Onut Brännström
Transparency vs Privacy

• The fundamental openness:
All public institutions are obliged to have public access to everything (by law)

• The privacy law
Protection of subjects’ personal integrity
The 4 concepts

1. Secrecy
   Defined by the Official Secrets Act

2. Professional secrecy
   e.g. doctors, dental healthcare, social services

3. Anonymity or de-intentifying
   Subjects remain anonymous from the data they provide to research

4. Confidentiality
   Protecting the information from unauthorized individuals
A researcher, Adam, collects data from a specific group of adult informants. He promises that no one outside his research group will have access to the data. Later his findings are questioned by two other researchers, Brian and Cecilia, who request access to his source data. Adam refuses to hand them over, referring to his promise to his informants. The case reaches an unexpected conclusion when colleagues of Adam’s say they have destroyed the source data on their own initiative.
Conflicts, ethical problems

- Adam’s conflicts: privacy vs openness
  He promised to keep privacy but research data should be made available

- Adam’s ethical problems:
  because of his promise by revealing the data would violate the rights of the informants to remain confidential

- What about the colleagues?
  Destroying the data was unacceptable:
    - the results can’t be verified
    - the research can not be verified for misconduct
    - the findings were a “public good” and now is gone
Solutions

- Adam as a researcher cannot promise secrecy

- But... He could have anonymized the informants

- Convince the informants to the change in the agreement

- Otherwise remove the informants from the database
Who is affected by Adam’s actions

• The informants – their privacy is affected

• The research organization

• Brian and Cecilia – they can’t continue the

• Research

• The funding agencies
What do we value most?

• The privacy
• The value of the research