Handling of research material
”Hantering av integritetskänsligt material”

Ethics of technology and science
Seminar I – 16/02/2017
Conflict

Human research ethics
• Protect privacy and privacy-sensitive information
• Declaration of Helsinki (World Medical Association)

Transparency in public organisations
• Required by law
• Openness and data accessibility
• Universal Declaration of Human Rights

Risk that studies will be performed outside these transparent areas
Göteborg example
Handling privacy-sensitive research material

• Collected material is not the private property of the researcher or research group

• Secrecy
• Professional secrecy
• Anonymity
• Confidentiality
Documentation

• Research material must be stored (Archives Act)

• Verification

• Re-use

• Documenting present conditions for the future
What would you do in the following situation?

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.

Is the action taken by Adam’s colleagues ethically acceptable? Is it compatible with existing legislation? Has Adam promised more than he can deliver?
<table>
<thead>
<tr>
<th>solutions</th>
<th>Participants</th>
<th>Adam (research group)</th>
<th>Society</th>
<th>Science</th>
<th>Future studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>destroy data</td>
<td>✔️</td>
<td>✗ rep. with participants ✗ scientific group ✗ legally</td>
<td>✗</td>
<td>✗</td>
<td>✔️ participants trust researchers</td>
</tr>
<tr>
<td>share (original)</td>
<td>✗</td>
<td>✔️ easy ✗ guilty</td>
<td>✔️</td>
<td>✔️</td>
<td>✗ trust</td>
</tr>
<tr>
<td>share (anonymously)</td>
<td>✔️ or ✗</td>
<td>✔️ of - compromise</td>
<td>✔️</td>
<td>✔️</td>
<td>- compromise</td>
</tr>
<tr>
<td>ask participants</td>
<td>✔️</td>
<td>✔️ honor ✗ sci. Reputation - outcome ✗ time</td>
<td>-</td>
<td>✗ could biased data</td>
<td>✔️ trust ✗ trust</td>
</tr>
<tr>
<td>repeat study</td>
<td>✔️</td>
<td>✔️ honor ✗ sci. Reputation ✗ time, money - if repeated ✗ waste of tax, payer money</td>
<td>✗ improved study design ✗ quality of data - if repeated</td>
<td>✔️ trust</td>
<td></td>
</tr>
<tr>
<td>not destroy + not share</td>
<td>✔️</td>
<td>✔️ Adam 'feels good' ✗ sci. Reputation ✗ legally</td>
<td>✗ study is useful ✗ cant be peer reviewed ✗ less scientific</td>
<td>✗</td>
<td>✔️ trust</td>
</tr>
</tbody>
</table>