

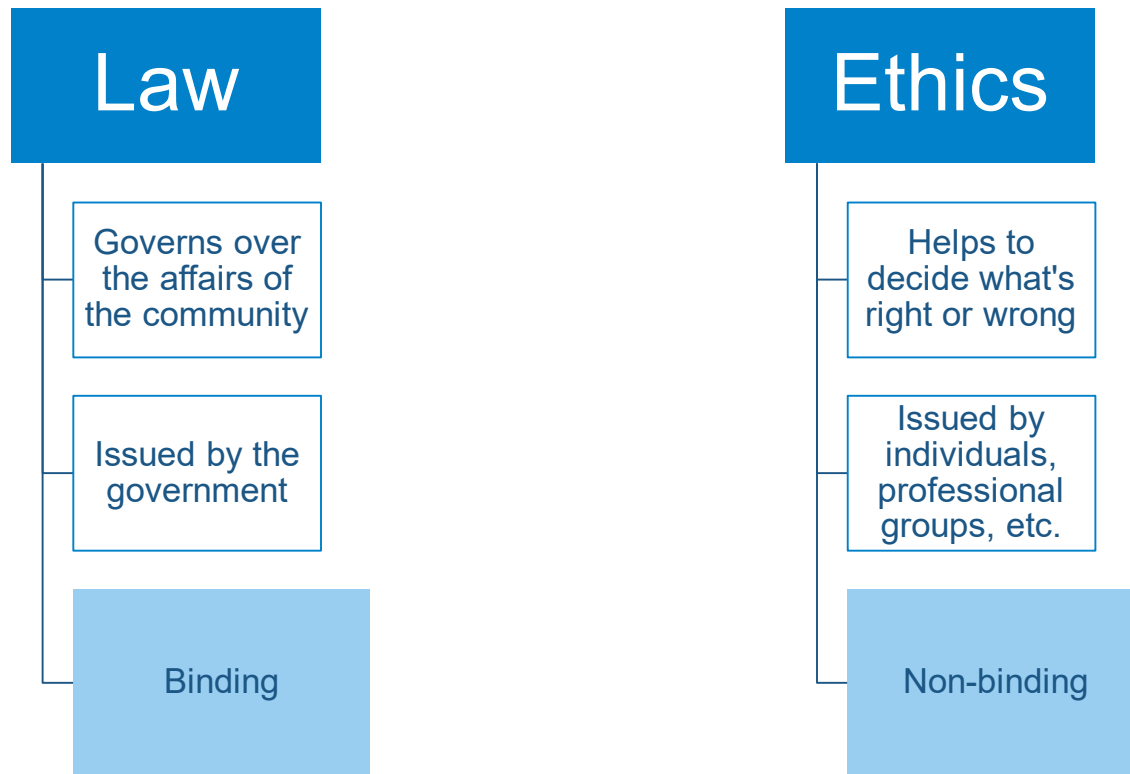
Ethical considerations around data sharing

Faculty of Humanities and Social
Sciences
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Outline

1. Ethical versus legal
2. Regulating frameworks
3. Guiding codes of research ethics
4. Ethics of data sharing
5. Ethical data sharing
6. Conclusion

Ethical versus legal



Data protection = protection of people

An action may be legal but unethical or illegal but ethical

Testimony of Pinar Selek, a turkish researcher working on the PKK

“One day... a beautiful sunny day, yes... In July 1998, I found myself in the hands of police officers. They arrived suddenly, they made me suddenly get into a car and took me for questioning. They seized all my working documents and immediately began to question me about this research and people I had talked to. I told them that I worked a lot with excluded groups and that such work was based on respect for the anonymity of the people interviewed, and that in this sense it was impossible for me to inform the police. For this research, I made an express commitment to the interviewees, guaranteeing them not to reveal their identity. It was an ethical problem for me and a condition for sociological inquiry: I could not give the names.” (Laurens & Neyrat, 2010)

Regulating frameworks

Depending on disciplines, there may be strong incentives to apply ethical guidelines:

- **Ethical committees:** It may be obligatory to go through an ethics review.
- **Codes of ethics:** professional associations representing various fields may provide recommendations.
- **International guidelines**

Guiding codes of research ethics

The EU RESPECT project identifies three main codes:

- **Upholding scientific standards:** researchers should always try to take into account all the relevant evidence and present their research without omission, misrepresentation or deception
- **Compliance with the law:** researchers need to ensure that they are aware of all the relevant national and international laws that may affect their projects.
- **Avoidance of social and personal harm:** researchers should aim to avoid or minimize social harm to groups or individuals when conducting their research projects.

Source: CESSDA Expert Tour Guide

In the context of research ethics, harm can be defined as:
“to include extreme physical pain or death, but also involves such factors as psychological stress, personal embarrassment or humiliation, or myriad of influences that may adversely affect the participant in a significant way” (Drew et al., 2008)

Ethics of data sharing

Ethical grounds in favour of data sharing:

- No burden (over-researched populations)
- Make best use of hard to obtain data
- Extend voices of participants
- Provide greater research transparency
- Enable fullest use of rich data

Source: UKDA presentation

Ethical grounds against data sharing:

- Harm to research participants

Main exceptions to data sharing

Legal

Example: sensitive, non-anonymised data for which no consent has been obtained

Ethical

Example : Data for which consent has been obtained but where the risks to participants are too high

Copyright

Example : data that have been produced by someone else and are legally protected

Confidentiality

Example : data that have been obtained on the condition that they remain confidential.

Data shareability continuum:

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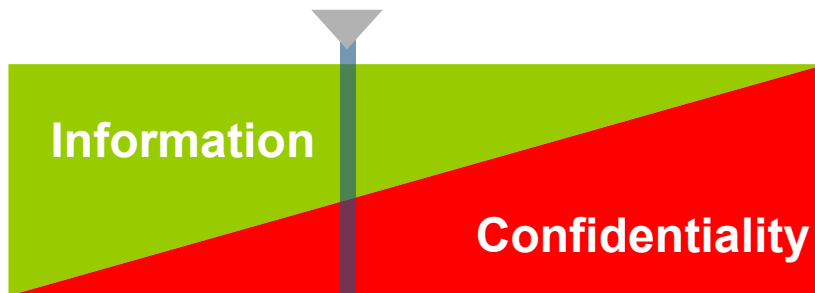


Ethical data sharing

- Informed consent
 - 'Ethical consent'
 - Consent for sharing

Adding the discussion of data sharing and archiving permits the participant to make an informed decision.

- Anonymisation



- Risk assessment

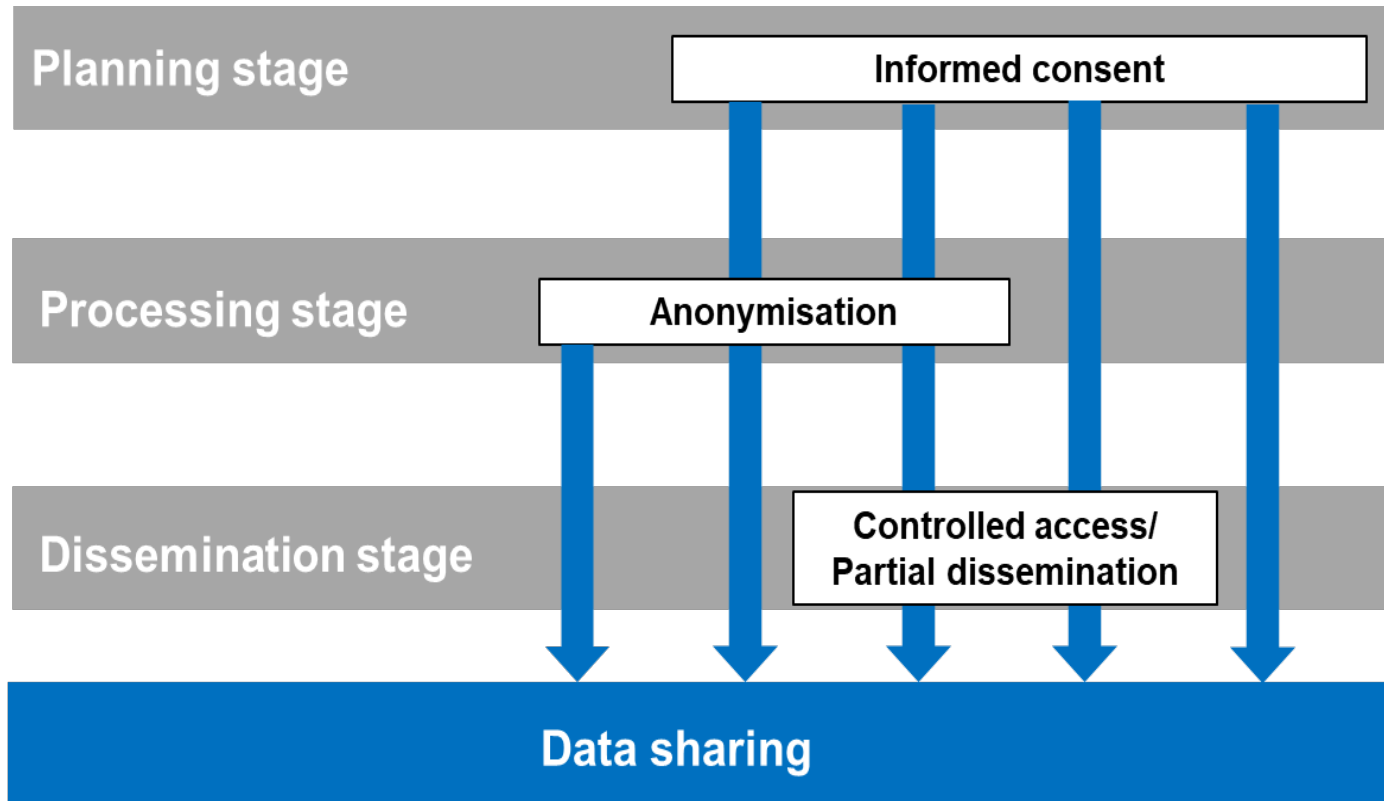
Ethical self-assessment

- Evaluate **potential impacts** on private life
- Evaluate the **extent of the potential harm**
- Evaluate the **likelihood for harm to happen**

Data protection impact assessment

Article 35 of the GDPR provides that before any processing activity «likely to generate a high risk for the rights and freedoms of individuals», the controller must carry out a data protection impact assessment (DPIA).

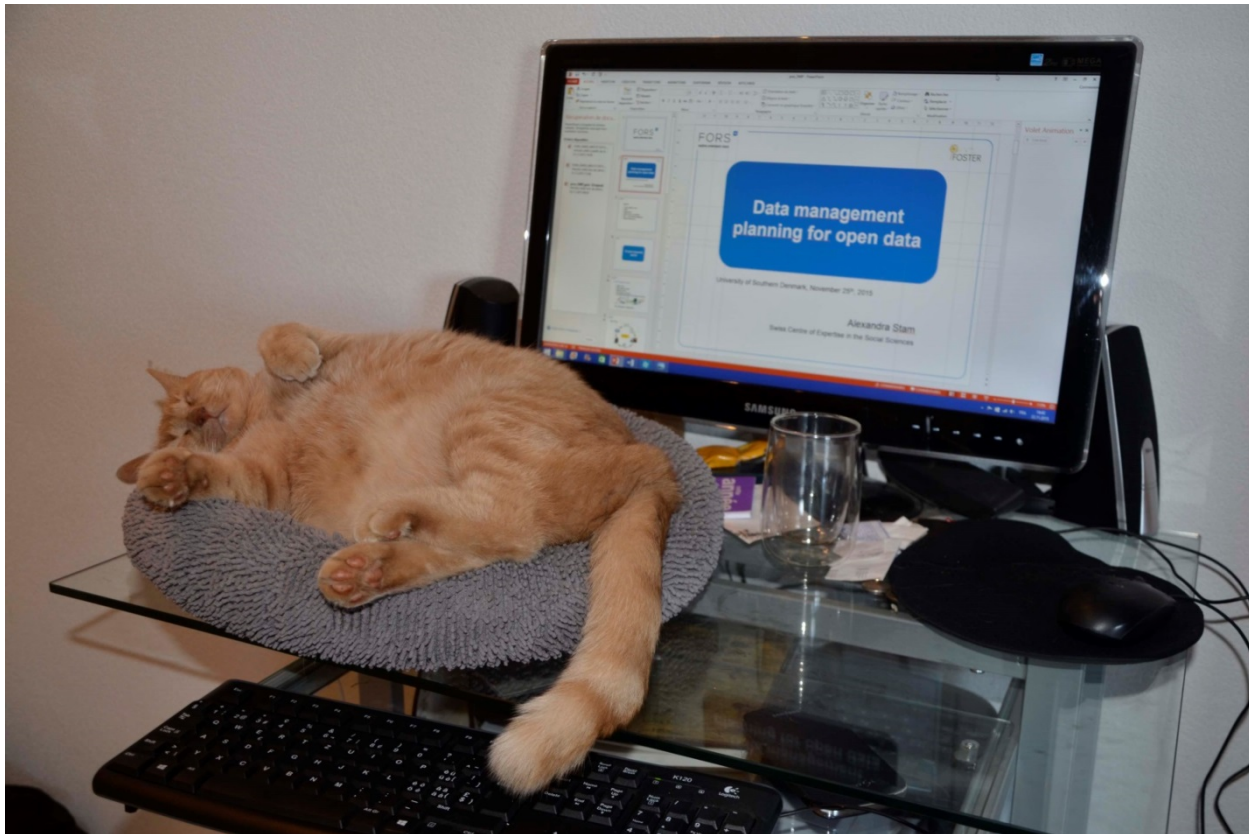
- Multi-layered approach



Conclusion

It is about finding a good balance between:

- Data protection and data sharing
- Openness and accessibility
- Science and participants' well-being



Thanks for your attention

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