



Course for Doctoral Students

RESEARCH DATA MANAGEMENT AND OPEN DATA

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Faculty of Social Sciences, University of Ljubljana

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A large, stylized orange dandelion seed head is positioned in the bottom left corner. Several individual seeds are scattered across the bottom of the slide, some appearing to blow away from the left.

LEGAL AND ETHICAL ISSUES: OPEN ACCESS TO DATA IN RESEARCH WITH PEOPLE AS PARTICIPANTS

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How to archive, share, re-use research data from
'human participants' within ethical and legal
boundaries?



Discussion

- What do you see as challenging aspects for research data from human participants ?



Research with people as participants

- Research data may contain personal data - data that allows living individuals to be identified
 - Legal: data protection / privacy legislation (data about living individuals)
 - Inform participants how personal data will be used, stored,....
 - Store securely, avoid disclosure
 - Need consent from participant to share such data
- Research data may contain confidential information - information given in confidence, agreed to be kept confidential (secret) between two parties
 - E.g. information on business, income, health, political opinion,...
 - Legal: duty of confidentiality
 - Ethical: do no harm
 - Need consent from participant to share such data

Debate

- Half of the audience: generate AS MANY reasons as you can for why researchers should share their data.
 - What are the benefits of sharing data?
 - Who does sharing data benefit?
 - How does it benefit them?
- Other half of audience: generate AS MANY reasons as you can for why researchers should not share their data.
 - What are some of the downsides of sharing data?
 - What are some of the impediments to sharing data?
 - What are some of the concerns associated with sharing data?
- Take about 6-8 minutes.
- Then we'll debate the issue!



Tensions

- Between protecting participants, researchers and institutional reputation
and
- Maximising the value of research data collected from public funding
- RECs/IRBs tendency to be risk averse, require data destructions etc.

Ethical obligations and data sharing

- Research with human participants usually requires ethical review (Research Ethics Committee)
- Ethical conduct in research and protection of safety, rights and well-being of research participants - ‘do no harm’
- Data archives such as ADP, UK Data Archive,... facilitate ethical re-use of research data, protection of participants and safeguarding of personal data
 - data anonymisation
 - regulate data access
 - data sharing is NOT violation of data privacy or research ethics

Ethical arguments *for* archiving data

- Not burden over-researched, vulnerable groups
- Make best use of hard-to-obtain data, e.g. elites, socially excluded, over-researched people
- Extend voices of participants
- Provide greater research transparency
- Enable fullest ethical use of rich data

Best practice for legal compliance

- Investigate early which laws apply to your data
- Do not collect personal or sensitive data if not essential to your research
- Seek advice from your research office
- Plan early in research
- If you must deal with personal or sensitive data
 - inform participants about how their data will be used
 - remember: not all research data are personal (e.g. anonymised data are not personal)

Our advice to researchers

- Do not collect personal or sensitive data if not essential to your research
- Plan early in research
- If you collect personal or sensitive data, inform participants how their data will be used
- Not all research data are personal, e.g. anonymised data are not personal



Options for sharing research data that may contain confidential information

- Obtain informed consent, also for data sharing and preservation / curation
- Protect identities e.g. anonymisation, not collecting personal data
- Regulate access where needed (all or part of data) e.g. by group, use, time period

Questions ?

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