Course for Doctoral Students

RESEARCH DATA MANAGEMENT AND OPEN DATA

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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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