Ethical considerations in creating shareable data

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Social Science Data Archives

Seminar How to Get the maximum from Research Data, Estonia: Tartu, 29. May 2018
Training team at CESSDA ERIC

- Topic specific webinar / workshop (How to find data in Europe, Ageing, Political Behaviour, Migration, Labour Force Survey)
- RDM workshops / summer schools / guides

9 Service providers actively involved in 2018 (11 in 2019)  Σ 20 PM / year

Source: http://www.statistics.gr
Expert tour guide on Data Management

About this expert tour guide

This tour guide aims to put social scientists like yourself at the heart of making their research data findable, sustainably accessible and (re)usable.

You will be guided by European experts who are - on a daily basis - busy ensuring long-term access to valuable social science datasets, available for discovery and reuse at one of the 15 CESSDA social science data archives. With this guide and training events throughout Europe, we want to accompany and inspire you in your travels through the research data lifecycle.
Chapters in the expert guide on Data Management

Presentations and exercises
Recurring elements in each chapter

» Expert Tips

» European diversity

» Qualitative vs. Quantitative data

» Adapt your DMP

Source: Braukmann, 2018
Recurring elements

Adapt your Data Management Plan

A list of Data Management Questions based on the Expert Tour Guide on Data Management

Source: Braukmann, 2018
This chapter highlights legal and ethical obligations and shows how a combination of gaining consent, anonymising data, gaining clarity over who owns the copyright to your data and controlling access can enable the ethical and legal sharing of data.

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Libby Bishop

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5. Protect

- Ethics and data protection
- Ethical review process
- Processing personal data
- Diversity in data protection
- Informed consent
- Anonymisation
- Copyright
  - Diversity in copyright
- Adapt your DMP: part 5
- Sources and further reading
Sensitive personal data
Research Ethics

Disciplinary Code of Ethics (ASA)

European Code of Research Integrity
University (UNI-LJ)
Institute

Funder – H2020 / other EC projects / grants
Scientific Journal < -ethical committee approval before publishing

Ethics are an integral part of a research project, from the conceptual stage of the research proposal to the end of a research project.
ASA Code of Ethics

“This Code of Ethics articulates a common set of values upon which sociologists build their professional and scientific work. The Code is intended to provide both the general principles and the rules to cover professional situations encountered by sociologists. It has as its primary goal the welfare and protection of the individuals and groups with whom sociologists work. It is the individual responsibility of each sociologist to aspire to the highest possible standards of conduct in research, teaching, practice, and service.”

-> Requires a personal commitment to a lifelong effort to act ethically.
ASA – General principles

A. Professional Competence
   only the task for which they are qualified; ongoing education; consult with other

B. Integrity
   honest, fair, and respectful of others; inspire trust and confidence

C. Professional and Scientific Responsibility
   adhere to the highest sci. and prof. standards and accept responsibility for their work;
   don’t compromise public trust

D. Respect for People’s Right, Dignity and Diversity
   They strive to eliminate bias in their prof. activities, and they do not tolerate any forms
   of discrimination based on age, gender, race, ethnicity ...

E. Social Responsibility
   responsibility to the communities and societies; make public their knowledge in order
   to contribute to the public good
Guidelines for ensuring compliance with ethical principles in Horizon 2020 / Main ethical principles

1. Respecting human dignity and integrity
2. Ensuring honesty and transparency towards research subjects and, notably, getting free and informed consent (as well as assent whenever relevant)
3. Protecting vulnerable persons
4. Ensuring privacy and confidentiality
5. Promoting justice and inclusiveness
6. Minimising harm and maximising benefit
7. Sharing the benefits with disadvantaged populations, especially if the research is being carried out in developing countries
8. Maximising animal welfare, by ensuring replacement, reduction and refinement in animal research
9. Respecting and protecting the environment and future generations
10. Following the highest standards of research integrity (i.e. avoiding any kind of fabrication, falsification, plagiarism, unjustified double funding or other type of research misconduct)
Ethical Review Process

Is about helping you as a researcher to think through the ethical issues surrounding your research.

The principles of good research practice encourage you to consider the wider consequences of your research and engage with the interest of your participants.

Ethics review by a Research Ethics Committee (REC) is typically required when (sensitive) personal data are being collected or when people are involved.

The role of a REC is to protect the safety, rights and well-being of research participants and to promote ethically sound research.

Among other duties, this involves ensuring that research complies with national and international data protection laws regarding the use of personal information collected in research.

Source: Summers, 2018
“Consider that ethics issues arise in many areas of research. Apart from the obvious example, the medical field, research protocols in social sciences, ethnography, psychology, environmental studies, security research, etc. may involve the voluntary participation of research subjects and the collection of data that might be considered as personal. **You must protect your volunteers, yourself and your researcher colleagues.**

Start thinking about ethics while designing your research protocols. Don't wait until the last minute to seek advice or check requirements under national and EU law.

**Your first source should always be at your institution** (specialised ethics departments or ethic advisers UNI, hospital research ethics committees, data protection officers). “
### Research involve human participants? (H2020)

<table>
<thead>
<tr>
<th>Question</th>
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<tbody>
<tr>
<td>Are they volunteers for social or human sci. research?</td>
</tr>
<tr>
<td>Details of recruitment, inclusion and exclusion criteria and informed consent procedures.</td>
</tr>
<tr>
<td>Are they persons unable to give informed consent (including children / minors)?</td>
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<tr>
<td>Details of your procedures for obtaining approval from the guardian / legal representative and the agreement of the children or other minors. What steps will you take to ensure that participants are not subjected to any form of coercion?</td>
</tr>
<tr>
<td>Are they vulnerable individuals or groups</td>
</tr>
<tr>
<td>Details of the type of vulnerability. Details of recruitment, inclusion and exclusion criteria and informed consent procedures. These must demonstrate appropriate efforts to ensure fully informed understanding of the implication of participants.</td>
</tr>
<tr>
<td>Are they children/ minors?</td>
</tr>
<tr>
<td>Details of the age range. What are your assent procedures and parental consent for children and other minors? What steps will you take to ensure the welfare of the child or other minor? What justification is there for involving minors?</td>
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</tbody>
</table>

Source: Cessda Eric
Research involve human participants?

<table>
<thead>
<tr>
<th>Are they patients?</th>
<th>What disease / condition / disability do they have? Details of recruitment, inclusion and exclusion criteria and informed consent procedures. What is your policy on incidental findings?</th>
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<tr>
<td>Are they healthy volunteers for medical studies?</td>
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Physical intervention (human cells, biological samples)... -> Risk assessment

Potential misuse of research results -> Risk assessment
Personal data  (H2020 – Self-Assessment)

Does your research involve personal data collection and/or processing?

Does it involve the collection or processing of sensitive personal data (e.g. health, sexual lifestyle, ethnicity, political opinion, religious or philosophical conviction)?

Does it involve processing of genetic information?

Does it involve tracking or observation of participants (e.g. surveillance or localization data, and Wan data, such as IP address, MACs, cookies etc.)?

Does your research involve further processing of previously collected personal data (‘secondary use’) (including use of pre-existing data sets or sources, merging existing data sets, sharing data with non-EU member states)?
Personal data – information to be provided

Details of your procedures for data collection, storage, protection, retention, transfer, destruction or re-use (including, collection methodology (digital recording, picture, etc.), methods of storage and exchange (LAN, cloud, etc.), data structure and preservation (encryption, anonymisation, etc.), data-merging or exchange plan, commercial exploitation of data sets, etc.).

Details of your data safety procedures (protective measures to avoid unforeseen usage or disclosure, including mosaic effect, i.e. obtaining identification by merging multiple sources).

Details of data transfers to non-EU countries (type of data transferred and country to which it is transferred).

-> Copies of notifications/authorisations for collecting and/or processing the personal data (if required).
-> Informed Consent Forms + Information Sheets + Other consent documents (opt-in processes, etc.) (if relevant).
-> Copy of authorisation for data transfer to non-EU country (if required)
The ethical and legal sharing of data

Respect Ethical standards!!!!

Use a combination of consent, information sheet, anonymising data, gaining clarity over who owns the copyright to your data and controlling access.

Informed consent is the process by which a researcher discloses appropriate information about the research so that a participant may make a voluntary, informed choice to accept or refuse to cooperate.
Consent is needed across the data lifecycle

Engagement in the research process
  What activities are involved in participating in the project?

Dissemination in presentations, publications, the web
  Consent for use of quotes for articles and video publicity

Data sharing and archiving
  Consider future uses of data

* Consent is always dependent on the research context – special cases of covert research and verbal consent

Source: Summers, 2018
Informed Consent – Research (1)

To obtain informed consent in practice, researchers should:

- Inform participants about the purpose of the research;
- Discuss what will happen to their contribution (including the future archiving and sharing of their data);
- Indicate the steps that will be taken to safeguard their anonymity and confidentiality;
- Outline their right to withdraw from the research, and how to do this.

Source: Summers, 2018
The best way to achieve informed consent for data sharing is to identify and explain the possible future uses of their data and offer the participant the option to consent on a granular level.

For example, in a qualitative study, this may involve allowing the participant to consent to data sharing of the anonymised transcripts, the non-anonymised audio recordings and the photographs.

Source: Summers, 2018
Information Sheet

A/ General information about the research and the collected research data

Purpose of the research

Type of research intervention, e.g. questionnaire, interview, etc.

Voluntary nature of participation

Benefits and risks of participating

Procedures for withdrawal from the study

Usage of the data during research, dissemination and storage, including how the information will be shared with participants and any access and benefits-sharing that may be applicable (e.g. traditional knowledge under the Nagoya protocol)

Future publishing, archiving and reuse of the data, explaining to participants the benefits of data sharing and indicating whether research data will be deposited in a data repository, naming the organisation responsible for the repository (e.g. UK Data Service, your institutional repository)

Contact details of the researcher, with institution, funding source, how to file a complaint

Source: Summers, 2018
B/ Additional information if personal information is collected from participants (for example their name, where they live, information that can disclose their identity)

- How personal information will be processed and stored, and for how long (e.g. signed consent forms, names or email addresses in online surveys, people’s visuals in video recordings)
- Procedures for maintaining confidentiality of information about the participant and information that the participant shares
- Procedures for ensuring ethical use of the data: procedures for safeguarding personal information, maintaining confidentiality and de-identifying (anonymising) data, especially in relation to data archiving and reuse

Source: Summers, 2018
Sources

CESSDA ERIC. [webpage] https://www.cessda.eu/DMGuide


Summers S. (2018). Gaining consent from study participants. Workshop: Legal and ethical aspects of research data management. Ljubljana


Working Group of European Research Administrators at German Universities. (2017). Guidelines for ensuring compliance with ethical principles in Horizon 2020 – from proposal to Grant Agreement.
Questions

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