Research Ethics and Legal Compliance: Informed Consent and Data Licensing

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Informed Consent
Informed Consent

• Obtaining agreement from your participants to participate in your study

• Weak consent will lead to poorer data because participants may try to protect themselves
  ⇒ causes item (sensitive data) or even unit non-response
EU-Directive 1995/46/EC

- Participants in research have the right to
  - withdraw from participation
  - access their data
  - get information about the use of their data

- Personal data need special protection
  - have to be stored in the EU
  - have to be anonymized
Elements of Consent Forms

- Informed consent includes information on:
  - project and the researcher(s)
  - participation in the study
  - use of information within and beyond the project
  - protection of personal data
  - right to withdraw

- Can be given written form (favourable) or verbally
  ⇒ always obtain informed consent
Anonymization

Research

Archiving & registering

Study planning

Data analysis

Data collection
Anonymization

• Strategy to protect the identity of participants
  – legal requirements, e.g. EU-Directive 1995/46/EC
  – ethical reasons (protection from harm)

• Identifying participants
  – direct identifiers, e.g. names, addresses, pictures etc.
  – indirect identifiers, i.e. combination of different information in the data

• Anonymization is an early task (study planning)
  – types of data to collect
  – data protection laws
Anonymization Strategies

- **Direct identifiers**
  - keep sensitive data on separate files
  - use meaningful pseudonyms and replacements
  - remove variables with sensitive data
  - voice alteration or image blurring

- **Indirect identifiers**
  - restrict upper and lower ranges of variables
  - low-level aggregation of data
Anonymization: Keep in Mind

- Document anonymization and changes undertaken
- Avoid
  - inconsistency
  - over-anonymization
- If anonymization is impossible
  - obtain informed consent for using and sharing non-anonymous data
  - control access and regulate reuse
  - place confidential data under embargo
Data Licensing

Data collection → Data analysis → Archiving & registering → Study planning → Research → Data collection
Intellectual Property Rights

- Intellectual Property Rights (IPR)
  - cover scientific work
  - do neither extend to an idea nor subsist in facts but to an organized collection of data
- IPRs are not universal
  - vary from country to country
  - are territorial
  \[ \Rightarrow \text{it matters where they are applied not where they originate} \]
Reusing Data

• Copyright
  – assigns the owner of IPR protects against unauthorized copies or derivatives of work

• The right of usage
  – defines conditions of reused ⇒ reusing data, clarify conditions, first

Image by A. Herrema & H. Bouwteam (CC-by)
Licensing Data

• Give permission to someone else to reuse data

• To license data
  – clarify who owns the data, first
  – check for template license of your institute of funder

• Licenses can be
  – irrevocable and
  – not suitable for third party licensing or for confidential, sensitive objects etc.
What Licenses Look Like

• Licenses define conditions of reuse
• Extract of UKDA end user license

http://ukdataservice.ac.uk/get-data/how-to-access/conditions
– not to use the data for commercial purposes …
– …no transfer of any interest in intellectual property
– …without warranty or liability of any kind
– …abide by any further conditions notified to you
– …ensure that the means of access … are kept secure
– …use the correct methods of citation … in publications

+ access conditions for weakly anonymized data
Further Readings

- Ball, Alex (2014): How to License Research Data. Available at: http://www.dcc.ac.uk/resources/how-guides/license-research-data.
- Creative Commons. Available at https://creativecommons.org/.
- Open Data Commons. Available at http://opendatacommons.org/.
- UK Data Service: Consent for data sharing: http://ukdataservice.ac.uk/manage-data/legal-ethical/consent-data-sharing/consent-forms [Examples on various consent forms].
DMP Section 4: Ethics and ...

- work in 2-4 groups,
- time: about 30 minutes
- choose one of the following topics
DMP Sections 4: Ethics and ...

a) informed consent (*Section 4.1*)
   ⇒ outline the process of obtaining informed consent …
   … how you gained consent (for data sharing and preservation)
   … how you handle sensitive data and
   how protect participants’ identity

b) Intellectual Property Rights (*Section 4.2*)
   ⇒ reusing data of others, under which conditions
   ⇒ processing data, consider …
   … who is the owner
   … will the data be licensed
   … the conditions of reuse
DMP Sections 4.1: Informed Consent

- seek informed consent in written form
- outline
  - aim of your project as well as name of primary researcher(s) and institute(s)
  - importance and implication of participation
  - use of data within the project as well as beyond the project (archiving and sharing)
  - protection of sensitive information, e.g. via anonymization
  - right to withdraw, access the data etc.
⇒ get the consent form signed and hand over a copy
DMP Sections 4.2: Intellectual Property Rights

• re-using data from others, consider …
  … who is the copyright holder and who needs to be cited
  … what are the conditions of reuse
⇒ better seek for permission than for forgiveness

• licensing data for the reuse of others, consider …
  … how sensitive your data are
  … if and how you have to control access
  … if your data need additional protection, e.g. being accessible only via a Secure Data Center
⇒ archive your data to control access and use