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Consortium of European Social Science Data Archives
European Research Infrastructure Consortium

Research Data Management

International Summer School in Uganda

Dr. Anja Perry

Oliver Watteler

gesis Leibniz Institute for the Social Sciences

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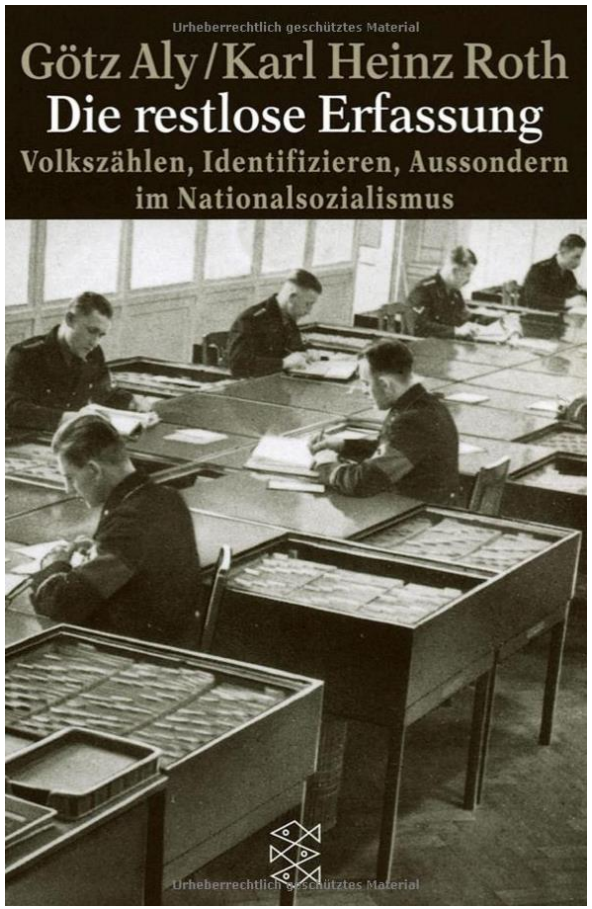
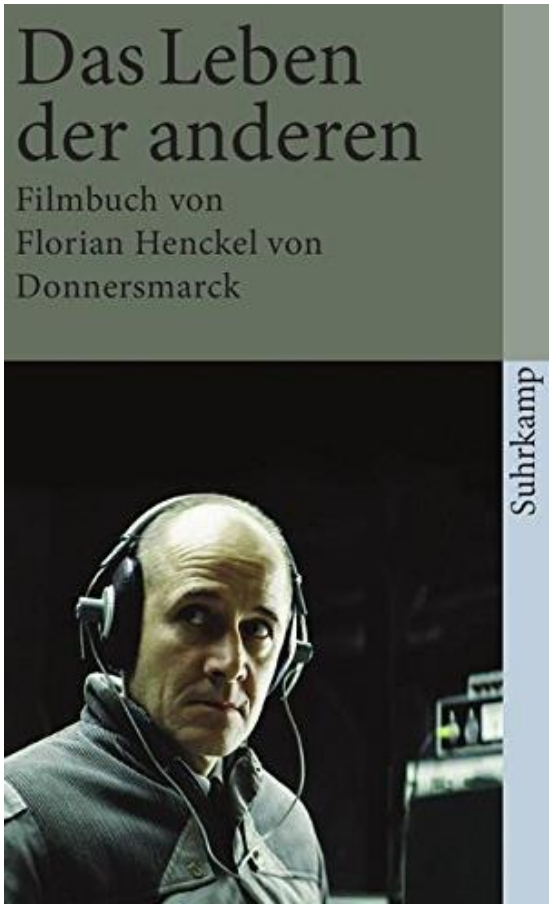
Ethics

Where does data protection come from?



Aly & Roth (2000). Die restlose Erfassung. FISCHER Taschenbuch



Henckel von Donnersmarck (2007). Das Leben der anderen: Filmbuch. Suhrkamp Verlag

Data protection

- To protect participants from harm resulting from participating in a study
- Often a constitutional/fundamental right
- Often regulated in specific country law
- Principle of data avoidance and minimisation

→ do not collect, store, and process data without

- **Purpose**
- **Informed consent**

Data Protection in the EU

General Data Protection Regulation of the EU (GDPR)

http://data.europa.eu/eli/reg/2016/679/oj

- Introduced in May 2018
- Aim was to unify country regulations within the EU
- Comprises issues layed out in German Data Protection Law (first of its kind in 1977)
- Applies directly in all EU member states, to all individuals in the EU
- "… the most consequential regulatory development in information policy in a generation" (Hoofnagle et al., 2019)

"The European Union general data protection regulation: what it is and what it means"

Data protection in Uganda

Data Protection and Privacy Act (DPPA)

https://ulii.org/ug/legislation/act/2019/1

- Introduced in February 2019
- Mirrors the UK Data Protection Act 1998
- Follows the Convention on Cyber Security and Personal Data Protection by the African Union
- Applies to all individuals in Uganda and to data related to Ugandan citizens

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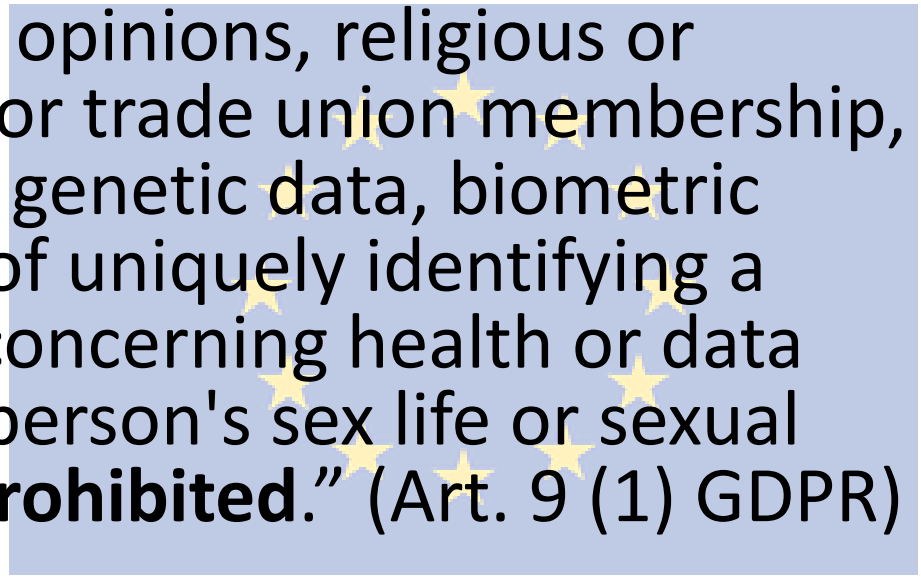
What is personal data (in the EU)?

- " 'personal data' means any **information relating to an identified or identifiable natural person** ('data subject')" (Art. 4 (1) GDPR)
- "**Processing of personal data** revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation **shall be prohibited**." (Art. 9 (1) GDPR)



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GDPR

Exception to the rule: processing personal data, e.g.

- for **purposes** "in the public interest, scientific or historical research purposes or statistical purposes" (Art. 5.1 GDPR)
- if "the data **subject has given consent** to the processing of his or her personal data for one or more specific purposes" (Art. 6.1 GDPR)
- if required by law (Art. 6.1 GDPR)

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GDPR

- **Always obtain freely given consent**
- **Personal data need special protection**
  - stored in the EU or in a country with similar protection
  - have to be “pseudonomized”
  - personal data need special protection

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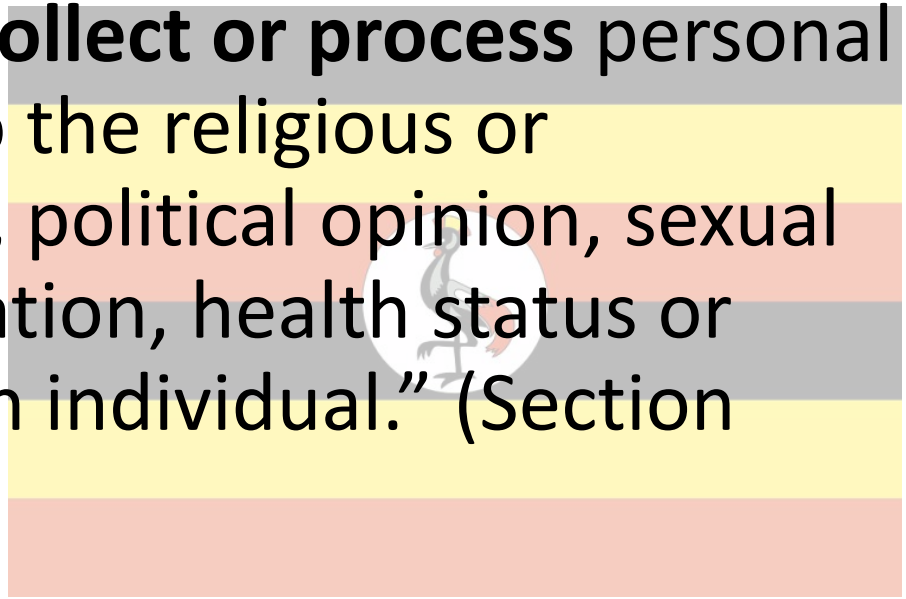
What is personal data (in Uganda)?

- " 'personal data' means **information about a person from which the person can be identified**" (Section 2, DPPA)
- "A person **shall not collect or process** personal data which relates to the religious or philosophical beliefs, political opinion, sexual life, financial information, health status or medical records of an individual." (Section 9(1), DPPA)



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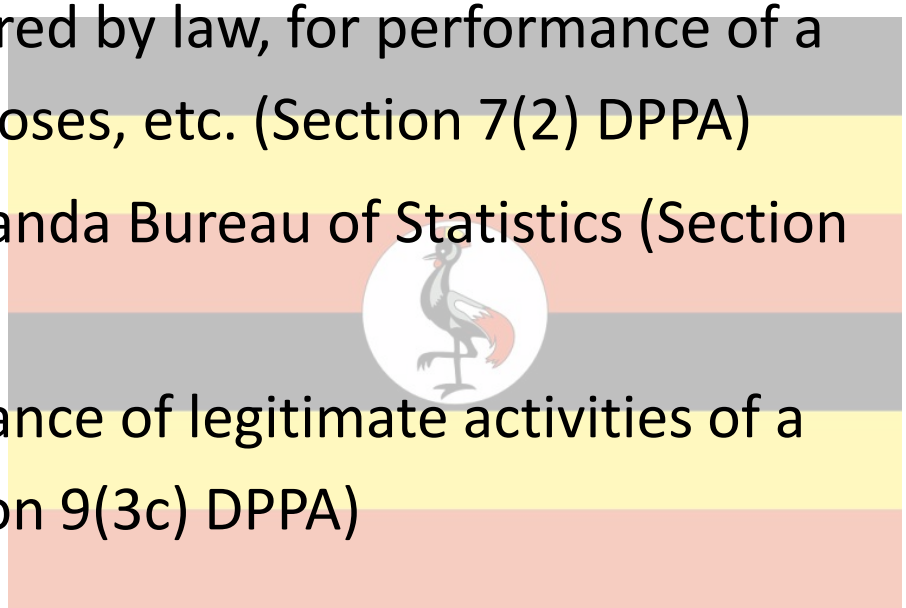
Data Protection and Privacy Act

Exception to the rule: processing personal data, e.g.

- With "prior **consent of the data subject**" (Section 7(1) and Section 9(3b) DPPA)
- When authorized or required by law, for performance of a contract, for medical purposes, etc. (Section 7(2) DPPA)
- When collected by the Uganda Bureau of Statistics (Section 9(2) DPPA)
- When collected in furtherance of legitimate activities of a body or association (Section 9(3c) DPPA)



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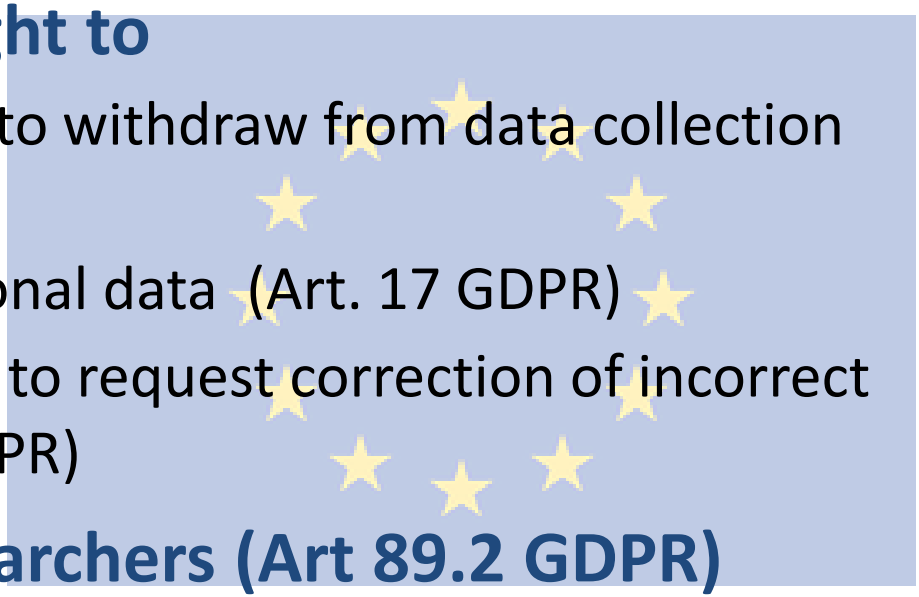
Informed Consent

What is informed consent?

- **Getting agreement to participate and protecting participants from harm**
- **Consent must be given voluntarily**
- **Weak consent will lead to poorer data**
  - creates mistrust
  - respondents try to protect themselves and their personal data
  - causes item (sensitive data) or even unit non-response

Participants rights

- **Researcher must "be able to demonstrate that the data subject has consented to processing of his or her personal data" (Art 7.1 GDPR)**
- **Participants have the right to**
  - to withdraw consent, i.e. to withdraw from data collection (Art. 7.3 GDPR)
  - to obtain erasure of personal data (Art. 17 GDPR)
  - to access stored data and to request correction of incorrect personal data (Art. 16 GDPR)
- **Privileges apply for researchers (Art 89.2 GDPR)**



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Participants rights on information

Participants must be informed about (Art. 13 GDPR)

- the data processor (name and contact information)
- the purpose of data collection
- recipients or categories of recipients of the data
- period for which the personal data will be stored
- existence of the rights to request from the controller

⇒ this is why informed consent is required

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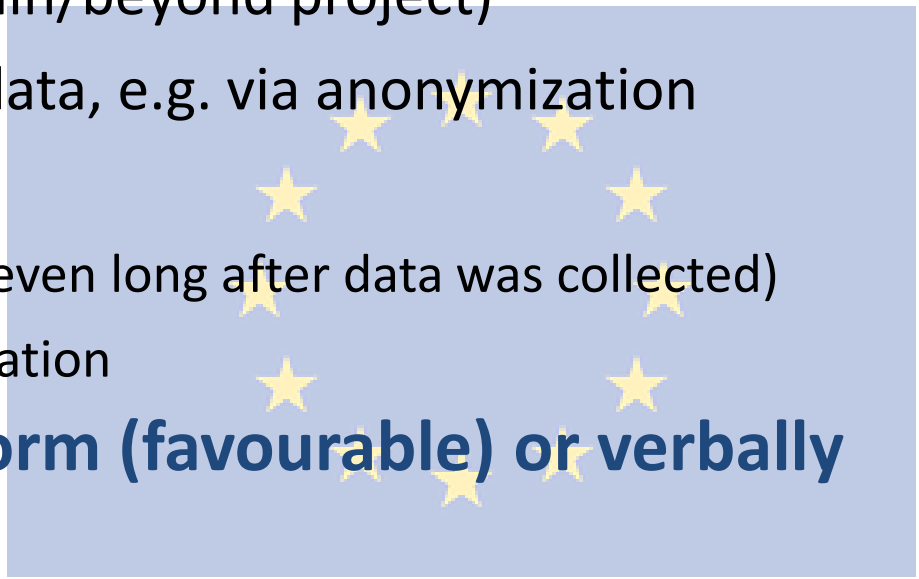
The Elements of Consent Forms

- **Informed consent includes information on:**
  - project and the researcher(s)
  - participation in the study
  - use of information (within/beyond project)
  - protection of personal data, e.g. via anonymization
  - right to
    - withdraw at any time (even long after data was collected)
    - access personal information
- **Can be given written form (favourable) or verbally**



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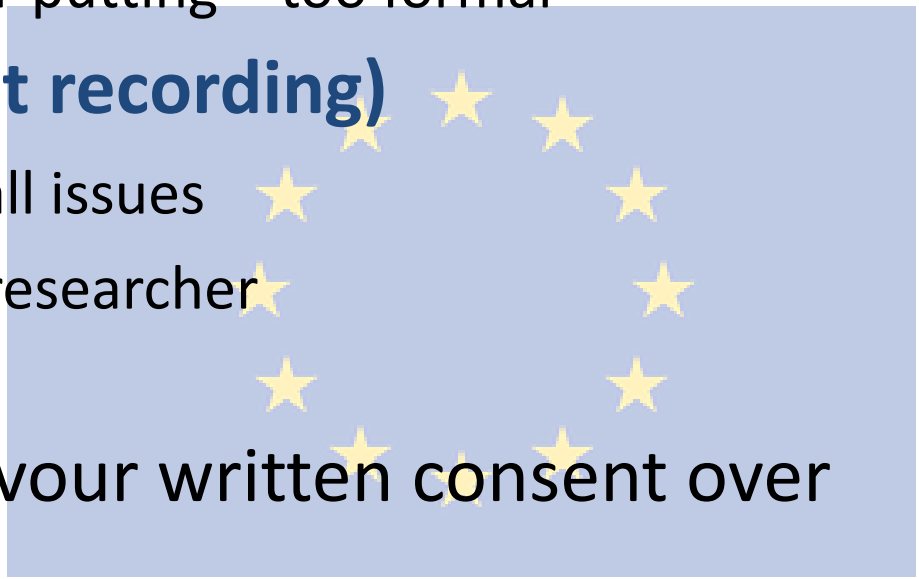
Types of informed consent

- **Written**
  - legal certainty for both parties
  - not possible in some cases: illiterate, illegal activities
  - can be perceived to be off-putting – too formal
- **Verbal (with or without recording)**
  - can be difficult to clarify all issues
  - possibly greater risks for researcher
  - best if recorded

⇒ Whenever possible, favour written consent over verbal



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Some special cases

- **Illiterate respondents**
- **Children who are too young**
  - to understand what's going on
  - "the processing of the personal data of a child shall be lawful where the child is at least 16 years old (…) Member States may provide by law for a lower age (…) not below 13 years. " (Art. 8 GDPR)
- **Employees, having duty of confidentiality to employer**
- **Retrospective consent due to covered research, e.g. in observational psychological experiments**

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Participants rights

- **A person "shall not collect or process personal data without the prior consent of the data subject" (Section 7(1) DPPA)**
- **Participants have the right to**
  - to withdraw consent during data collection (Section 7(3) DPPA)
  - request to correct or delete personal data that is inaccurate or obtained unlawfully (Section 16(1a) DPPA)
  - request to correct or delete personal data which the controller has no longer the authority to retain (Section 16(1b) DPPA)

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Participants rights on information

Information to be given to data subject before collection of data (Section 13 DPPA):

- Nature and category of data being collected
- Contact information of person responsible
- Purpose of data collection
- Whether discretionary or mandatory
- Recipients of the data
- Period for which the data will be retained
- …

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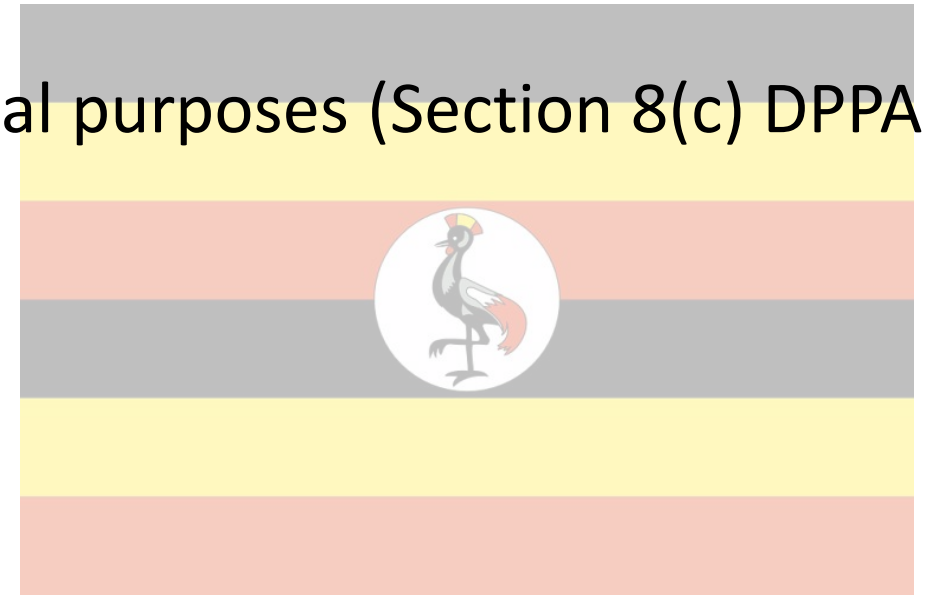
Informed consent from children

- Data collection prohibited (Section 8 DPPA)
- Unless „with prior consent of the parent or guardian“ (Section 8(a) DPPA) or
- For research or statistical purposes (Section 8(c) DPPA)



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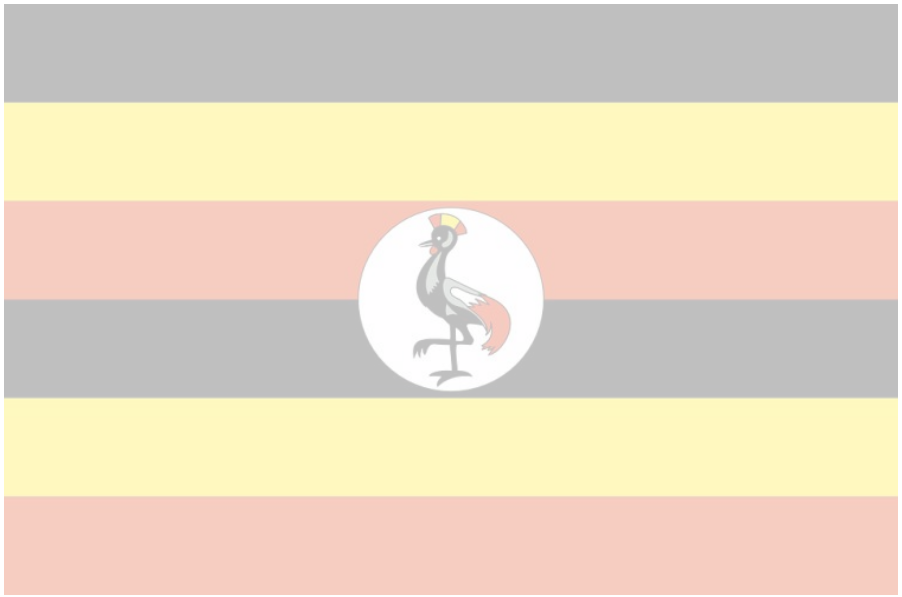
Deletion of data

One may request to correct or delete data „that is inaccurate, irrelevant, excessive, out of date, incomplete, misleading, or obtained unlawfully“ (Section 16 (1) DPPA).



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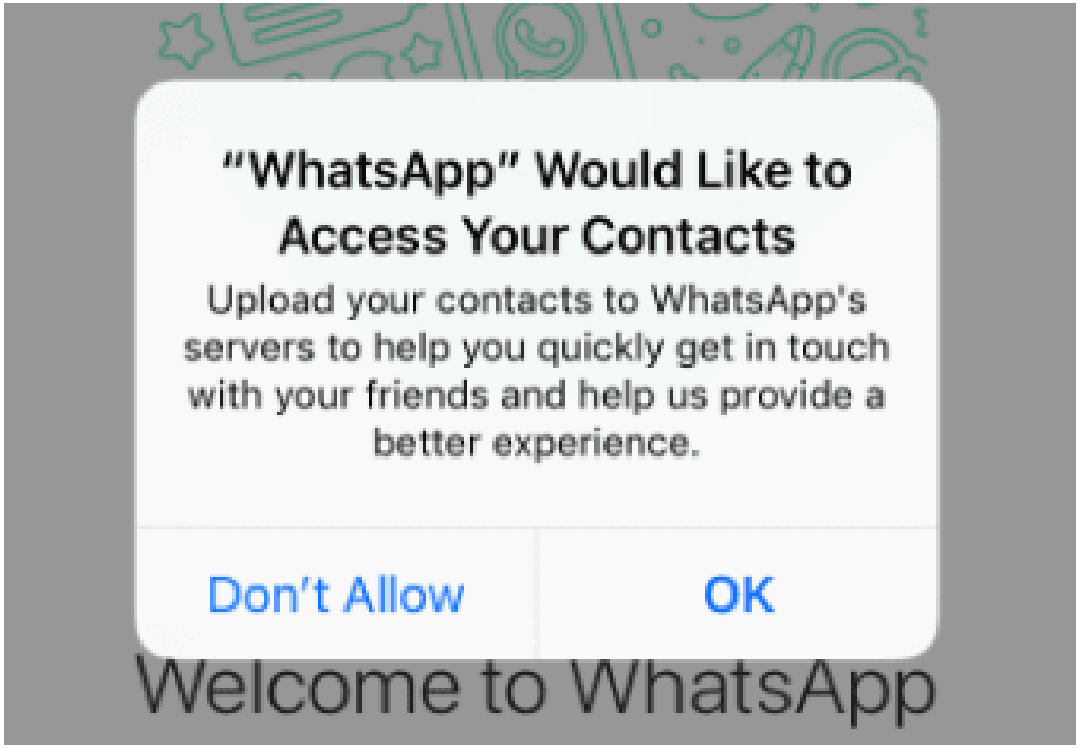
When to obtain informed consent?

- **It depends on your research context**
- **Two strategies**

1) one-off, e.g. at the beginning of data collection
   ⇒ simple, with minimal irritation,
   but sometimes research outputs not known in advance

2) ongoing in the research process
   ⇒ flexibility in research project but sometimes irritating to participants; bears risk to not get consent before losing contact

Everyday problem



"Privacy is not an option, and it shouldn't be the price we accept for just getting on the Internet"

Gary Kovacs, former CEO of Mozilla

World Economic Forum, 2012, CC-BY-SA

Research Ethics

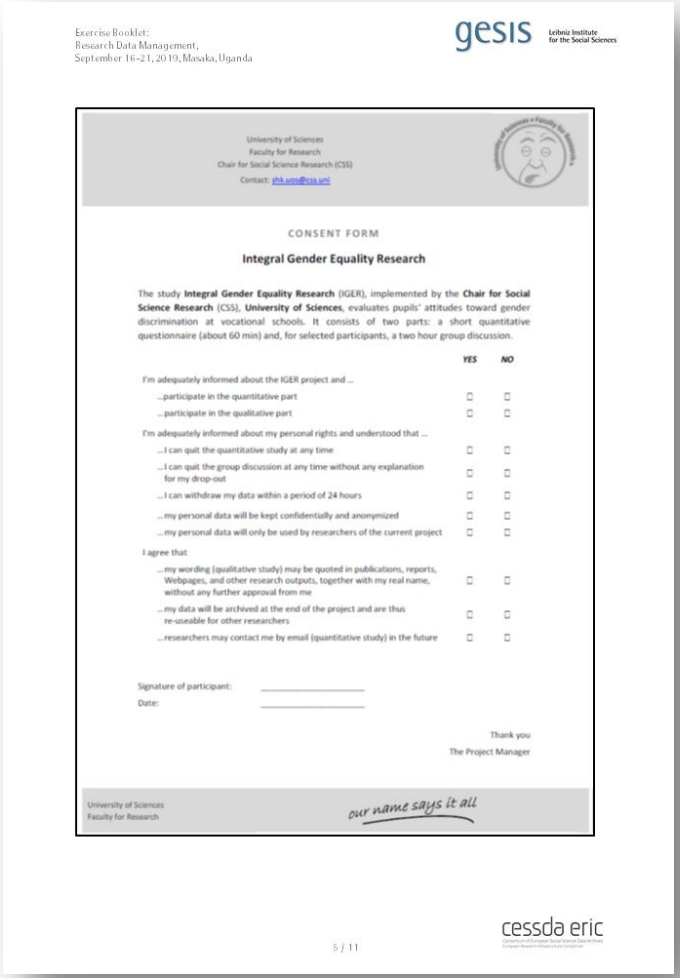
= responsible and respectful conduct of scientists in regard to the subjects of their research (→ human beings)

- Scientists' conduct should be governed by
  - disciplinary or institutional rules,
  - laws, but also by
  - individual considerations concerning the benefits and possible risks or harm for the individuals under observation

- Privacy protection, or data protection one specific area of research ethics, especially the "informed consent"

Exercise: Informed consent

- work in 5-6 groups
- time: about 30 minutes
- afterwards, we will commonly discuss your suggestions
- see Exercise-Booklet for details on Exercise 3



Exercise Booklet:
Research Data Management,
September 16-21, 2019, Masaka, Uganda

gesis Leibniz Institute for the Social Sciences

University of Sciences
Faculty for Research
Chair for Social Science Research (CSS)
Contact: phk.uos@css.uni

CONSENT FORM

Integral Gender Equality Research

The study **Integral Gender Equality Research** (IGER), implemented by the **Chair for Social Science Research** (CSS), **University of Sciences**, evaluates pupils' attitudes toward gender discrimination at vocational schools. It consists of two parts: a short quantitative questionnaire (about 60 min) and, for selected participants, a two hour group discussion.

	YES	NO
I'm adequately informed about the IGER project and ...		
...participate in the quantitative part	☐	☐
...participate in the qualitative part	☐	☐
I'm adequately informed about my personal rights and understood that ...		
...I can quit the quantitative study at any time	☐	☐
...I can quit the group discussion at any time without any explanation for my drop-out	☐	☐
...I can withdraw my data within a period of 24 hours	☐	☐
...my personal data will be kept confidentially and anonymized	☐	☐
...my personal data will only be used by researchers of the current project	☐	☐
I agree that		
...my wording (qualitative study) may be quoted in publications, reports, Webpages, and other research outputs, together with my real name, without any further approval from me	☐	☐
...my data will be archived at the end of the project and are thus re-useable for other researchers	☐	☐
...researchers may contact me by email (quantitative study) in the future	☐	☐

Signature of participant: _____
Date: _____

Thank you
The Project Manager

University of Sciences
Faculty for Research

our name says it all

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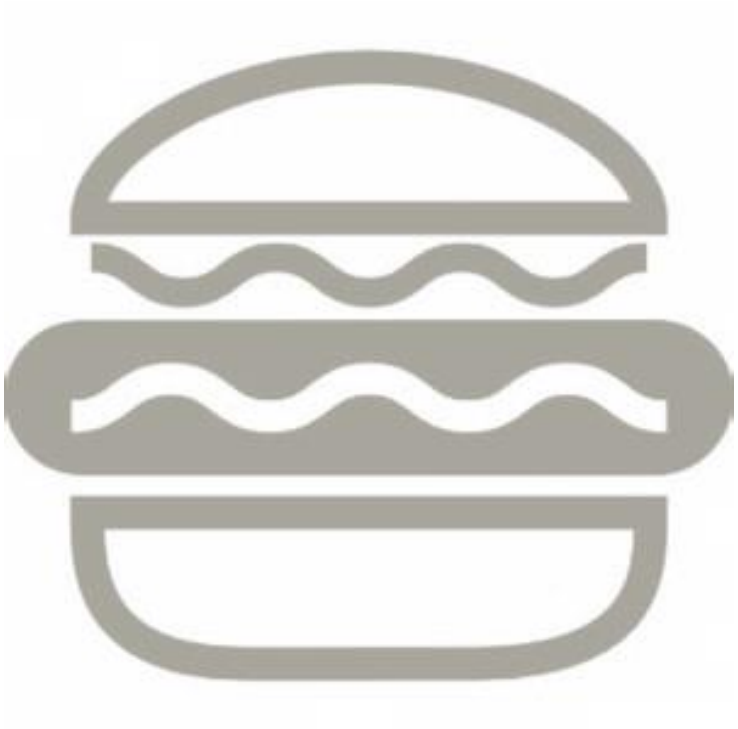
Thank you for your attention!

anja.perry@gesis.org
oliver.watteler@gesis.org



Adapt your DMP

- **Informed consent**
  - … go through the respective sections and fill in the information needed for your study
- **Develop a basic structure for the consent form, considering…**
  - … which information will be provided
  - … how the handling of sensitive data and the question of data sharing will be addressed
  - … when informed consent will be obtained