



Fact Sheet on «Informed Consent»

When collecting personal data

Please note that the information below is not legally binding. This information sheet is intended only as an aid when collecting and processing personal data. It does not apply to:

- Data collected wholly anonymously (see separate fact sheet)
- “Sensitive data” covered by [special legislation](#) (such as the Swiss Human Research Act, HRA)

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1. What does informed consent include?

- Details of the person responsible for the project who will be processing the data (the “principal investigator” (PI), project manager, etc.), including their contact information
- Purpose of the data collection and processing
 - In a brief project description, explain the specific purpose of the data collection and data processing.
 - **Please note:** Any later changes or additions to this purpose (such as reusing the data for another purpose, etc.) require the renewed consent of the data subject.
 - **Important:** If the personal data is no longer needed for the original purpose, it should be deleted. Legal exemptions or other requirements (e.g. of funders, institutions, etc.) may present an obstacle to deletion. Any such purposes related to the research project (e.g. publication, archiving, etc.) must be disclosed.
- The nature, extent and duration of data processing
 - What data is processed, how, and over what period of time.
 - Transparency concerning the method of data processing (e.g. transcription, statistical analysis, etc.).
- Information on the method, location and duration of data storage and the security measures in place (in particular the server location, key management, etc.).
- The fact that participation is voluntary and consent can be revoked at any time
 - Specific instructions concerning how and to whom to send the revocation.
 - Validity and effect of the revocation (especially the question of what happens to the collected data, e.g. anonymisation, deletion, etc.).
 - The data subject will not experience disadvantages because of refusal or revocation of consent.
- Explanation of the rights of the data subject in regard to the collected and processed data
 - Especially the right to information about and correction of, as well as potentially deletion of the data.



- Any disclosure and/or passing on to third parties
 - Information about the research team, external persons and/or services (e.g. transcription tools, clouds, etc.) that have access to and/or knowledge of the data.
 - **Please note:** It is important to check whether data can be disclosed or passed on to third parties (e.g. based on a contract or commissioned data processing). If you have any questions, please contact: datenschutz@unibas.ch.
- Confidentiality
- The option of being informed of the research results
- Personal details and signature of the data subject
 - Place, date, name, signature

2. How do I word a declaration of informed consent?

- Transparency
 - Personal data may only be collected and processed for a specific purpose which the data subject must be able to understand.
- choice of word and language must be adapted to the data subject.
- The written form is recommended, as it functions as evidence

3. When must consent be obtained?

- Consent must be obtained before the data is collected.

4. Who can consent under data privacy law?

- Capacity of judgement is a prerequisite for consent
 - A person (regardless of age) possesses capacity of judgement if they can act «rationally», i.e. if they can understand an action, conceive of its consequences, and act in accordance with them (see Art. 16 Swiss Civil Code, CC; SR 210).
 - **Important:** The more complex an action or situation and the more serious the possible consequences, the higher the standards imposed on the ability to act rationally must be.
 - «Rational» action requires not only reasoning ability and general life experience, but also specialist knowledge: level of education and relevant knowledge must also be taken into consideration.
- Please also note:
 - Separate information sheet on children's capacity of judgement.
 - A declaration of informed consent is part of the ethics application documentation that must be submitted to the responsible ethics committee.