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Data Management Planning

Informed Consent

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FORS and DaSCH

FORS – Swiss Centre of Expertise in the Social Sciences

- national infrastructure for Social Sciences' research data mainly funded by SNSF
- services: consulting / training / workshops /events for data management and archiving, SWISSUbase repository for the social sciences, mandates around the data collection and analysis, FORS Guides

DaSCH – Swiss National Data and Service Center for the Humanities

- national infrastructure for Humanities' research data mainly funded by SNSF
- services: consulting / training / workshops /events, virtual research environment, FAIR open data repository (DSP) including data publication and persistent identifiers at object level, metadata browser

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Programme

01 Introducing Informed Consent

02 Validity criteria

03 Insights from the Perspective of the Social Sciences

04 Insights from the Perspective of the Humanities

05 Consent form - the example of the University of Basel

06 Best Practises and Conclusion

07 Questions?

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Introducing Informed Consent

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Informed Consent - What?

"Informed consent is the **process** by which a fully **informed competent** person **voluntarily** chooses whether to become a human **participant** in research. This process involves describing the research to potential participants, what they are being asked to do, what will happen to their data and how it will be managed, and their rights as a participant. The process is ongoing, beginning before consent forms are signed and continuing until the subject is no longer involved in the study".

https://www.ucd.ie/researchethics/t4media/HRECG2%20Informed%20Consent%20-%20100921-V3.pdf

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Informed Consent - Why?

Informed consent serves two main purposes

- Consent for research ethics
- Consent as a legal basis for the processing of personal data

Since social science research generally involves the processing of personal data, it is absolutely necessary to know how to obtain proper consent.

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Informed Consent - How?

Informed consent should address the following topics:

- Consent for research participation
- Consent for the use of collected information
- Consent for future use and reuse of information

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Informed Consent - Who?

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.

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Validity criteria

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Informed Consent – Validity criteria

To be valid, consent must have (at least) the following five qualities:

1. Specific
2. Free
3. Informed
4. Explicit
5. Dynamic

Validity criteria - Specific

For consent to be specific, the data subject must give their consent for a **given purpose**. This means:

- There must always be a (stated) purpose for collecting the data.
- There is no such thing as “general consent” (HRA = exception)
- Once the purpose has been achieved, consent is no longer valid

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Validity criteria – Specific (2)

⚠ It's important to find the right balance between general and specific (depending on the project)

⚠ If a researcher wishes to use the data beyond a specific project, it's better to announce a broader purpose (e.g. research program)

⚠ If a researcher wishes to share the data in ORD (via an archive), it's better to make this part of the purpose.

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Validity criteria - Free

For consent to be considered free, anything that might compromise freedom of choice must be avoided, for example:

- Hierarchical links (e.g. going through employers)
- Authority figures (e.g. teachers)
- Overcompensation (e.g. from poor participants)

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Validity criteria - Informed

Participants to a research project must be notified as a minimum of the following:

- The voluntary nature of participation
- The identity of the researchers (PI)
- The purpose of the processing (purpose of the research)
- The categories of the data recipients where a disclosure of data is planned
- De-identification measures
- Right to withdraw
- Data sharing policy

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Validity criteria – Informed (2)

For consent to be considered informed, all information must be communicated clearly, in suitable form and language:

- Avoid copying and pasting from research projects
- Prefer descriptive and transparent approaches
- Avoid impossible promises (e.g. anonymization
- Always accompany written forms with oral explanations
- Always communicate sufficiently in advance

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Validity criteria - Explicit

- For consent to be considered explicit, the individual must respond unambiguously after having been duly informed and questioned about their wish to participate.
- This can be done by means of a checkbox, a signature at the bottom of a form, an oral response, etc.

⚠️ Opt-out is not an option for the processing of sensitive data.

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Validity criteria - Dynamic

Consent is often understood in a procedural way. It usually consists of a document signed at the beginning of the research.

Instead, it should be considered as a process which is ongoing:

- Depending on the methodology, researchers may find it difficult to provide a complete description of their research design at the beginning of the research
- People do not always know what they are going to say in an interview

💡 Consent may need to be obtained at different stages of the research project.

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About the form

Consent can be **oral** or **written**. That said:

- Keeping a record is useful (the burden of proof is on the researcher)
- Sometimes oral is the best solution (depending on the population)

💡 What counts = being understood

⚠️ Under the HRA, the rule = writing (with exceptions)

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Consent as a contract

Consent is a promise made to participants. In this sense, it constitutes a binding contract that cannot be breached without consequences (ethical and legal).In particular, it sets out:

- What the data can be used for (purpose)
- Who has access to the data (and for what purpose)
- How long the data is kept (and how)
- How confidentiality is managed (storage, etc.)
- Etc.

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Some Insights from the Perspective of the Social Sciences

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Consent and children

- Adolescents (aged between 14/16 and 18) are generally assumed to be capable of judgement.
- It’s always necessary to make a case-by-case analysis.
- The complexity of the project, the sensitivity of the data and the risks (present and future) must always be taken into account.

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Consent and children (2)

Double consent (legal representatives/minors) is often preferable (except for certain research) for both:

- Protecting minors
- Acknowledge the minor's agency (do not regard him or her as a passive object)

⚠️ For children not having capacity of judgement, at least leave room for expression of opposition

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Consent and social media

If a person makes their personal data available to anyone (without opposition), the law allows an exception to the need of a legal basis. While this exemption may be useful, particularly for processing data from social networks, there are some conditions:

- The data subjects must have published their data themselves
- The data subject must not have objected to the processing by third parties.
- The general terms and conditions of use (GTCU) of the sites must not object to the processing.
- The conditions of the GTCU must be respected.
- Data subjects must be informed (sometimes in the GTCU)

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Consent and social media (2)

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Consent and deception

"Deception is when a researcher gives false information to subjects or intentionally misleads them about some key aspect of the research. This could include feedback to subjects that involves creating false beliefs about oneself, one's relationship, or manipulation of one's self-concept. Incomplete Disclosure is a type of deception that involves withholding some information about the real purpose of the study, or the nature of the research procedures"

https://research.oregonstate.edu/irb/research-involving-deception#_ftn3

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Consent and deception (2)

Some methodologies require the use of deception. It is usually (legally) acceptable:

- When using deception, people still know they are participating in a research project
- People are aware they are giving personal data for research
- The research purpose is globally understood
- There generally is a debriefing (after a short experiment)

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Some Insights from the Perspective of the Humanities

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Multimedia Files displaying people

- Research team at work
- Recognisable persons

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Multimedia Files displaying people

- Art performance

Source: Wikimedia Commons, Thomas Grabka, CC BY 3.0

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Multimedia Files displaying people

- Open house day
- Public space
- Crowd in concert

Source: Wikimedia Commons, Camille Gévaudan, CC BY-SA 2.0

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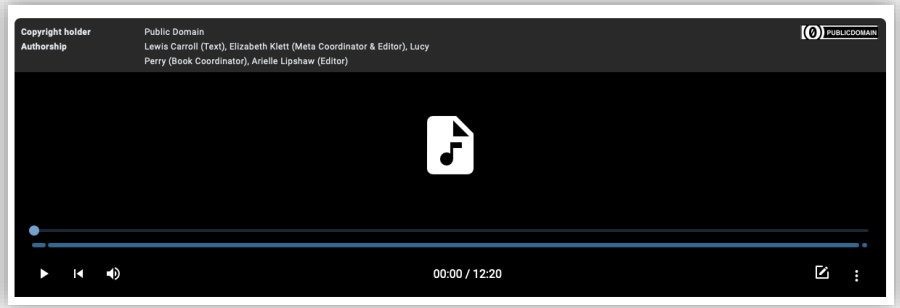
Multimedia Files displaying people

- Audio files



Source: Wikimedia Commons, Camille Gévaudan, CC BY-SA 2.0

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Consent form
-
the Example of University of Basel

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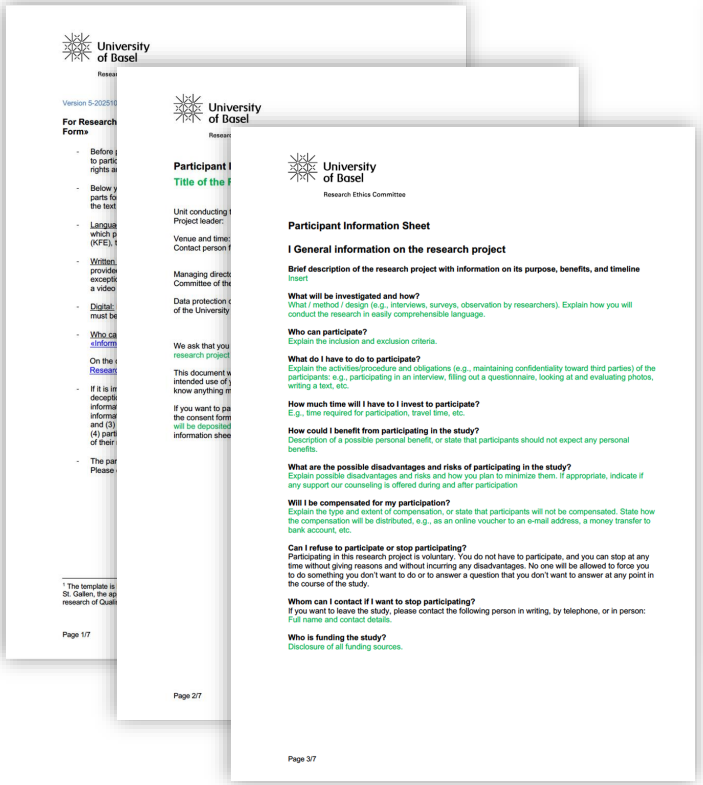
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Participant Information Sheet

I General information on the research project

Brief description of the research project with information on its purpose, benefits, and timeline
Insert

What will be investigated and how?
What / method / design (e.g., interviews, surveys, observation by researchers). Explain how you will conduct the research in easily comprehensible language.

Who can participate?
Explain the inclusion and exclusion criteria.

What do I have to do to participate?
Explain the activities/procedure and obligations (e.g., maintaining confidentiality toward third parties) of the participants: e.g., participating in an interview, filling out a questionnaire, looking at and evaluating photos, writing a text, etc.

How much time will I have to I invest to participate?
E.g., time required for participation, travel time, etc.

How could I benefit from participating in the study?
Description of a possible personal benefit, or state that participants should not expect any personal benefits.

What are the possible disadvantages and risks of participating in the study?
Explain possible disadvantages and risks and how you plan to minimize them. If appropriate, indicate if any support our counseling is offered during and after participation

Will I be compensated for my participation?
Explain the type and extent of compensation, or state that participants will not be compensated. State how the compensation will be distributed, e.g., as an online voucher to an e-mail address, a money transfer to bank account, etc.

Can I refuse to participate or stop participating?
Participating in this research project is voluntary. You do not have to participate, and you can stop at any time without giving reasons and without incurring any disadvantages. No one will be allowed to force you to do something you don't want to do or to answer a question that you don't want to answer at any point in the course of the study.

Whom can I contact if I want to stop participating?
If you want to leave the study, please contact the following person in writing, by telephone, or in person:
Full name and contact details.

Who is funding the study?
Disclosure of all funding sources.

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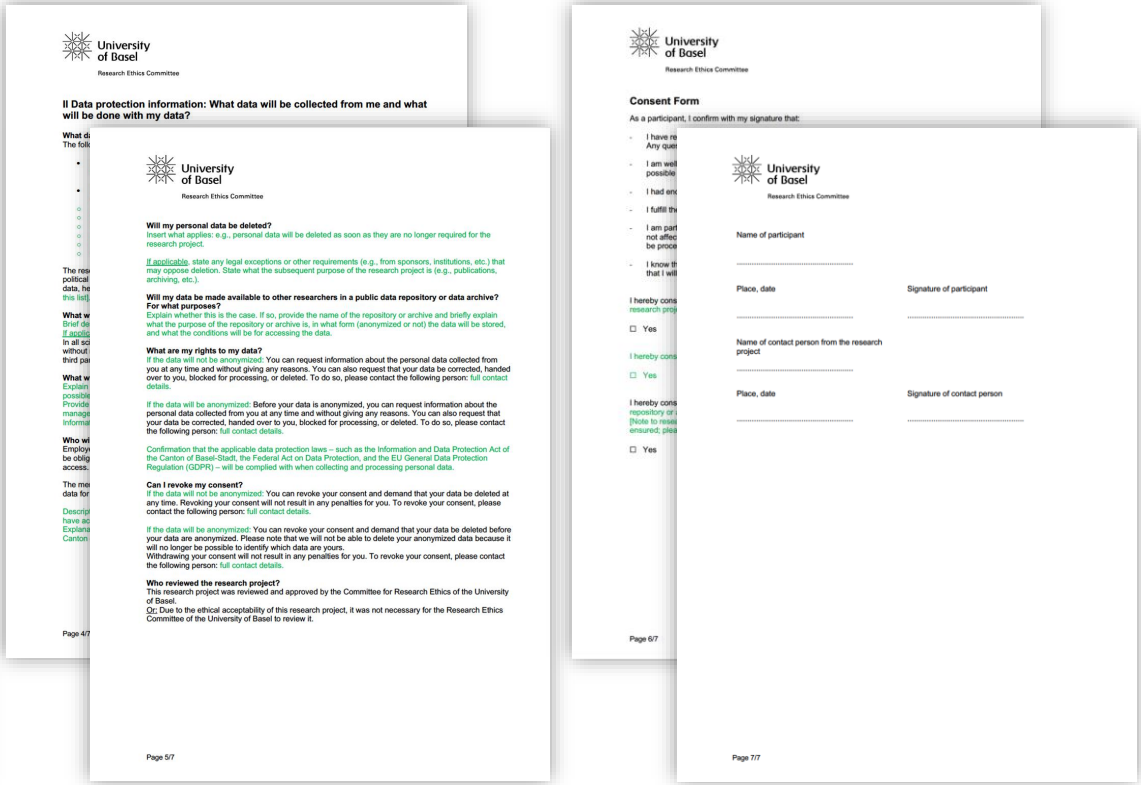
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II Data protection information: What data will be collected from me and what will be done with my data?

Will my personal data be deleted?
Insert what applies: e.g., personal data will be deleted as soon as they are no longer required for the research project.

If applicable, state any legal exceptions or other requirements (e.g., from sponsors, institutions, etc.) that may oppose deletion. State what the subsequent purpose of the research project is (e.g., publications, archiving, etc.).

Will my data be made available to other researchers in a public data repository or data archive?
For what purposes?
Explain whether this is the case. If so, provide the name of the repository or archive and briefly explain what the purpose of the repository or archive is, in what form (anonymized or not) the data will be stored, and what the conditions will be for accessing the data.

What are my rights to my data?
If the data will not be anonymized: You can request information about the personal data collected from you at any time and without giving any reasons. You can also request that your data be corrected, handed over to you, blocked for processing, or deleted. To do so, please contact the following person: full contact details.

If the data will be anonymized: Before your data is anonymized, you can request information about the personal data collected from you at any time and without giving any reasons. You can also request that your data be corrected, handed over to you, blocked for processing, or deleted. To do so, please contact the following person: full contact details.

Confirmation that the applicable data protection laws – such as the Information and Data Protection Act of the Canton of Basel-Stadt, the Federal Act on Data Protection, and the EU General Data Protection Regulation (GDPR) – will be complied with when collecting and processing personal data.

Can I revoke my consent?
If the data will not be anonymized: You can revoke your consent and demand that your data be deleted at any time. Revoking your consent will not result in any penalties for you. To revoke your consent, please contact the following person: full contact details.

If the data will be anonymized: You can revoke your consent and demand that your data be deleted before your data are anonymized. Please note that we will not be able to delete your anonymized data because it will no longer be possible to identify which data are yours.
Withdrawing your consent will not result in any penalties for you. To revoke your consent, please contact the following person: full contact details.

Who reviewed the research project?
This research project was reviewed and approved by the Committee for Research Ethics of the University of Basel.
Or: Due to the ethical acceptability of this research project, it was not necessary for the Research Ethics Committee of the University of Basel to review it.

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Consent Form

As a participant, I confirm with my signature that:

Name of participant

Place, date

Signature of participant

Name of contact person from the research project

Place, date

Signature of contact person

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Source: https://www.unibas.ch/en/Research/Values-Ethics.html

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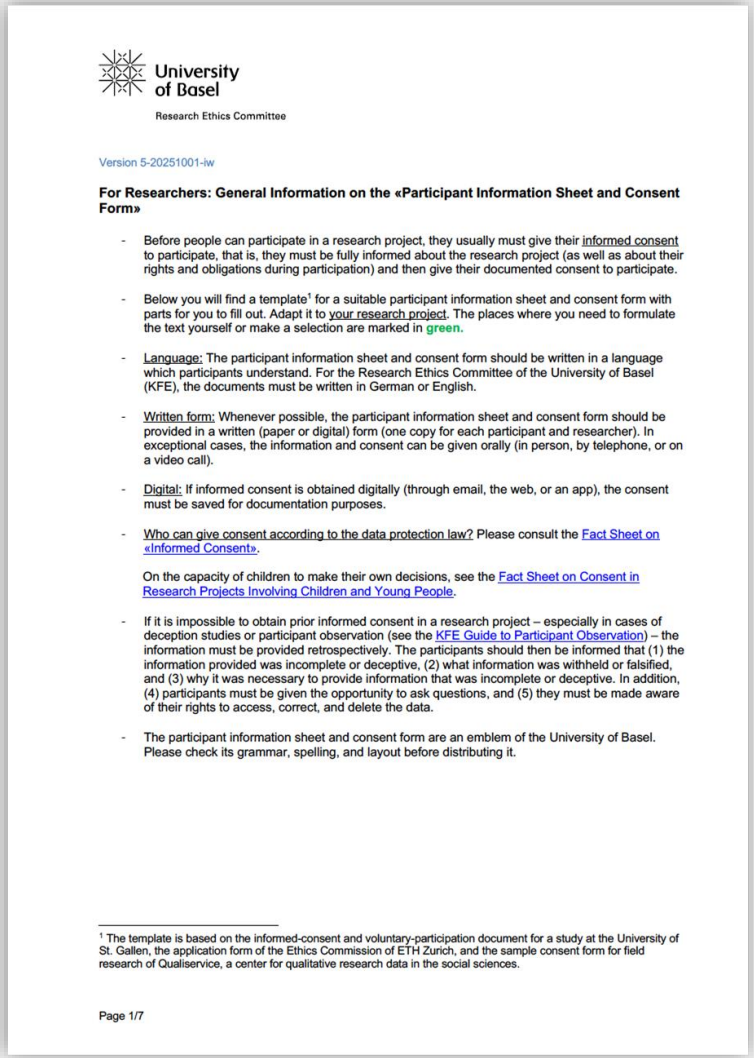
General Information for researcher



University of Basel
Research Ethics Committee

Version 5-20251001-iw

For Researchers: General Information on the «Participant Information Sheet and Consent Form»

- Before people can participate in a research project, they usually must give their informed consent to participate, that is, they must be fully informed about the research project (as well as about their rights and obligations during participation) and then give their documented consent to participate.
- Below you will find a template[1] for a suitable participant information sheet and consent form with parts for you to fill out. Adapt it to your research project. The places where you need to formulate the text yourself or make a selection are marked in **green.**
- Language: The participant information sheet and consent form should be written in a language which participants understand. For the Research Ethics Committee of the University of Basel (KFE), the documents must be written in German or English.
- Written form: Whenever possible, the participant information sheet and consent form should be provided in a written (paper or digital) form (one copy for each participant and researcher). In exceptional cases, the information and consent can be given orally (in person, by telephone, or on a video call).
- Digital: If informed consent is obtained digitally (through email, the web, or an app), the consent must be saved for documentation purposes.
- Who can give consent according to the data protection law? Please consult the Fact Sheet on «Informed Consent».

  On the capacity of children to make their own decisions, see the Fact Sheet on Consent in Research Projects Involving Children and Young People.
- If it is impossible to obtain prior informed consent in a research project – especially in cases of deception studies or participant observation (see the KFE Guide to Participant Observation) – the information must be provided retrospectively. The participants should then be informed that (1) the information provided was incomplete or deceptive, (2) what information was withheld or falsified, and (3) why it was necessary to provide information that was incomplete or deceptive. In addition, (4) participants must be given the opportunity to ask questions, and (5) they must be made aware of their rights to access, correct, and delete the data.
- The participant information sheet and consent form are an emblem of the University of Basel. Please check its grammar, spelling, and layout before distributing it.

[1] The template is based on the informed-consent and voluntary-participation document for a study at the University of St. Gallen, the application form of the Ethics Commission of ETH Zurich, and the sample consent form for field research of Qualiservice, a center for qualitative research data in the social sciences.

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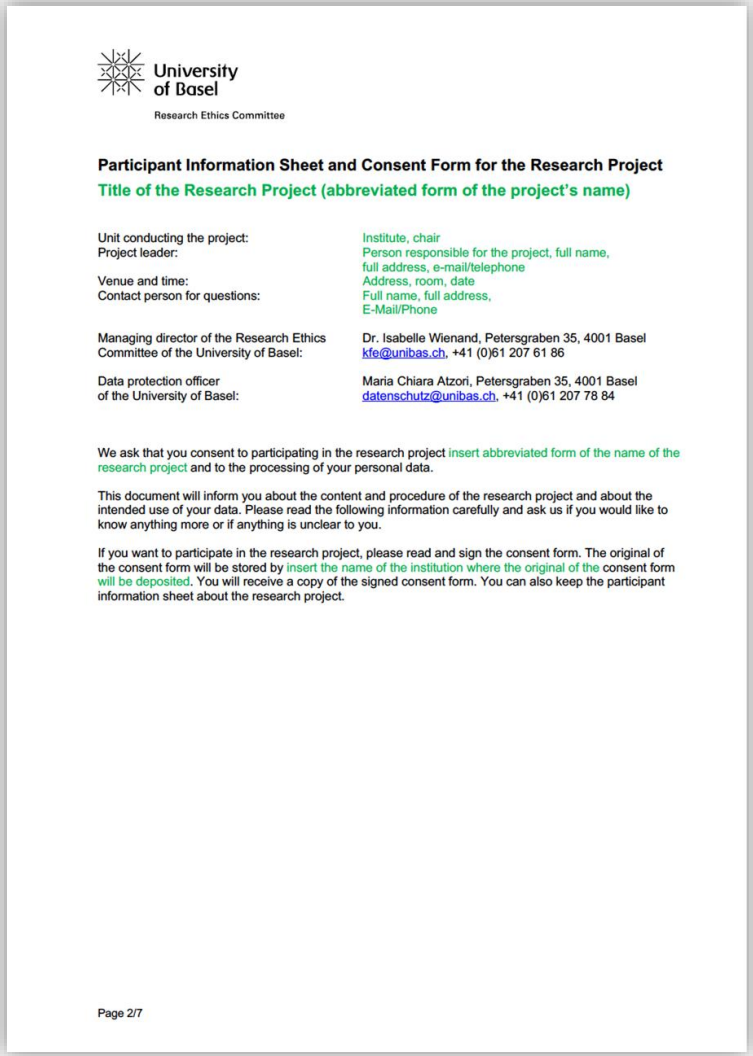
Participant Information Sheet

Consent Form for the Research Project



University of Basel
Research Ethics Committee

Participant Information Sheet and Consent Form for the Research Project

Title of the Research Project (abbreviated form of the project's name)

Unit conducting the project:	Institute, chair
Project leader:	Person responsible for the project, full name, full address, e-mail/telephone
Venue and time:	Address, room, date
Contact person for questions:	Full name, full address, E-Mail/Phone
Managing director of the Research Ethics Committee of the University of Basel:	Dr. Isabelle Wienand, Petersgraben 35, 4001 Basel kfe@unibas.ch, +41 (0)61 207 61 86
Data protection officer of the University of Basel:	Maria Chiara Atzori, Petersgraben 35, 4001 Basel datenschutz@unibas.ch, +41 (0)61 207 78 84

We ask that you consent to participating in the research project insert abbreviated form of the name of the research project and to the processing of your personal data.

This document will inform you about the content and procedure of the research project and about the intended use of your data. Please read the following information carefully and ask us if you would like to know anything more or if anything is unclear to you.

If you want to participate in the research project, please read and sign the consent form. The original of the consent form will be stored by insert the name of the institution where the original of the consent form will be deposited. You will receive a copy of the signed consent form. You can also keep the participant information sheet about the research project.

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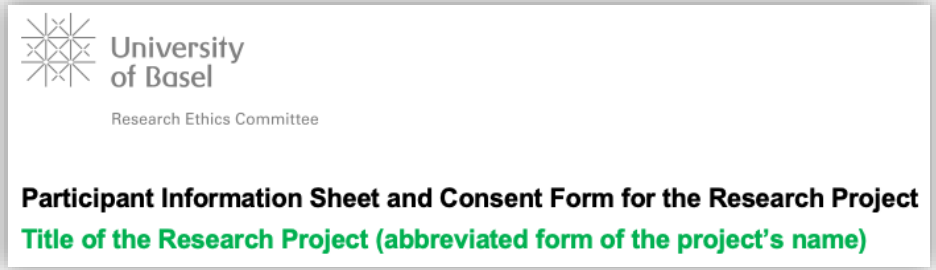
Title of the Research Project



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Contact information

- Person responsible for the project (the “principal investigator” (PI), project manager, etc.)

- Research Ethics Committee
- Data Protection Officer

Unit conducting the project:	Institute, chair
Project leader:	Person responsible for the project, full name, full address, e-mail/telephone
Venue and time:	Address, room, date
Contact person for questions:	Full name, full address, E-Mail/Phone
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Data protection officer of the University of Basel:	Maria Chiara Atzori, Petersgraben 35, 4001 Basel datenschutz@unibas.ch, +41 (0)61 207 78 84

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General information about the document

- Subject
- Content
- Storage place

We ask that you consent to participating in the research project insert abbreviated form of the name of the research project and to the processing of your personal data.

This document will inform you about the content and procedure of the research project and about the intended use of your data. Please read the following information carefully and ask us if you would like to know anything more or if anything is unclear to you.

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Participant Information Sheet (I)

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Participant Information Sheet

I General information on the research project

Brief description of the research project with information on its purpose, benefits, and timeline
Insert

What will be investigated and how?
What / method / design (e.g., interviews, surveys, observation by researchers). Explain how you will conduct the research in easily comprehensible language.

Who can participate?
Explain the inclusion and exclusion criteria.

What do I have to do to participate?
Explain the activities/procedure and obligations (e.g., maintaining confidentiality toward third parties) of the participants: e.g., participating in an interview, filling out a questionnaire, looking at and evaluating photos, writing a text, etc.

How much time will I have to I invest to participate?
E.g., time required for participation, travel time, etc.

How could I benefit from participating in the study?
Description of a possible personal benefit, or state that participants should not expect any personal benefits.

What are the possible disadvantages and risks of participating in the study?
Explain possible disadvantages and risks and how you plan to minimize them. If appropriate, indicate if any support our counseling is offered during and after participation

Will I be compensated for my participation?
Explain the type and extent of compensation, or state that participants will not be compensated. State how the compensation will be distributed, e.g., as an online voucher to an e-mail address, a money transfer to bank account, etc.

Can I refuse to participate or stop participating?
Participating in this research project is voluntary. You do not have to participate, and you can stop at any time without giving reasons and without incurring any disadvantages. No one will be allowed to force you to do something you don't want to do or to answer a question that you don't want to answer at any point in the course of the study.

Whom can I contact if I want to stop participating?
If you want to leave the study, please contact the following person in writing, by telephone, or in person:
Full name and contact details.

Who is funding the study?
Disclosure of all funding sources.

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Project description
Investigation method

- Brief project description
  - specific purpose of the data collection and 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.)

Brief description of the research project with information on its purpose, benefits, and timeline
Insert

What will be investigated and how?
What / method / design (e.g., interviews, surveys, observation by researchers). Explain how you will conduct the research in easily comprehensible language.

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Participants

- Inclusion / exclusion criteria
- Modalities to participate
  - Interview
  - Questionnaire
  - Evaluation
  - etc.

Who can participate?
Explain the inclusion and exclusion criteria.

What do I have to do to participate?
Explain the activities/procedure and obligations (e.g., maintaining confidentiality toward third parties) of the participants: e.g., participating in an interview, filling out a questionnaire, looking at and evaluating photos, writing a text, etc.

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Benefits and disadvantages

- Potential benefit
- Possible disadvantages
  - risks
  - Support & counseling
- Eventual compensation
  - Will there be one?
  - Distribution

How could I benefit from participating in the study?
Description of a possible personal benefit, or state that participants should not expect any personal benefits.

What are the possible disadvantages and risks of participating in the study?
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Refusal & Revocation

- Participation is voluntary, no obligation to participate
- No obligation to answer to a question
- Conditions of revocation
- Validity and effect of the revocation
    - Anonymisation
    - Deletion
- Contact and procedure in case of revocation

Can I refuse to participate or stop participating?
Participating in this research project is voluntary. You do not have to participate, and you can stop at any time without giving reasons and without incurring any disadvantages. No one will be allowed to force you to do something you don't want to do or to answer a question that you don't want to answer at any point in the course of the study.

Whom can I contact if I want to stop participating?
If you want to leave the study, please contact the following person in writing, by telephone, or in person:
Full name and contact details.

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Study Funding

- List of funding sources

Who is funding the study?
Disclosure of all funding sources.

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Participant Information Sheet (II.1)

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Research Ethics Committee

II Data protection information: What data will be collected from me and what will be done with my data?

What data will be collected from me?
The following data will be collected from you as part of the research project:

- Contact data for administrative purposes: specify all personal data, e.g., name, address, telephone number, email address.
- Research data, that is, the information about you that will be generated in the research project, such as:
  - audio recordings of an interview,
  - video recordings,
  - textual transcript of an interview,
  - personal data from a questionnaire,
  - texts you write,
  - etc.

The research data may also include sensitive personal data, such as data about your ethnic origins, political opinions, religious or ideological beliefs, or trade-union membership, or genetic data, biometric data, health data, or data concerning your sex life or sexual orientation [please delete as appropriate from this list].

What will my data be used for?
Brief description of how the data will be used. Any use of contact details, e.g., for long-term studies.
If applicable: e.g., for publications, conferences, etc.
In all scientific publications and at any congresses or conferences, the research results will be published without reference to you personally. Interviews will only be quoted in excerpts, so it will not be possible for third parties to identify you.

What will happen to my data? Where will my data be securely stored and for how long?
Explain what will happen to the data: pseudonymization, anonymization, etc., so that it will no longer be possible to figure out who the participant is.
Provide information about the storage location, especially the location of the server, and, e.g., the key management and separate storage for pseudonymized data.
Information about how long the data will be stored.

Who will have access to my data? And will my data be made known or be given to third parties?
Employees of the research project and authorized researchers will have access to your data. They will all be obliged to comply with data protection requirements. The data will be protected against unauthorized access.

The members of the Research Ethics Committee of the University of Basel will be able to view the original data for the purpose of reviewing and checking them, but only under strict confidentiality obligations.

Description of any external people and/or services (e.g., AI tools, transcription tools, clouds, etc.) that will have access to the data or be able to view it (e.g., survey institutes).
Explanation of how the data processing complies with the Information and Data Protection Act (of the Canton of Basel-Stadt, of the contractual obligations with third parties, etc.).

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Nature of data collection

- Data for administrative purposes
- Research data
  - Audio, video, photo, transcription, …
- Eventual sensitive data

What data will be collected from me?
The following data will be collected from you as part of the research project:

- Contact data for administrative purposes: specify all personal data, e.g., name, address, telephone number, email address.

- Research data, that is, the information about you that will be generated in the research project, such as:
  - audio recordings of an interview,
  - video recordings,
  - textual transcript of an interview,
  - personal data from a questionnaire,
  - texts you write,
  - etc.

The research data may also include sensitive personal data, such as data about your ethnic origins, political opinions, religious or ideological beliefs, or trade-union membership, or genetic data, biometric data, health data, or data concerning your sex life or sexual orientation [please delete as appropriate from this list].

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Usage of the data

- How will the data be used?
  - Publications
  - Conferences
  - etc.
- Anonymity of the participant

What will my data be used for?
Brief description of how the data will be used. Any use of contact details, e.g., for long-term studies.
If applicable: e.g., for publications, conferences, etc.
In all scientific publications and at any congresses or conferences, the research results will be published without reference to you personally. Interviews will only be quoted in excerpts, so it will not be possible for third parties to identify you.

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Processing
Storage

- Anonymisation, pseudonymisation
- Storage location during the project
- Duration of the storage

What will happen to my data? Where will my data be securely stored and for how long?
Explain what will happen to the data: pseudonymization, anonymization, etc., so that it will no longer be possible to figure out who the participant is.
Provide information about the storage location, especially the location of the server, and, e.g., the key management and separate storage for pseudonymized data.
Information about how long the data will be stored.

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Disclosure
Passing on to third parties

- Persons having access to/knowledge of the data
  - Research team
  - External persons
  - etc.
- Data protection
  - Measures taken

Who will have access to my data? And will my data be made known or be given to third parties?
Employees of the research project and authorized researchers will have access to your data. They will all be obliged to comply with data protection requirements. The data will be protected against unauthorized access.

The members of the Research Ethics Committee of the University of Basel will be able to view the original data for the purpose of reviewing and checking them, but only under strict confidentiality obligations.

Description of any external people and/or services (e.g., AI tools, transcription tools, clouds, etc.) that will have access to the data or be able to view it (e.g., survey institutes).
Explanation of how the data processing complies with the Information and Data Protection Act (of the Canton of Basel-Stadt, of the contractual obligations with third parties, etc.).

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Participant Information Sheet (II.2)

University of Basel
Research Ethics Committee

Will my personal data be deleted?
Insert what applies: e.g., personal data will be deleted as soon as they are no longer required for the research project.

If applicable, state any legal exceptions or other requirements (e.g., from sponsors, institutions, etc.) that may oppose deletion. State what the subsequent purpose of the research project is (e.g., publications, archiving, etc.).

Will my data be made available to other researchers in a public data repository or data archive? For what purposes?
Explain whether this is the case. If so, provide the name of the repository or archive and briefly explain what the purpose of the repository or archive is, in what form (anonymized or not) the data will be stored, and what the conditions will be for accessing the data.

What are my rights to my data?
If the data will not be anonymized: You can request information about the personal data collected from you at any time and without giving any reasons. You can also request that your data be corrected, handed over to you, blocked for processing, or deleted. To do so, please contact the following person: full contact details.

If the data will be anonymized: Before your data is anonymized, you can request information about the personal data collected from you at any time and without giving any reasons. You can also request that your data be corrected, handed over to you, blocked for processing, or deleted. To do so, please contact the following person: full contact details.

Confirmation that the applicable data protection laws – such as the Information and Data Protection Act of the Canton of Basel-Stadt, the Federal Act on Data Protection, and the EU General Data Protection Regulation (GDPR) – will be complied with when collecting and processing personal data.

Can I revoke my consent?
If the data will not be anonymized: You can revoke your consent and demand that your data be deleted at any time. Revoking your consent will not result in any penalties for you. To revoke your consent, please contact the following person: full contact details.

If the data will be anonymized: You can revoke your consent and demand that your data be deleted before your data are anonymized. Please note that we will not be able to delete your anonymized data because it will no longer be possible to identify which data are yours.
Withdrawing your consent will not result in any penalties for you. To revoke your consent, please contact the following person: full contact details.

Who reviewed the research project?
This research project was reviewed and approved by the Committee for Research Ethics of the University of Basel.
Or: Due to the ethical acceptability of this research project, it was not necessary for the Research Ethics Committee of the University of Basel to review it.

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Data deletion

- Time after which the data are deleted
- Legal exceptions
- Publications

Will my personal data be deleted?
Insert what applies: e.g., personal data will be deleted as soon as they are no longer required for the research project.

If applicable, state any legal exceptions or other requirements (e.g., from sponsors, institutions, etc.) that may oppose deletion. State what the subsequent purpose of the research project is (e.g., publications, archiving, etc.).

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Data archival

- Nature of the data archived
- Archival place
  - Public data repository
  - Data archive
- Access status (restricted or public)

Will my data be made available to other researchers in a public data repository or data archive? For what purposes?
Explain whether this is the case. If so, provide the name of the repository or archive and briefly explain what the purpose of the repository or archive is, in what form (anonymized or not) the data will be stored, and what the conditions will be for accessing the data.

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Participant rights to their own data

- Non-anonymised data
  - Information about and correction of data
  - Potential deletion of the data
- Anonymised data
  - Same but only before data get anonymised
- Eventual mention of the data protection laws

What are my rights to my data?

If the data will not be anonymized: You can request information about the personal data collected from you at any time and without giving any reasons. You can also request that your data be corrected, handed over to you, blocked for processing, or deleted. To do so, please contact the following person: full contact details.

If the data will be anonymized: Before your data is anonymized, you can request information about the personal data collected from you at any time and without giving any reasons. You can also request that your data be corrected, handed over to you, blocked for processing, or deleted. To do so, please contact the following person: full contact details.

Confirmation that the applicable data protection laws – such as the Information and Data Protection Act of the Canton of Basel-Stadt, the Federal Act on Data Protection, and the EU General Data Protection Regulation (GDPR) – will be complied with when collecting and processing personal data.

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Consent revocation

- Non-anonymised data
  - Consent revocation and data deletion at any time
- Anonymised data
  - Consent revocation and data deletion possible before anonymisation
- Contact person

Can I revoke my consent?
If the data will not be anonymized: You can revoke your consent and demand that your data be deleted at any time. Revoking your consent will not result in any penalties for you. To revoke your consent, please contact the following person: full contact details.

If the data will be anonymized: You can revoke your consent and demand that your data be deleted before your data are anonymized. Please note that we will not be able to delete your anonymized data because it will no longer be possible to identify which data are yours.
Withdrawing your consent will not result in any penalties for you. To revoke your consent, please contact the following person: full contact details.

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Review of the project

Information about a review of the Ethics Committee

- Approved
- Not necessary

Who reviewed the research project?
This research project was reviewed and approved by the Committee for Research Ethics of the University of Basel.
Or: Due to the ethical acceptability of this research project, it was not necessary for the Research Ethics Committee of the University of Basel to review it.

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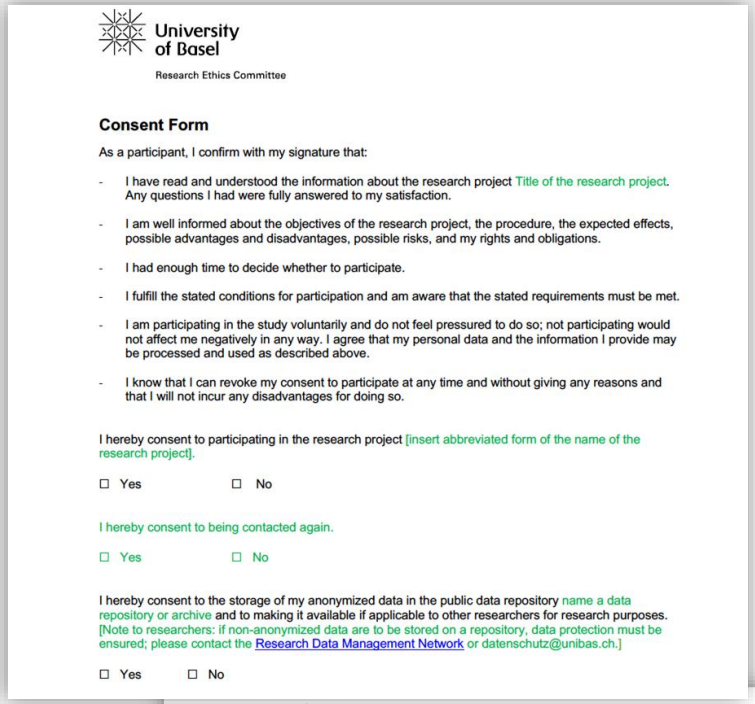
Consent Form



University of Basel
Research Ethics Committee

Consent Form

As a participant, I confirm with my signature that:

- I have read and understood the information about the research project Title of the research project. Any questions I had were fully answered to my satisfaction.
- I am well informed about the objectives of the research project, the procedure, the expected effects, possible advantages and disadvantages, possible risks, and my rights and obligations.
- I had enough time to decide whether to participate.
- I fulfill the stated conditions for participation and am aware that the stated requirements must be met.
- I am participating in the study voluntarily and do not feel pressured to do so; not participating would not affect me negatively in any way. I agree that my personal data and the information I provide may be processed and used as described above.
- I know that I can revoke my consent to participate at any time and without giving any reasons and that I will not incur any disadvantages for doing so.

I hereby consent to participating in the research project [insert abbreviated form of the name of the research project].

☐ Yes ☐ No

I hereby consent to being contacted again.

☐ Yes ☐ No

I hereby consent to the storage of my anonymized data in the public data repository name a data repository or archive and to making it available if applicable to other researchers for research purposes. [Note to researchers: if non-anonymized data are to be stored on a repository, data protection must be ensured; please contact the Research Data Management Network or datenschutz@unibas.ch.]

☐ Yes ☐ No

Name of participant

.....

Place, date

.....

Signature of participant

.....

Name of contact person from the research project

.....

Place, date

.....

Signature of contact person

.....

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Signature conditions

- Project information
- Objectives, risks, rights and obligations
- Time to take the decision to participate
- Voluntary participation
- Revocation rights

As a participant, I confirm with my signature that:

- I have read and understood the information about the research project Title of the research project. Any questions I had were fully answered to my satisfaction.
- I am well informed about the objectives of the research project, the procedure, the expected effects, possible advantages and disadvantages, possible risks, and my rights and obligations.
- I had enough time to decide whether to participate.
- I fulfill the stated conditions for participation and am aware that the stated requirements must be met.
- I am participating in the study voluntarily and do not feel pressured to do so; not participating would not affect me negatively in any way. I agree that my personal data and the information I provide may be processed and used as described above.
- I know that I can revoke my consent to participate at any time and without giving any reasons and that I will not incur any disadvantages for doing so.

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Consent to participate

- Checkbox stating consent or not

I hereby consent to participating in the research project [insert abbreviated form of the name of the research project].

☐ Yes ☐ No

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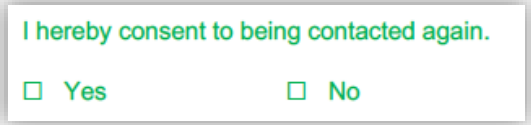
Consent to further contacts

- Checkbox stating consent or not



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Consent to data storage and archival

- Checkbox stating consent or not

I hereby consent to the storage of my anonymized data in the public data repository name a data repository or archive and to making it available if applicable to other researchers for research purposes. [Note to researchers: if non-anonymized data are to be stored on a repository, data protection must be ensured; please contact the Research Data Management Network or datenschutz@unibas.ch.]

☐ Yes ☐ No

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Signatures

- Participant
- Contact person from research project

Name of participant

.....

Place, date

.....

Signature of participant

.....

Name of contact person from the research project

.....

Place, date

.....

Signature of contact person

.....

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Best Practices and Conclusion

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Informed Consent

- Language
  - Choice of word and language must be adapted to the data subject
  - Language accepted by the Ethics committee of the University if necessary

- Written form
  - Recommended, as it functions as evidence
  - One copy for each participant and researcher
  - Digital form: must be saved for documentation purposes

- Transparency
  - Personal data may only be collected and processed for a specific purpose which the data subject must be able to understand

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Approval from Ethics Committee

In some cases, an informed consent is not sufficient

- The project involves minors, vulnerable persons, persons lacking the capacity to consent
- The project processes sensitive personal data or special categories of personal data
- The study involves personal behaviour (observation, location, analyse)
- Research takes place in settings with **high risks** for researchers, participants, or third parties (war zones, authoritarian of fragile settings, …)
- Other (deception of participants, …)

In some universities, an approval from the Ethics Committee is mandatory!

Some editors ask from an ethics committee approval before a paper can be published!

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Plan the data archiving from the beginning

- Decide as soon as possible which collected data should be archived and under which form
- Find a repository/archive that suits your needs and contact them at the beginning of the project
- Determine if there should be an access control to some of your data (copyright issues, …)
- Gather all legal information for your data (License, Copyright, Authorship)

All these information are important to create an informed consent form!

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Be ethical

- Use a self-assessment tool to determine if an informed consent / decision of the Ethics committee is necessary (soon available on https://dasch.swiss)
- Use a pre-existing template for informed consent
- In doubt, ask the Data Protection Officer or the Ethics Committee of your University

- Do not use AI on non-anonymised data
- If you use AI on anonymised data, mention it in the consent form and in the repository where data get archived

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Be FAIR and simplify the re-use of your data

- **Document your data**, archive
  - filled self-assessment form with the dataset
  - template(s) of informed consent

- **DO NOT** archive on public repositories
  - non-anonymised sensitive personal data
  - non-anonymised personal data if not necessary
  - filled informed consents from participants

Data re-use is the future of research!

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References

- European Commission - Guidelines on Ethics in Social Sciences and Humanities: https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/horizon/guidance/ethics-in-social-science-and-humanities_he_en.pdf
- European Commission - Ethics and Data Protection Decision Tree: https://ec.europa.eu/assets/rtd/ethics-data-protection-decision-tree/index.html
- Federal Data Protection and Information Commissioner (FDPIC) - Policies about Photos and Privacy: https://www.edoeb.admin.ch/en/photos-and-privacy
- DaSCH - Fundamentals on Research Ethics https://dasch.swiss/knowledge-hub/fundamentals-ethics
- FORS - FORS guides https://forscenter.ch/publications/fors-guides/?lang=fr

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Save the Date!

Sixth Webinar

Topic **Workflows for Anonymisation**

When **February 26, 2026**

Where **Online**

Source: Freepik, Marsiholo

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Questions?

Source: Abscent84 / Getty Images