

Ethics & GDPR Instruction

Always check for the latest version on <https://aihr.uva.nl/about-aihr/ethics-committee/ethics-committee.html>

Introduction

The Ethics Committee of the Faculty of Humanities monitors the criteria for ethical conduct for all the research at the Faculty of Humanities in which human participants take part.

When you work with participants for your research, e.g. when you conduct interviews or questionnaires or do participant observations, and/or when you work with personal data, i.e. information that can be traced back to a person, you need approval of the Ethics Committee before you start your research.

Moreover, when you work with personal data, the GDPR applies and in order to work GDPR-proof – and therefore ethically – there are certain conditions that you must meet.

Ethics

The following issues are important when you work with human participants:

- Participants: are you working with mentally competent adults or with a vulnerable group (<16, mentally incompetent, socially vulnerable)?
- Selection method: could participants possibly feel pressure (socially, financially) to participate?
- Voluntary participation: can participants freely choose to participate and always stop participating without adverse consequences?
- Harmful effects: could participation, for example, have a negative effect on your job if your boss hears about it?
- Unexpected findings: what will you do if, for example, it shows up on a scan that a participant might have a tumor or if you inadvertently find out that someone was involved in something illegal?
- Uncomfortable research: are participants, for example, asked about emotional memories or will they have uncomfortable electrodes on their head (fx. EEG)?
- Anonymity and privacy: will the participants remain anonymous or are pseudonyms used or does the participant agree to disclosing his/her identity?
- Deception: sometimes you can't reveal what the research is about because it might influence the results. In those situations you have to debrief the participants directly after the research has finished.
- Information brochure and informed consent form: information and consent are essential in research with participants! The point is that participants must always know in advance exactly what will happen and what exactly they consent to.

GDPR

What is the GDPR?

The General Data Protection Regulation is a European regulation that standardises the rules for the processing of personal data by private individuals, companies and public authorities throughout the European Union. With the GDPR, the European Union has one common privacy law. The GDPR has been in force as of 25 May 2018.

What is personal data?

Personal data is all data that can be traced back to a natural person directly or indirectly, alone or in combination. This data can consist of text, images and sound. The definition "natural person" excludes legal persons and deceased persons. Personal data are:

- Name
- Address

- Telephone number
- Email
- Age / date of birth
- Gender
- Education
- Profession
- IP address
- Facial images / audio / video recordings

Additionally there are special personal data. This is very sensitive information that you must handle with the utmost care. If you are going to use special personal data, please contact the Data Steward (datasteward-fgw@uva.nl) for additional measures.

- Religion or belief
- Race / ethnic background
- Political preference
- Health
- Sexual orientation
- Biometric data
- Genetic data
- Trade union membership
- Criminal history

Then there is the BSN. This may only be used in situations stated by law. Research does not fall under this, in other words you may never ask your participants for a BSN for your research.

What exactly does “processing personal data” mean?

The “processing” of personal data includes everything that you as a researcher do with that data or have someone else do for you: download, save, store, analyse, anonymise, show to others, publish.

Can I work with personal data and if so, how?

Before you start working with personal data, you must consider two important questions:

1. Am I allowed to process personal data?
2. And if so, how do I process personal data in a proper manner?

For step 1 you need:

A. a **specific purpose** for the processing (fx.: requesting an email address to be able to send concrete information to a participant) and

B. a (legal) **basis** for the processing.

The legal basis for research is Informed consent or, in a very exceptional case, Legitimate Interest (the importance of the research weighed against the invasion of the participant’s privacy).

When you ask for consent from your participants, it is compulsory to inform them properly by means of an information brochure about your research so that they know exactly what it is they are consenting to. Active approval (so no pre-ticked boxes!) is required for:

- participation (also with anonymous research)
- audio and video recordings
- sharing personal data with third parties

You are only allowed to process personal information if you have both specific purpose and a legal basis.

If the conditions in step 1 are fulfilled, you can move on to step 2 in which the proper processing of the personal data is specified. This includes:

- Do not request more data than is necessary for the purpose
Dataminimisation; need to know NOT nice to know.
- Store data securely
 - ensure a safe storage place – preferably UvA storage and in the cloud (no Dropbox or Google Drive), delete data from mobile devices as quickly as possible;
 - use encryption (fx. Veracrypt) in addition to a password, especially on mobile devices;
 - separate contact information from research data;
 - anonymise your data as soon as possible (data is anonymized when the link with the participant is irrevocably broken - even the researcher cannot retrace the participants any longer!) or if that is not possible, pseudonymise your data (the participant can be found by using a key);
- Properly arrange access to the data (authorisations);
- Determine concrete retention periods (for personal data: as short as possible, delete as soon as they are no longer needed (data minimisation), for anonymous data: the standard retention period in the Humanities is 10 years);
- Draw up processing agreements if you share personal data with others or have them processed by others. If you work with student assistants let them sign a nondisclosure agreement.

Considerations when using personal data



In a nutshell

If you are planning to do research with participants, prior approval by the Ethics Committee is required. Research involving the processing of personal data is subject to the GDPR and should be registered. Both can be arranged through the [Ethics Data Management Review portal](#). The EDMR portal can be found at rr.uva.nl. You can log in to FGW with your UvAnetID. There you can create a new project and then answer the questions in the checklists.

Students cannot submit an application themselves. The teacher/supervisor is the responsible researcher and he/she must create the project in the portal and submit the application. However it is possible for the supervisor to appoint an assistant (under the tab collaborator). As soon as the project is created the student can fill out the checklists and upload the information brochure and informed consent form. When that is done the teacher/supervisor checks the application and, if all is to his/her liking, submits it.

For further information:

[Ethics Committee Faculty of Humanities](#)

[The GDPR and research at the UvA](#)

[FAQ GDPR and research](#)

[Research Data Management](#)