



Human-subject related research by Humanities students: Points of interest in the areas of ethics, privacy and data management

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This brochure is intended for students following a bachelor's, master's or research master's program within the Faculty of Humanities who, as part of their program, are conducting **research including human subjects**.

This includes research in which you have people perform tasks (intervention research or task research), interview them, submit questionnaires or observe them (observational research). It is also called **human-subject related research**.

This document will provide you with an **overview of points of interest** in terms of ethics, privacy and data management.

This document has been drafted for each program within the Humanities. Read through all the points to see **which apply to your research** (and tick them off). In any case, discuss these points with your supervisor before you contact any participants or, for example, schools.

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Ethics

1. Discuss with your supervisor the ethical guidelines that apply within the field in which you will conduct your research.

2. Are your participants able to participate completely voluntarily?

It is of utmost importance that your participants are completely free to decide whether they want to participate in your research. This is not only an *ethical* requirement, but is also required by the AVG, the General Data Protection Regulation, see **Informed consent and privacy**, and also see other relevant points under **Ethics** and **Participants**. Is it possible in any way that participants could feel manipulated, coerced or influenced to participate in the study?

3. Are participants adequately informed about your research?

Provide clear information (preferably in writing) and an opportunity to ask questions. This should be done prior to the study, before they consent to participate and for their data to be collected.

4. What risks are involved for participants?

Risks refer to the chances of physical, mental, or emotional harm to participants. In your judgment, are these risks acceptable and proportionate? Discuss with your supervisor how the risks can be minimized and also discuss how any adverse effects or chance findings (data you were not looking for, but are important to you and/or your participants) will be handled.

5. What is the burden on the participants?

In your judgment, is the burden (e.g., time, effort) acceptable and proportional? Discuss with your supervisor how the well-being of the participants will be ensured.

6. Does the design of the study involve misleading the participants?

In some studies, it is not possible to inform the participants in advance about the purpose of the study, because that information will undesirably influence the participants' behaviour. In such cases, it may be necessary to mislead participants about the purpose of the study. If this is the case, discuss this with your supervisor. Consider what consequences or harm that deception may cause, and consider whether it is necessary. Afterwards, participants should be informed of the true nature of the study (debriefing) as well as the fact that they can still withdraw their consent.

7. Does a conflict of interest exist?

It may regard a real, potential, or perceived conflict of interest on the part of the student, the researcher, the research institute, or the subsidiser.

8. Are you using the right research method?

It is important that you use the research methods from the field you work in properly. If you are going to interview, make sure to use "how to interview" manuals and don't just wing it; if you are going to let your participants perform tasks, do this according to the standards that exist within your field.

9. Will participants be informed of the results of your research?

Consider whether participants should be given information about the results of the research. Within some subject areas this is a requirement: discuss this with your teacher. In order to



maintain a relationship of trust with, for example, schools, gatekeepers or communities, it may be important to share your results. Decide on this in advance and stick to your agreements.

10. Does the research focus on sensitive topics?

Could participants experience the topics as confronting or upsetting, or are they topics where cultural differences may complicate data collection? If so, discuss with your supervisor the ethical implications, the potential harm and burden to participants, and how this may affect data collection. Which measures will be taken to mitigate negative effects?

11. Are you, as a student yourself, at any risk during or because of this research?

Is the research potentially harmful to you as a student? Such harm is conceivable, for example, in research on socially extreme groups or on deviant behaviour.

NB. It is important that you continue to think about the ethics of the research not only beforehand, but throughout the whole research process.

Participants

12. How many participants do you think are needed for this research?

The ethical principle is 'as few as necessary and methodically sound': burden as few people as possible with your research. This also reduces 'research fatigue' of certain organizations and/or groups. Is it realistic to recruit this number of participants for your research within the given time?

13. Do you have a personal (hierarchical) relationship with your participants?

This concerns a relationship between you and the participants that prevents completely voluntary consent (such as teacher-student). If this is the case, ethical and methodological concerns come into play, and the consent would not be legally valid based on the AVG. See the [Guidelines for Informed Consent](#), p. 7 en 8, discuss the situation and the consequences with your supervisor, and contact privacy.gw@uu.nl.

14. Is there any manipulation?

Could participants feel manipulated, coerced or influenced in any way to participate in the study?

15. Is there any particular compensation for your participants?

Are your participants compensated in any way (e.g., financially, in credits) for their participation in the study? If so, is this proportional and not a substantial amount that it no longer constitutes voluntary participation? The reward should not entice participants to do things they otherwise would not (want to) do.

16. Will the research be conducted in the Netherlands?

If not, discuss with your supervisor whether ethical review by another authority is necessary in the country where the research is being conducted. In any case, it is important that all considerations (ethical, but also privacy) take into account the cultural and political context.

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17. Do you experience differences in language or cultural background between you and your participants?

Do these differences exist between you and the participants? If so, discuss with your supervisor how this will be handled and how it may affect your data collection.

18. Do your participants belong to a potentially vulnerable and/or disadvantaged group?

Does the research require participants who belong to a potentially vulnerable and/or disadvantaged group? For example, children, disabled people, refugees. If so, discuss with your supervisor how the risks to these participants can and will be mitigated.

19. What role do so-called gatekeepers play?

In ethnographic research, you sometimes need help from so-called gatekeepers to gain access to your participants. Could this play a role in your research? If so, does the research require permission from these gatekeepers? Discuss the implications of asking for permission with your supervisor.

Informed consent and privacy

You need to be aware of the meaning of the AVG and you need to think about if and how the law affects your research. In particular, the terms 'anonymize' and 'personal data' have specific meanings in the AVG, so it is important to be familiar with the meaning of these terms (for more information, see the documents on '[Privacy and AVG](#)').

20. Discuss with your supervisor what personal data is according to the AVG.

Personal data is all data that can be traced back to a participant, even including yes/no answers. As long as data can be traced back to a participant, it is covered by the AVG. This is explained in the [Ethics and AVG](#) document, 'What are personal data?' and during the workshop '[Handling personal data in research](#)'. This workshop is open to students.

21. Do you know the AVG meaning of 'consent'?

Most of the time, participant data is collected on the basis of informed consent by participants. Do you know what informed consent means according to the AVG? See [Guidelines for Informed Consent](#) and the [action overview for informed consent](#).

22. How is informed consent obtained?

Have your participants sign a statement giving their consent to the research (see the [sample documents](#) and the [Guidelines for Informed Consent](#).)

What if the nature of the research does not allow for a signed consent statement, but a verbal statement of consent is possible? Follow the code of conduct of your field and consult with your supervisor first. If you still have questions after this: consult the faculty's privacy officer (privacy.gw@uu.nl).

23. Can informed consent legally be given?

Can all research participants legally give informed consent? Consider, for example, children under the age of 16. In that case, discuss with your supervisor the need to obtain both informed consent from parents/legal guardians and, for children 12-15 years of age, from themselves.



24. Can participants be asked for consent?

Sometimes it is not possible to ask participants for consent, for example in web scraping. In that case, you should try to inform the "participants" as best you can. For this, see [Tactful contact-free research](#) (in Dutch) and discuss this with your supervisor.

25. What information is essential for the participants?

Consider, and discuss with your supervisor, what information is essential to include in the informed consent documents (see [sample documents](#)).

26. Do you work with anonymous or anonymized data?

The terms "anonymous" and "anonymized" have a specific meaning in the AVG: there should be no way to trace from whom the data originated. Not by a key file, not by linking timestamps, not by IP addresses, etcetera. In the information to participants, these terms should be used and explained accordingly, see p. 3 and 4 of the [Guidelines for Informed Consent](#).

27. Will special personal data be collected?

See p. 2 of the [Ethics and AVG](#) document for the definition of special personal data as well as examples. Discuss with your supervisor whether it is necessary for your research to collect this data. If this is the case, how will the data be used and stored? How will confidentiality of this data be ensured?

28. Will photographs or audio or video recordings be made?

Are methods used that allow visual or auditory identification of participants (e.g., photographs or audio or video recordings)? Is this necessary (consider data minimization, see item 31)? If so, consider whether this data can be transcribed and whether the recordings can be deleted after transcription. Also discuss with your supervisor how this data should be stored to ensure confidentiality.

29. What is the native language of the research participants?

Consider whether informed consent documents should be provided in a language other than Dutch: participants should understand what they are consenting to.

30. Is a complaints procedure for participants in place?

What procedure is in place to address complaints about the research or about privacy and confidentiality? Discuss with your supervisor how you will draft a plan/procedure, also see the [sample documents](#).

Data management

Information on data management can be found on the Research Data Management Support [website](#). Their workshops are also open to students. For example, a relevant workshop is *Quick start to Research Data Management*.

31. Which data will you collect?

Is it necessary for the research that all this data is collected? Think about data minimization ('need to have' versus 'nice to have'): collect only the data that is strictly necessary for your research. For personal data, data minimization is also required by the AVG.



32. How will you process the data?

What processing will be done? What will be transcribed (recordings), aggregated, destroyed, anonymized, retained, stored, and how and by whom will this be done? See p. 5 of the [Guidelines for Informed Consent](#).

33. Are you conducting your research outside of UU?

For example, are you doing an internship outside of UU? If so, check with your supervisor who is responsible for the data and for processing that data. See p. 11 of the [Guidelines for Informed Consent](#). Your supervisor should always first contact privacy.gw@uu.nl in cases like this.

34. Where will the data be stored?

And how can this be done safely? For example, consider recording interviews on your cell phone. Such recordings should be transferred as soon as possible to a secure UU server (e.g. Yoda, Onedrive or O: drive with 2FA), and be deleted from your phone. Also consider paper documents such as permission slips. How do you handle these?

35. Can the collected data be shared?

Discuss with your supervisor whether data should be shared with others, i.e. outside of you and your supervisor. If data is shared, with whom, under what conditions, and how?

36. How do you inform your participants about your data management?

Make it clear to the participants how you will manage their data (how long will you keep it, will it be coded or anonymized when the research report is written, etc.).

Guidelines

Below are links to the most relevant laws and regulations.

- European General Data Protection Regulation (AVG) (2018)
<https://autoriteitpersoonsgegevens.nl/sites/default/files/atoms/files/gdpr.pdf>
- Legislation on Medical scientific research with human subjects (WMO)
<https://wetten.overheid.nl/BWBR0009408/2020-01-01> (in Dutch)

Codes of conduct

- Dutch Code of Conduct for Scientific Integrity (2018)
www.universiteitenvannederland.nl/files/documenten/Nederlandse%20gedragscode%20wetenschappelijke%20integriteit%202018.pdf (in Dutch)
- Universities of the Netherlands: Code of Conduct on the Use of Personal Data:
https://www.universiteitenvannederland.nl/en_GB/code-personal-data