C1 information and consent form

Consent (ethics) and public interest (privacy)

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| **Datum:** 08/12/2022**Classificatie:** Public |

How does the template work?

* Instructions are in *purple and italics*
* Mandatory fields are indicated
* [Text] = fill in yourself or make a choice
* Please remove all instructions and examples before sharing this document with participants.

May I deviate from the template?

Yes! As a researcher, you have a good grasp of your(potential) research population. Feel free to combine and/or rewrite the text in a way that suits your research. This also applies to compulsory text, but make sure the information is accurate. Submit the form to the ethics committee ([more information](https://www.eur.nl/en/research/research-services/research-quality-integrity/ethical-review/informed-consent)) and Privacy Officer ([your privacy contact](https://my.eur.nl/en/eur-employee/werkondersteuning/privacy/privacy-office)).

**Most importantly**: Consider the language level of the participant. During your explanation, take into account local beliefs and knowledge to best convey the information.

Do I have to provide all the information at the same time?

No! It is important to ensure that participants receive all relevant information, but it does not have to be all at once. Consider the use of:

* Flyers
* Further information on a project website
* Debrief sessions/forms
* More practical information (e.g., times, location etc) shared at a later time

**Information and consent form**

Title *Short and concise title (+/- 5 easy words)*

**Introduction**

*Briefly describe who you are, where you work and that you are inviting the participant to take part in the study. Assure the participant that if they do not understand words or concepts, you can provide an explanation. Let them know that they can ask additional questions at any time.*

*Choices you can make*

* *Choose whether to write the letter in first person singular or plural.*
* *If appropriate, start with a salutation.*

I am [name of researcher] and I [do research/work as a researcher] for Erasmus University Rotterdam. I am conducting research on [topic]. [The research is funded by [funding body].] We are conducting this research independently: the financial contribution has no influence on the outcomes of this study.

I will explain the study below. If you have any questions, please ask me. While reading, you can mark parts of the text that are unclear to you.

If you want to participate in the study, you can indicate this at the end of this form.

**What is the research about?**

*Explain the purpose of the research. Try to keep the description short and simple.*

*Choices you can make*

* *E.g., instead of 'What is the research about?' change the headline to 'Why this research?'*

[Briefly describe what the research is about]

**Why are we asking you to participate?**

*Please state why you selected the participant for the study.*

*This can be omitted unless the survey is aimed at a specific group. For example: a patient with a specific condition, someone with specific experiences or beliefs, someone from a specific community, etc. You may also combine this part with 'What is the research about'*

Example 1:

We ask you to participate because your [opinion/experience] as [...] helps us learn about [...].

Example 2:

In your community, [...] is common. We want to learn more about this. We believe that you can help us by telling us what you know about [...].

**What can you expect?**

*Describe what kind of research is being conducted. Include a comment on the participant's time spent on the research, e.g., how long the research is going to take and, if applicable, any follow-ups. If necessary, you can explain the rationale for the study (e.g., what topics will be discussed), how the study will be carried out, or what is expected of the participant. You can also give an example of a question or an example of a task that a participant will have to complete.*

The study lasts [6 months; 1 day; 2 hours].

If you participate in this study, you will take part in:

An interview:

Once a month, I will visit you at your home. Each interview will last 1 hour. If you do not want to answer a question during the interview, you are not required to do so.

I will make an audio recording of the conversation.

A focus group:

This is a discussion with 8 other people with the same experiences as you. I will organise the discussion together with [...].

You can decide what you want to share with us. The discussion will take place in Rotterdam on 6 October at 11:00 am.

We will make an audio recording of the discussion.

A survey:

You will receive a questionnaire by email or post.

You can fill in the questionnaire yourself or together with me.

An experiment:

The research takes place at the university.

During the study [describe the procedure and any tasks the participant will be asked to complete].

*If relevant, give participants the opportunity to reconsider their comments in individual interviews and have some or all of the recordings or notes erased.*

At the end of the interview/discussion, you will have the opportunity to comment on your answers. If you disagree with my notes or if I misunderstood you, you can ask to have parts of them amended or deleted.

**You decide whether to participate**

*Indicate that participation is voluntary. Consider whether there are scenarios in which the participant does not feel free to refrain from (further) participation in a practical sense, due to peer pressure or other reasons. If there are no such scenarios, the text between [xxx] can be omitted.*

Participation in this study is completely voluntary. [Not participating will not affect your work or work-related assessments or reports/ If you do not participate then your [type of care; treatment] will continue as usual]. You can stop at any time and would not need to provide any explanation.

**What are the potential risks and discomforts?**

* *Describe all potential risks and discomforts you foresee.*
* *Explain what precautions have been taken to ensure the safety of participants.*
* *Pay attention to any unintended/unexpected/incidental findings and consider how you will deal with such findings, if applicable.*

*Choices you can make:*

* *Add pictures of the experimental procedure (see example 1)*
* *Determine whether and, if so, what example applies and adapt it to your own research (combinations are possible).*

*Example 1 (shocking images)*

During this study, we will view and discuss in a group parts of war video games. This will include footage of (violence against) unarmed civilians. Should you feel uncomfortable with this, please remember that you can withdraw from the study at any time. After the interview, you will be given the opportunity to talk about these feelings with [indicate who, when and where accessible].

*Example 2 (talking about upsetting/traumatic events)*

During the interview, personal questions will be asked about potentially upsetting events you may have experienced. These may trigger unpleasant memories and emotions. You may therefore wish to invite a close friend or family member to attend the interview.

*Example 3 (post-participation care)*

If you need emotional support or a listening ear after the interview, you can contact Slachtofferhulp Nederland. They can also help you determine which further assistance may be needed and refer you on. You can contact them at 0900-0101 or via the chat on their website: [www.slachtofferhulp.nl](http://www.slachtofferhulp.nl).

*Example 4 (risk during experiment)*

During the study, you will be exposed to flashing lights. People with a history of epilepsy should therefore **not** participate in the study. Before we start, we will ask you some questions to ensure you are not at risk. Should you experience any discomfort, you can stop the study at any time.

*Example 5 (no risks or discomforts)*

We do not anticipate any risks or discomforts while participating in this study.

**What do you get for participating?**

*Clearly indicate what kind of compensation (cash, gift voucher, credits, or other) you are offering participants for their participation. N.b. if a bank account number or other personal information is needed to provide the compensation, please include this under the section ‘Use of your personal data.’*

We will pay you [...] for your time as well as a travel reimbursement.

As a psychology student, you will receive [...] credits for participating in the study.

After [the focus group, interview, survey], you will receive a gift card of [...] euros for [...].

If you quit the study earlier, you will be paid for the parts you participated in.

**What data will I ask you to provide?**

*(Required when personal data[[1]](#footnote-2) will be processed (e.g., collected, analyzed, stored, and shared)). Explain what personal data, especially special categories[[2]](#footnote-3) of personal data or data of a criminal nature[[3]](#footnote-4), you will be processing.*

I will store your data so that I can be in contact with you. For the study, I will also need other data from you.

*Please describe what personal data will be processed or provide the questions you will be asking.*

During [the interview/survey/focus group], the following personal data will be collected from you: Name, age, gender, ..., audio or visual recordings, occupation, cultural background, ethnic background, sentiments about / feelings about / opinions about, IP address, information about physical or mental health.

[In addition, it is also possible that you will talk about your political affiliation and religious or philosophical beliefs and those of others, as these may also relate to your opinion about [...].]

*If compensation/credits/sharing of results applies.*

I need your bank account number, to transfer the payment.

I need your student number, to award credits.

I also need your [email address; home address], to send the results of the study to you [by email; by post].

*(Mandatory) The following text indicates which GDPR basis is used to legitimize the processing of personal data. Besides the well-known legal basis of consent, there are five other legal bases. This template is based on the public interest.*

*The processing of personal data is thus done on the basis of Public Interest, but from an ethical perspective and for the processing of special categories of personal data and personal data processing which is not necessary for the research, consent is still required and therefore included at the end of the form.*

At Erasmus University, we conduct scientific research. We do this to learn, help people, and contribute to society. Since we are an academic institution conducting scientific research, we process your personal data exclusively for research on the basis of public interest.

**Who can see your data?**

*Explain how the research team will ensure confidentiality of data related to the participant and data shared by the participant. Explain the boundaries of confidentiality. Look carefully at which parts of the sample text apply to your research, and adjust or supplement as needed.*

* [I store/we store] all your data securely.
* Only persons involved in the research can see (some of) the data. [Only the principal investigator has access to your data such as your name, address...or xxx information].
* *[Recordings]* Recordings are transcribed. Your name is replaced with a number/made-up name.
* Data such as your [name, address...and recordings] (direct personal data) will be [stored/deleted separately from your answers/the transcription].
* We will write an article about the results of the study which will be published (publicly share the results) in (academic) journals and/or books. The results will be accessible by anyone.
* We may use your specific answers in the article. If your answer can be traced to you or we would like to mention your name, we will ask your permission first.

*Focus groups (or other group circumstances) present a challenge in terms of confidentiality because, once something is said in the group, it is common knowledge. Explain to the participant that you will encourage group participants to respect confidentiality, but that you cannot guarantee it.*

Because you are participating in a group discussion, you should realize that the other participants will also hear your opinion about [...]. We ask all participants not to talk to people outside the group about what was said in the group.

**How long will your personal data be stored?**

*Here you explain how long personal data will be stored. According to the EUR Research Data Management Policy, EUR researchers must ensure that:*

* *All published and unpublished data, software codes, and research materials are managed and stored securely for at least ten years, so that the integrity of the research can be verified.*
* *Please contact the faculty data steward if you believe that a different retention period should be used for your research.*

Your data will be retained for a minimum of 10 years. We retain the data so that other researchers have the opportunity to verify that the research was conducted correctly.

**Using your data for new research**

*Here you explain whether data collected will be used or made available to others for future research.*

*According to the EUR research management data policy, EUR researchers should:*

* *Take appropriate measures, such as anonymization and pseudonymization, as much and as soon as possible. When taking these measures, consider the feasibility of the research and ensuring integrity.*
* *Anonymization must be done before data is placed in a repository or used for publication (unless). Simply omitting a name is often not sufficient.*

*In addition, The Netherlands Code of Research Integrity 2018 asks researchers in the Netherlands to:*

* *Ensure that data, following the FAIR principles[[4]](#footnote-5), are as open as possible, as closed as necessary.*

*This paragraph is about sharing data anonymously and publicly. If, after consulting your faculty’s data steward/privacy officer, you conclude that data anonymization is not possible and/or participant's safety cannot be guaranteed, you can skip this section.*

(Part of) the data we collect may be useful in anonymized form, for example for educational purposes and future research, including in very different research areas. We will make the data publicly available after proper anonymization. We ensure that the data cannot be traced back to you/we do not disclose anything that identifies you.

*The following section refers only to the further use of personal data for academic research. The researcher, in consultation with the faculty’s data steward/privacy officer, can also frame the scope of further use by indicating for which follow-up/other academic research the data will be used. Personal data are only shared with other parties if appropriate agreements are in place. For each follow-up/new study, you should consider which personal data are relevant. Only relevant personal data will be provided. Consent is sought for the use of contact data for new studies.*

*Further use of personal data for scientific research*

In addition, your personal data [, excluding name, mail address, ... recordings - indicate which is applicable] may be used for follow-up or other scientific research. The data shared are [(potentially) traceable to you/pseudonymized]. You have the right to object to further use.

**What happens with the results of the study?**

*Disclose when you plan to share the results with participants. You may also inform the participants that the research results will be shared more broadly, for example through publications, data repositories, and at conferences.*

*Choices you can make:*

* *Choose one of three examples (if applicable)*
* *Example 2; specify how a participant can indicate that they would like to receive the results*

*Example 1*

Each participant will receive a summary of the results [by email].

*Example 2*

You may indicate if you would like to receive the results.

*Example 3*

We publish the results on a website [website] so that interested parties can learn about the study.

**Do you have questions about the study?**

*As a researcher, you are the point of contact for the participants. Crucially, this also means that you are responsible for the timely and proper routing of any privacy-related questions. When providing contact information, also keep in mind that different participants may have different skill levels. For example, not everyone is good at sending an email. In that case, try to include a second contact method.*

If you have any questions about the study or your privacy rights, such as accessing, changing, deleting, or updating your data, please contact me.

Name: [naam]

Phone number: [phone number]

Email: [email address]

Do you have a complaint or concerns about your privacy? Please email the Data Protection Officer (fg@eur.nl) or visit www.autoriteitpersoonsgegevens.nl. (T: 088 - 1805250)

**Do you regret your participation?**

*This section applies if the participant indicates that they no longer wish to participate. This includes both the withdrawal of ethical consent and consent given to process special or criminal personal data.*

*Stopping participation (a passive action - not showing up) is not the same as actively withdrawing consent. Withdrawing consent should be straightforward and should be as simple as a participant actively indicating they no longer wish to participate - retracting participating (verbally, by email, or unchecking a consent field). If consent is withdrawn, the data collected from that research participant must be deleted or anonymized.*

*The possibility to withdraw data is limited or no longer possible if published or data have been extensively pseudonymized (Article 11 GDPR) or anonymized.* ***Use the text of the scenario (1-3) that is most applicable to your research.*** *When publishing, also consider publishing the data in a trusted online repository.*

1. *Limitations due to publication (if you keep a key file, participants remain traceable)*

You may regret your participation. Even after participating, you can still stop. Please indicate this by contacting [me/us]. [I/We] will delete your data. Sometimes we need to keep your data so that, for example, the integrity of the study can be checked.

*Or*

1. *Anonymization/pseudonymization - delete personal data (if you are going to anonymize/pseudonymize well ahead of publication). If this is the case, inform the ethics committee how you will anonymize and how you will ensure the integrity of the research.*

You may regret your participation. Please indicate this by contacting [me/us]. Deleting your data is no longer possible if the data has been anonymized, making it impossible to trace which data came from you. Anonymizing the data is done within [indicate when it happens] period after the data was collected.

*Or*

1. *If data is collected anonymously. It is advisable to have your faculty privacy officer review the intended anonymization method if you wish to use the following passage. And possibly also name it in the questionnaire.*

Until you submit the survey, you can still decide not to take part in the research. [If you stop, your data will not be stored.] After you click ‘send’, we cannot trace what data you have shared with us anymore.

**Ethics approval**

*Research in which you involve people must be reviewed by an ethics committee. When ethical approval is obtained, it can be included in the consent form.*

This research has been reviewed and approved by an internal review committee of Erasmus University Rotterdam. This committee ensures that research participants are protected. If you would like to know more about this RERC/IRB, please contact [add contact information or website].

Declaration of Consent

*This section should be included at the end of the consent form. Each participant must issue their consent before participating in the study. One way to do this is with this consent form. The consent form signed by the participant is only a representation of their consent. Always check that the participant really understands what the study is about by asking some pointed questions.*

*Participants may not always be able or willing to give written consent. They may have difficulty reading and writing or feel uncomfortable signing forms. For these cases, there are other ways to give consent:*

1. *You can ask a witness the participant trusts to sign the consent form.*
2. *You can record verbal consent in an audio or video recording. Make sure the participant is comfortable with this option.*
3. *In rare cases, it may be impossible to obtain consent. Discuss this with the appropriate ethics review committee/internal review board.*

I have read the information letter. I understand what the study is about and what data will be collected from me. I was able to ask questions as well. My questions were adequately answered. I know that I am allowed to stop at any time.

I understand that my data will be anonymized for publication, and further use for teaching and research; and

I understand that my data may be used in pseudonymized form for other scientific research.

*Please include the necessary elements:*

**Check the boxes below if you consent to this.**

*Required for research participation,*

**Data [about specify].**

*In case you intend to process* ***special personal data or data of a criminal nature****, you must ask explicit consent for this. The different categories of special personal data are listed in purple, leave what is applicable and remove the rest. Make sure you provide adequate information about the special personal data.*

I consent to the researcher's collection, use and retention of the following data: *[health,ethnicity, political opinions, religious beliefs, ideological beliefs, union membership, sexual behavior, sexual orientation, genetic data, biometric data and/or data of a criminal nature].*

Audio **recording**

I consent to [the interview] being audio recorded.

**Visual recording**

I consent to [the interview] being filmed.

**Sharing of data outside the EEA**

*An explanation to the participant of the risks of the transfer of the data should be provided here. You should also indicate specifically what data is involved. Ask the Privacy Officer for advice.*

I consent to the sharing of my data with [name of organization] in [country].

*Optional (ask now or after the research)*

**My answers in the article**

*In case an answer is traceable to a participant, you should ask permission for this. Ask permission if you know what you would like to quote. For quotes that cannot be traced back to the person, information is included earlier in this form.*

I give permission for my answers to be used in papers, such as an article in a journal or book. My name will not be included.

**My answers in the article with my name**

*Ask permission if you know what you would like to quote.*

I give permission for my name to be used with my answers in an article.

**New research**

I give permission to be contacted again for new research.

**Name of participant:**

**Participant's signature:**  **Date:**

*Optional:*

**You will receive a copy of the complete information and consent form.**

*It is recommended to provide at least information about where the results will be published as well as contact information (e.g., a website).*

1. Examples are: name, address, phone number, email address, video recording (direct identifiers); date of birth, gender, job/function, place of work (indirect identifiers). [↑](#footnote-ref-2)
2. Personal data revealing racial or ethnic origin; Political opinions; Religious or philosophical beliefs; Trade union membership; Genetic data and biometric data processed for the purpose of uniquely identifying a natural person; Data concerning health; Data concerning a natural person’s sex life or sexual orientation. [↑](#footnote-ref-3)
3. Data if criminal nature… [↑](#footnote-ref-4)
4. *See the GoFair website:* [*https://www.go-fair.org/fair-principles/*](https://www.go-fair.org/fair-principles/) [↑](#footnote-ref-5)