# PARTICIPANT INFORMATION SHEET

*This Participant Information Sheet Template includes essential information that you are obliged to provide to research participants. This template is a guide to help researchers design study information sheets. You can alter the text as relevant for your study, but headings should remain (if not mentioned otherwise).*

**Study title:** One consistent title should appear on all your study documents**.**

**Invitation to participate in a research study**

For example: We'd like to invite You to take part in our research study*, where*…. provide a brief outline of the purpose of your study in lay language. You should explain briefly why and how the participant was invited/chosen/recruited. State how many participants you are intending to involve.

# This information sheet describes the study and Your role in it. Before you decide, it is important that You understand why the research is being done and what it would involve for You. Please take time to read this information, and discuss it with others if You wish. If there is anything that is not clear, or if You would like more information, please ask us. After that we will ask You to sign a consent form to participate in the study.

**Voluntary nature of participation**

The participation in this study is voluntary. You can withdraw from the study at any time without giving any reason and without there being any negative consequences. If You withdraw from the study or withdraw Your consent, any data collected from You before the withdrawal can be included as part of the research data.

**Purpose of the study**

Provide a paragraph to describe the research study and why it is being done. Include the principle aim of the study in brief. Please don´t mention here that this is a thesis or other fulfillment of an educational qualification - it’s not the main aim of the study.

**Who is organising and funding the research?**

Describe the consortium, which is organising and funding the research. Name the leader organization and the responsible researcher. What’s the role of your organisation in this research? Who are financing the research?

**What will the participation involve?**

You should give potential participants an idea of what they should expect if they agree to take part. What sort of information will be sought and why the collection of this information is relevant for achieving the objectives of the study. It is important that you consider participant´s perspective. For example:

* How long will the participant be involved
* How long will the research study last
* How often will the participants meet the researcher/s
* How long will the meetings with the researcher/s be
* What exactly will happen – e.g. collecting personal information, questionnaires, interviews, focus groups, tests*,* use of any recording (audio, video) or photographs *etc.*
* What is the research method used
* Where is the research taking place

**Possible benefits of taking part**

Any benefits to the participants that can reasonably be expected should be stated. If there are none, this should also be stated. Indirect benefits, such as potential benefits to future patients, to the wider community and/or contributing to knowledge can be included here*.*

**Possible disadvantages and risks of taking part**

Any reasonably foreseeable discomforts, disadvantages and risks for the participants need to be stated.

**Financial information**

Participation in this study will involve no cost to You. You will receive no payment for Your participation. You should explain if reimbursements (e.g. travel) are available.

Inform potential participants which organisations are funding / sponsoring your research.

**Insurance policies**

Insurance policies possibly taken out for the participants should be indicated here. Delete this item if not relevant.

**Informing about the research results**

Describe how the results or a summary of the results will be made available to the participants. Reassure potential participants that they will not be identified from any report or publication placed in the public domain. In this chapter, you can mention that this study is Bachelor's, Master’s or Doctoral Thesis of [insert name of the person]

**Termination of the study**

The researcher(s) conducting the study can also terminate the study… mention any foreseeable reasons for termination.

**Potential reuse/preserving/opening of research data [if necessary]**

Describe what happens to your research data after the completion of the study.

* Will the data be preserved in an anonymised or pseudonymised form for future use? Where will it be stored, and for what purpose?
* Will the data be publicly opened in an anonymized form? In which data repository? For example, CSC's Fairdata services, Zenodo, Finnish Social Science Data Archive?
* Will the data be submitted for archiving, and where? Is the submitted data anonymous? To whom can the data be released from the archive, and for what purpose? **OR**

**Destruction of research data**

* + Describe who, when, and how the data will be destroyed.

**Further information**

Further information related to the study can be requested from the researcher / person in charge of the study.

**Contact details of the researchers**

Name at least the principal investigator and the person in charge of the study. [insert name and the contact details of the researcher conducting the study. In the case of Bachelor's, Master’s or Doctoral Thesis, insert also the contact details of your supervisor]

Researcher / Student

Name:

Tel. number:

Email:

Person in charge of the study / Supervisor

Name:

Name of the organisation / Faculty

Tel. number:

Email:

**Appendix to the Participant Information Sheet: A Privacy Notice for Scientific Research**

[If you don’t process personal data during this research study, you can leave this appendix out.]

Within this study, Your personal data will be processed according to the European Union General Data Protection Regulation (679/2016) and current national regulation. The processing of personal data will be described in the following items.

**Data controller of the study**

Data controller is the natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data.

Write the name of the data controller: organization name and address.

**Responsibilities of joint controllers**

If there are two or more controllers, who jointly determine the purposes and means of processing personal data, they are joint controllers. Describe the roles and the division of responsibilities between the parties here.

**Contact person for matters related to the processing of personal data**

Write the name, email-address, phone number of the contact person for matters related to the processing of personal data

**Types of personal data that will be collected**

Write all of the personal data and personal data types that you will process. If necessary, you can use a separate appendix. Personal data can be e.g. a name, a personal identity code, an email address that contains a real name, facial data, voice data, fingerprints, the iris of an eye, the shape of a palm, a traditional signature, an address, a phone number, an IP address, a student number, an insurance number, an account number, detailed income information, a given title such as a chairmanship, gender, age, home municipality, profession, place of study, specific dates (date born, date died, time of an event) as well as sensitive data (race, ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic or biometric data, health data, sexual orientation).

There is no statutory or contractual requirement to provide Your personal data, participation is entirely voluntary.

**Personal data will be collected also from other sources**

Describe if personal data will be collected from other sources, for example from official registries. What kind of data will be collected and on what basis?

**Personal data protection principles**

Describe the information systems, software, applications etc., which are used for collecting and processing personal data.

Describe the how the information systems has been protected. *For example*:

The data that is to be processed in the information systems has been protected using the following:

 ☐ user ID ☐ password ☐ user registration ☐ access control (physical location)

 ☐ other methods, please specify:

**For what purpose will personal data be processed?**

Please write a short description of the purpose of the study.

**Legal basis of processing personal data**

Please enter here the same legal basis as you have selected in the Privacy Notice.

In scientific research, the legal basis is usually a task carried out in the public interest.

In Bachelor's or Master’s Thesis, the legal basis is typically a consent granted by the data subject

If the legal basis is a consent granted by the data subject, You have the right to withdraw the consent at any time as described in this Privacy Notice.

**Nature and duration of the research (how long will the personal data be processed):**

[ ] One-time research [ ]  Follow-up research

Duration of the research:

= time frame needed for collecting and analyzing the data and for the publication of the study (plus three years for possible reclamations about the research results and time needed to respond to them) .

**What happens to the personal data after the research has ended?**

Please describe here the measures at the end of the study, will the personal data be destroyed or archived and for how long. *For example*:

How the personal data will be processed after the research has ended:

☐ Any research materials containing personal data will be destroyed

☐ Any research materials containing personal data will be archived

☐ without identifiers

☐ with identifiers

Where the materials will be archived and for how long:

**Data transfer outside of research registry**:

Please describe whether personal data will be transferred outside the research group (to whom and for what purpose). Please also take into account possible transfers to data processors (for example translators).

**Possible transfer of personal data outside the EU or the EEA:**

Please describe if data will be transferred to a third country. For example:

Your data will not be / will be transferred outside of the EU or the EEA.

If yes, specify the data to be transferred, the purpose and the object of the transfer, as well as the legal basis for the transfer in line with the GDPR.

**Your rights as a data subject**

Because Your personal data will be used in this study, You will be registered to study registry.Your rights as a data subject are the following

# Of the following two options, please choose the one that is line with your processing basis and delete the extra text. It is sufficient to enter a list of the rights and to mention how they can be exercised.

If your *processing basis is a task carried out in the public interest*, please list the following rights:

* Right to obtain information on the processing of personal data
* Right of access
* Right to rectification
* Right to restriction of processing
* Notification obligation regarding rectification of personal data or restriction of processing
* Right to object to the processing
* Right not to be subject to a decision based solely on automated processing
* Right to notify the Data Protection Ombudsman if you suspect that an organization or individual is processing personal data in violation of data protection regulations.

You can exercise your rights by contacting the data controller of the study.

If your *processing basis is consent granted by the data subject*, please list the following rights*:*

* Right to obtain information on the processing of personal data
* Right of access
* Right to rectification
* Right to erasure (right to be forgotten)
* Right to withdraw the consent regarding processing of personal data
* Right to restriction of processing
* Notification obligation regarding rectification or erasure of personal data or restriction of processing
* Right to data portability
* The data subject can allow automated decision-making (including profiling) with his or her specific consent
* Right to notify the Data Protection Ombudsman if you suspect that an organization or individual is processing personal data in violation of data protection regulations.

If the purposes for which a controller processes personal data do not or do no longer require the identification of a data subject by the controller, the controller shall not be obliged to maintain, acquire or process additional information in order to identify the data subject for the sole purpose of complying with this Regulation. If the controller cannot identify the data subject the rights of access, rectification, erasure, notification obligation and data portability shall not apply except if the data subject provides additional information enabling his or her identification.

You can exercise your rights by contacting the data controller of the study.

**Personal data collected in this study will not be used for automated decision-making**

In scientific research, the processing of personal data is never used in any decisions concerning the participants of the research.

**Pseudonymisation and anonymisation**

Please modify the next two chapters to suit your study and delete the unnecessary parts:

All information collected from you will be handled confidentially and according to the legislation. Individual participants will be given a code, and the data will be stored in a coded form in the research files. Results will be analyzed and presented in a coded, aggregate form. Individuals can not be identified without a code key. A code key, which can be used to identify individual research participants and their responses, will be stored (by whom), and the data will not be given to people outside the research group. The final research results will be reported in aggregate form and it will be impossible to identify individual participants. Research registry will be stored (where) for (XX) years, after which it will be destroyed (please describe how). (Or alternative method).

Researcher has to inform the participant if the collected data will be used for later research (for example “The data collected from You can be later used in theses. The participant has the right to request information of people who have received data for their use”). If the legal basis for processing personal data has been consent and you wish to use the data in further studies, a specific consent for that has to be received.

Please mention if you intend to cooperate internationally and clarify the confidentiality and protection of the data as well as possible agreements on data processing.