# Privacy statement

Date: Click here to enter text.

Names of the authors: Click here to enter text.

Instructions: Please refer to the instructions at each section when completing the form.

## Title of the research

Instructions: Write the title of the research here.

Click here to enter text.

## Research data controller

Instructions: Write the name and address of the organisation acting as the research data controller. If there are several, list all including their contact information. If the organisations collaborating on the research process the same personal data as part of the research and together define the purposes and methods of processing the data, they are joint controllers.

Click here to enter text.

## Contact person for matters relating to the data registry

Instructions: Provide information about the person who may be contacted with questions about the processing of personal data (name, address, email address, phone number). If there are joint data controllers, the contact person should forward the request to the other organisations acting as joint data controllers.

Click here to enter text.

## Individuals and organisations involved in the research and their responsibilities

Instructions: List all individuals and organisations involved in the research and indicate their specific responsibilities. If the project is a collaboration between several organisations or departments, describe their individual responsibilities in the area of personal data handling. Also list any parties not directly involved in the research as well as any other partners participating in the research.

Click here to enter text.

## Principal researcher or team

Instructions: Provide information about the principal researcher. Each project must have a designated principal researcher or team. If team, indicate the name of the team and provide contact information for one of its members (name, address, email address, phone number).

Click here to enter text.

## Research personnel

Instructions: List all persons authorised to process data in the research register during the project. You need not list individual persons, but can refer to categories of professionals (e.g. researchers in unit X or research assistants)

Click here to enter text.

## Contact information of the data protection officer

Instructions: Provide the contact information of the data protection officer (name, address, email address, phone number). If the project is a collaboration involving several data controllers, also list here the data protection officers of the other data controllers. It is also possible to designate a separate data protection officer for the research.

Click here to enter text.

## Type and duration of the research

Instructions: Indicate the exact duration of the research if known. If not known, describe how the duration of the processing will be determined.

The research is

One-time study

Cohort study

Duration (how long the personal data are processed):

Click here to enter text.

## Description of the research project and the purpose of processing personal data

Instructions: Describe the project in a way that helps the subject understand how his or her personal data are processed. Describe in sufficient detail the purpose for which personal data are used: how they are used, which types of data are required and how long they need to be stored.

Processing refers to any operation that may be performed on personal data. This includes collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, use for survey purposes, disclosure, alignment, combination, restriction, erasure and destruction.

Click here to enter text.

## Operating environment for the processing of research data

Instructions: Indicate a secure operating environment for the processing of research data (e.g. Findata Kapseli).

Click here to enter text.

## Legal grounds for the processing of personal data

The legal grounds for the processing of personal data are the following, as defined in Article 6(1) of the EU General Data Protection Regulation:

Consent given by the data subject

Compliance with the data controller’s legal obligations

Scientific or historical research, compilation of statistics or the exercise of official authority vested in the data controller and carried out in the public interest

Legitimate interest; please specify:

Other, please specify: Click here to enter text.

## Special categories of personal data

No special categories of personal data are processed as part of the research.

The following special categories of personal data are processed as part of the research:

Racial or ethnic origin

Political opinions

Religious or philosophical beliefs

Trade union membership

Genetic data

Biometric data processed for the purpose of uniquely identifying a person

Health data

Sex life or sexual orientation of a natural person

The processing of the special categories of personal data is based on the following specific provision of Article 9(2) of the Regulation:

Explicit consent of the data subject

Scientific or historical research purposes or statistical purposes

Data subject has made public the sensitive data being processed

The processing of the data is necessary for reasons of substantial public interest

Other, please specify: Click here to enter text.

## Types of personal data included in the research materials

Instructions: List the data or types of data collected and stored on data subjects. Describe who the persons registered are (e.g. clients, employees, patients) and what types of data about them are processed (e.g. data used for identification such as name, date of birth or contact details; information about the services obtained by the client, delivery of the services, and invoicing). Describe separately the data used for identification and the other research data. The information can also be provided in a separate document.

Personal data is any data concerning an identified or identifiable natural person. ‘Identifiable natural person’ refers to a person who can be identified either directly or indirectly by reference to an identifier (e.g. name, personal identity code, location, online identifier) or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that person.]

Click here to enter text.

## Sources used for the personal data collected from the participants

Personal data for use in the research are collected from the participants in the following ways:

Interview

Mailed questionnaire

Online questionnaire

Video recording

Some other method of collecting information directly from the participants, please specify: Click here to enter text.

Participants are not under obligation to supply the necessary personal data; participation is voluntary.

## Other sources of personal data

Instructions: For example registry and documentary material: indicate the data controllers from which data are obtained

Data are collected from non-participants. Please specify which sources and which data: Click here to enter text.

## Transfer or release of data outside the research team

Instructions: Indicate whether personal data are transferred or released outside the research team. Describe the data released, the recipient and the grounds for releasing the data. Also indicate whether personal data are transferred to a data processor (for example a transcriber or other outside service provider). If no data are transferred or released, write “No transfer or release of data.”]

Click here to enter text.

## Transfer or release of data outside the EU or EEA

Instructions: If data are transferred, specify the legal grounds provided by the Regulation enabling the DATA transfer of data, such as Commission decision on the adequacy of data protection (Article 45) / binding corporate rules (Article 47) / standard data protection clauses (Article 46(2)) / derogations and safeguards if the data subject has explicitly consented to the proposed transfer after having been informed of the possible risks of such transfers (Article 49). If possible, please provide a link to the relevant document or details on where and how information is accessible. If no data are transferred or released, write “No transfer or release of data.”]

Click here to enter text.

## Automated decisions

No automated decisions are made. The personal data collected for purposes of the research are not used in decisions concerning the participants.

## Principles of protecting personal data

The data are confidential

Data processed manually:

No data are collected for manual processing

Some data are collected for manual processing; the following precautions will be taken to protect the data:

Data processed electronically:

User ID

Password

Access logging

Physical access control

Other please specify: Click here to enter text.

Anonymisation/Pseudonymisation of data:

The data are anonymised upon the creation of the dataset (all identifying details are removed completely to prevent deanonymisation or linkage with other data).

Directly identifying details are removed upon the creation of the dataset (pseudonymised dataset which allows deanonymisation by using a code or other comparable means and allows linkage with other data). The key code combining the identifying details and the research numbers is stored carefully isolated from the personal data and the data used in the research, and it is available only to limited team personnel.

The data are analysed with the help of direct identifiers because (specify the reason for the retention of direct identifiers):

Precautions to safeguard sensitive data:

Research plan

Name of the person in charge of the research: Click here to enter text.

Personal data are processed and released only for research purposes and delivered in a way that prevents data concerning any individual from being revealed to outsiders

A data protection impact assessment has been carried out.

## Processing of personal data after conclusion of the research

The research register is erased

The research register is archived without identifying details

The research register is archived with identifying details

Indicate where the materials are archived and for how long:

## Rights of the research participants and possible restrictions on them

The legislation on data protection guarantees rights to research participants which they can exercise to ensure that their fundamental right to privacy is not infringed. Participants who wish to exercise their right may contact the person named in section 3.

### Withdrawal of consent (Article 7 of the Regulation)

Data subjects have the right to withdraw their consent provided that the processing of personal data is based on consent. The withdrawal of consent has no implications for the lawfulness of any consent-based processing of data prior to the withdrawal of the consent.

### Right of access (Article 15 of the Regulation)

Data subjects have the right to obtain information on whether their personal data are processed as part of the research and what types of data are processed. They also have the right to request a copy of the personal data being processed.

### Right to rectification (Article 16 of the Regulation)

Data subjects have the right to demand that the data controller rectifies without delay any inaccurate or incorrect data concerning their person.

### Right to erasure (Article 17 of the Regulation)

Data subjects have, in the following cases, the right to demand that their personal data are erased:

a) the personal data are no longer needed for the purposes for which they were collected or processed

b) the data subject withdraws a consent that formed the basis for the processing of data, and there are no other legal grounds for continuing the processing

c) the data subject objects to the processing of the data and there are no justified grounds for processing the data

d) the personal data have been processed unlawfully

e) the personal data must be erased in order to comply with legal requirements applicable to the data controller and based on European Union law or national legislation.

### Exceptions to rights

Exceptions to the rights in the case in section 19 (The rights of research participants and exceptions to them) are possible on grounds specified in the legislation on data protection insofar as the exercise of the rights renders impossible or significantly impairs the achievement of scientific, historical research or statistical purposes. The need to make exceptions to the rights is always assessed on a case-by-case basis.

### Right of complaint

Data subjects have the right to file a complaint with the office of the Data Protection Ombudsman if they believe that prevailing legislation on data protection has been breached in processing their personal data.

Contact information:

Office of the Data Protection Ombudsman

Location: Ratapihantie 9, 6th floor, 00520 Helsinki

Mailing address: PL 800, 00521 Helsinki

Telephone exchange: 029 56 66700

Fax: 029 56 66735

E-mail: tietosuoja@om.fi