

Privacy Notice – Scientific Research

This privacy notice describes how we process your personal data in compliance with data protection legislation. In data protection legislation, the term “data subject” refers to the person whose personal data are processed. In this privacy notice, we refer to data subject as “you” and controller as “we”.

This privacy notice may be updated or edited if necessary. You will be notified of any significant changes as mandated by data protection legislation.

This privacy notice came into force on 6.2.2026

1. Controller

The controller of the research project is:

Tampere University Foundation sr. (Tampere University)

Business ID: 2844561-8

Kalevantie 4 FI-33100 Tampere, Finland

The research project will be conducted by salaried employees of Tampere University Foundation (Tampere University).

The contact person for questions about data processing is Eija Pavilainen, Professor in Nursing Science, who can be reached at eiija.paavilainen@tuni.fi, 040 190 4079. To call Tampere University’s switchboard, dial +358 (0) 294 52 11.

If you have general questions about data protection at Tampere University, please email our Data Protection Officer at dpo@tuni.fi.

2. Scope and purpose of data processing

Name of the research project: Babies at Risk in the Service System: Perspectives on Rights, Experiences, and Professionals practices. VAUPRO (In Finnish: Riskissä olevat vauvat palvelujärjestelmässä – oikeuksien, kokemusten ja ammattilaisten näkökulmia)

This is a one-time research project that will last until 31.12.2028.

We will process your personal data as part of a research project. The purpose of processing your personal data is to conduct the research project specified above.

The aim of the study is to investigate how to improve the identification of infants born into high-risk situations, as well as to anticipate and ensure safe care in relation of the infant's development. During the study, data will be processed as part of data collection and analysis of research results. Personal data will be processed only by the researchers involved in this sub-study.

The principal investigator (lead researcher) is responsible for overseeing the research project. The research group may also be assigned to serve as the principal investigator, with its members participating in conducting the research project.

The research findings, reported in aggregate form so that individual research participants cannot be identified, are intended to be published in relevant scientific journals.

3. Lawful basis for processing personal data

The lawful basis for processing your personal data is:

- consent (of the data subject)
- controller's legal obligation
- protection of vital interests
- a task carried out in the public interest or the exercise of official authority
 - scientific or historical research or compilation of statistics
 - archiving of research and cultural heritage material
- legitimate interests of the controller or a third party

In case special categories of personal data (such as health data or criminal offence data) will be processed, the lawful basis for processing is:

- explicit consent (of the data subject)
- protecting vital interests when the data subject is physically or legally incapable of giving consent.
- establishing, exercising or defending legal claims
- scientific or historical research in the public interest or conduct of statistics
- public interest in the area of public health based on national legislation¹
- other lawful basis that complies with data protection legislation and is specified in national legislation: ____

¹ This refers to processing that is conducted to ensure the reliability of research, the safety of research participants, or compliance with statutory notification, reporting or archiving obligations.

For medical research, Section 6, Paragraph 2 of the Finnish Data Protection Act (1050/2018) will apply.

4. Sources and types of personal data

Depending on the circumstances, we may collect personal data either directly from you or from other sources. We will collect data from:

- you as the data subject
- the following regular data sources: Social and health care client and patient register

We will process the following types of personal data:

- General personal data: Name, personal identity code and municipality of residence
- Special category data (sensitive personal data):
 - health data: The data used in the study consists of health care patient registry data on the study participants
 - racial or ethnic origin
 - political opinions or religious/philosophical beliefs
 - trade union membership
 - sexual behaviour or orientation
 - genetic data
 - biometric data for unique identification
 - criminal convictions or offences

Technical data: ____

Other data: ____

We will process data on the following categories of data subjects:

employees students research participants research staff others, please specify: ____

5. Transfer and disclosure of personal data

Under certain circumstances, your personal data may be transferred to a third country or an international organisation located outside the European Union (EU) or the European Economic Area (EEA). During such transfers, personal data will be appropriately protected by employing suitable transfer mechanisms (such as standard contractual clauses) and technical measures.

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

Your personal data will not be regularly disclosed to other controllers.

In some cases, your personal data may be processed by data processors with whom we have signed appropriate data processing agreements. No external data processors are involved in the processing of personal data.

6. Protecting personal data

Your personal data will be protected using appropriate technical and organisational measures. We will protect your data through technical measures, including antivirus software, firewalls and regular software updates. Users who can access personal data are required to log in with a username and password or, in some cases, with multi-factor authentication.

We will also protect your data through organisational measures. Our staff are obligated to maintain confidentiality, and access to data is restricted. If necessary, we will implement additional safeguards to protect data, such as separate storage locations.

Any physical documents will be safeguarded by storing them in locked facilities.

Material will be:

collected with direct identifiers

collected without direct identifiers

pseudonymised after collection

stored with personally identifiable information, which is necessary for the following reasons:

To ensure that the research questions are answered, the high scientific quality of the study, reliability, and methodological accuracy, it is important to know the details of the sample and the individuals associated with them exactly as they are recorded in the documents. If this information is concealed or altered, understanding, analysing the data, and drawing conclusions becomes challenging and unreliable.

During this research project, your data will also be protected through the following measures: The data is stored in a secure data processing environment in accordance with the provisions of the Secondary Use Act of Health and Social Data, to which only researchers involved in the research project have access. The data is anonymized during analysis. The data permission authority Findata verifies the anonymization of the results before they are transferred out of the secure environment.

7. Retention period for personal data

We will retain your personal data for only as long as necessary, as determined on a case-by-case basis. The retention period also depends on the requirements set out in data protection legislation. We will adhere to our Data Management Plan and all applicable legislation when determining the retention period of personal data.

Your personal data will be retained as follows: The data will be retained for five years following the completion of the research project, until 31 December 2033. The data must be retained after permitted use under the Act on the Secondary Use of Health and Social Data, as the processes of data analysis and scientific publication may extend beyond the duration of the project. It is possible that a permit for further use of the data will be applied to enable follow-up research. It is ethically important to make full use of the research data.

After the research project has been completed, the research records containing personal data will be:

- destroyed in their entirety
- anonymised and archived without personally identifiable information.
- archived with personally identifiable information.

8. Profiling and automated decision-making

We will not use your personal data for profiling or automated decision-making.

9. Data subjects' rights and how to exercise them

Data protection legislation affords certain rights to data subjects, depending on the lawful basis for processing their personal data. Under certain circumstances, your rights may be restricted, for example, due to our legal obligations or if personal data are processed for scientific research, statistical or archiving purposes. If your rights have been restricted, we will implement appropriate and necessary technical and organisational measures to protect your privacy. As a data subject, you have the following rights which you can exercise by sending us a request.

Right of access

You have the right to request confirmation of whether we hold your personal data and to receive a copy of the data we hold.

Right to rectification

You have the right to request that any incorrect or incomplete personal data we hold about be revised or supplemented. You can also request to have any unnecessary personal data erased from our records.

Right to restrict processing

You may have the right to restrict the processing of your personal data in certain cases defined by law. For example, this right may apply if you believe the personal data we hold about you is incorrect or that your data are being processed in violation of data protection legislation, or if you have opposed the processing of your data.

Right to object

In certain circumstances, you have the right to object to the processing of personal data on grounds relating to your particular situation.

Right not to be subject to automated decision-making

You have the right not to be subject to decisions based solely on automated processing (such as profiling) that produce legal effects concerning you or otherwise similarly and significantly affect you. However, there are exceptions to this prohibition.

Right to lodge a complaint with a supervisory authority

You have the right to lodge a complaint with a supervisory authority (Data Protection Ombudsman), if you believe that the processing of your personal data violates data protection legislation.

Office of the Data Protection Ombudsman

Street address: Lintulahdenkuja 4, FI-00530 Helsinki, Finland

Postal address: PO Box 800, FI-00531 Helsinki, Finland

Switchboard: +358 29 56 66700

Fax: +358 29 56 66735

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