

Scientific research privacy notice EU General Data Protection Regulation, Articles 12-14

3 February 2023

Privacy notice

Information for study participants

This document describes how your personal data will be processed in research conducted by THL. Participation in the study is always voluntary. You will not face any negative consequences if you do not participate in the study or if you discontinue your participation in it. If you discontinue your participation in the study, the data collected before you do so can still be used in the study. Section 17 of this description includes more detailed information on your rights and how you may affect the processing of your data.

1. Controller of the study

National Institute for Health and Welfare (THL)

P.O. Box 30 FI-00271 Helsinki, Finland tel. +358 29 524 6000

Contact person for research matters:

Name: Johanna Hietamäki

Address: Mannerheimintie 166, FI-00271 Helsinki

Phone number: +358 29 524 7990 E-mail: etunimi.sukunimi@thl.fi

2. Description of the research project and purpose of the processing of personal data

The purpose of the preliminary Path to safety study (1st study) is to examine the shelters and other services used by the clients of the shelters for victims of domestic violence and the help they have provided. The information obtained in the study will be used in the preparation of the more extensive main study (2nd study), which will be carried out as a longitudinal study on clients who have experienced domestic violence and used shelter services. In the preliminary study, the most important information needs are obtaining specialist knowledge to focus the main study on the key issues and conducting the main study in a safe and data secure manner.

The intention is to have shelter staff, social welfare and health care staff and persons who have experienced domestic violence participate in the preliminary study. Persons who have experienced domestic violence are requested to the study through the violence prevention services. In the preliminary study, questions will not be asked about personal experiences of violence, but about matters that are more generally related to domestic violence and considered important. Questions will also be asked about the shelter services, other services and violence prevention, the areas requiring development in them and about functioning data collection methods for the future longitudinal study.

In the preliminary study, the study data will be collected by conducting group interviews with professionals. Group interviews with persons who have experienced domestic violence may be conducted with experts by experience who already know each other. In addition, interviews with individuals will also be conducted. The interviews, their analyses and reporting will be conducted anonymously. There will be approximately 6 group interviews with 2–6 participants per group for shelter staff. In addition, 1–2 group interviews with 2–6 participants per focus group will possibly be conducted with employees of open services in violence prevention. A total of approximately 6–10 individual interviews or group interviews with 2–7 participants per group will be conducted with persons who have experienced domestic violence. The interviews will be recorded. If necessary, on-site or remote interpretation can be used in the interview. In the interview, a basic information form will be completed, which does not include direct identifiers. The information in the basic



information form will not be linked to the interview. The participants will be requested to give verbal consent at the beginning of the interview.

The interview material will be recorded on a protected drive. A set of text material will be created of the recordings of the interview. The text material will be pseudonymised and, where necessary, translated into Finnish. At this stage, the possible information concerning names and other similar information will be anonymised. The analysis of the study data will be carried out using pseudonymised data. The background information on the interviewees will be presented classified in connection with the text material based on the interview.

The research subjects will be asked about their willingness to cooperate after the interview with regard to the longitudinal study that is being planned. No separate study data will be collected on that stage. If they wish, the persons who have participated in the study can register for a discussion concerning this study or the study that is being planned. The persons who have expressed their interest in this possibility will be contacted separately about it. The contact details of those who have registered for other cooperation within the study will be stored separately from the study data.

The study interviews will be conducted during 2023.

3. Parties and division of responsibilities for a study carried out as a cooperation project

The study is not conducted as a cooperation project.

4. Director or group in charge of the study

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Address: Mannerheimintie 166, FI-00271 Helsinki

Phone number: +358 29 524 7990 E-mail: etunimi.sukunimi@thl.fi

5. Data protection officer's contact information

The email address of THL's Data Protection Officer is: tietosuoja@thl.fi.

6. Parties carrying out the study

The study will be carried out by the researchers/a research group and research assistants of the Other Special Services Unit of THL Department of Government Services

7. Name, nature and duration of the study

Title of the study: Preliminary study of the Path to Safety study (1st study)	
⊠Single study	Follow-up study

Duration of study (how long the personal data will be processed): The study will run from 1 January 2023 to 31 December 2028. The audio files recorded in the interviews will be stored for 12 months. The data for the study will be collected between 1 January 2023 and 31 December 2023. The pseudonymised data will be stored for 10 years.

The contact details given for cooperation within the study will be stored for the duration of the cooperation related to the study. This will be for a maximum of 10 years.



8. Legal basis for the processing of personal data

In accordance wit of personal data i	th Article 6(1) of the EU General Data Protection Regulation, the legal basis for the processing s the following:
Compli	pant's consent iance with a legal obligation fic or historical research purposes in the public interest, statistical purposes or the exercise of vested in the controller (Data Protection Act, section 4, paragraph 3)
9. Sensitive pe	rsonal data
☐ No sen	sitive personal data are processed in the study:
The following sen	sitive personal data are processed in the study:
Politica Religio Trade u Genetic Proces Health Sexual	sing of biometric data for unambiguous identification of a person
	f sensitive data is based on the following special category under Article 9(2) of the General Regulation or special condition under section 6 of the Data Protection Act:
Scientific or h	nt of the research subject istorical research purposes or statistical purposes earch and cultural heritage materials for the purposes of the public
Processing is a Processing is Processing is a Processing is a Processing is a Processing is a	data to be processed has been made public by the research subject necessary based on a significant public interest necessary based on a significant public interest related to national health provided by law or it is derived directly from a duty set out for the controller by law provided by law or it is derived directly from a duty set out for the controller by law provided by law or it is derived directly from a duty set out for the controller by law lang a criminal conviction or offences are processed in the study.

10. Which personal data will be included in the study data

The personal data of the study data includes an audio tape recorded of the interview, of which pseudonymised text material will be written. A basic information form is collected in the study. No individualised personal data is asked in the form. If necessary, contact details are requested for conducting the interview. They will be destroyed immediately after the interview. The interviews concern the interviewees' views on shelter services and conducting a study on them. In addition, contact details are requested for later contacting from those who



have expressed their willingness to participate in further cooperation. The contact details will be stored separately from the study data and deleted as soon as they are no longer needed for further cooperation.

11. Sources of personal data collected

The interviewees and the basic information form related to the interview.

12. Transfer or disclosure of data outside of research group

Personal data will not be regularly disclosed or transferred outside THL.

Writing the interview materials into a text form, i.e. transcription, will be purchased as a service. In addition, translations for the transcribed and pseudonymised interview material will be purchased. Data secure connections will be used in transferring the data.

Collected study data from which personal data have been eliminated may be disclosed against a research proposal and an approved user authorisation application for the purposes of research conducted in cooperation with THL.

13. Transfer of data outside the EU or the European Economic Area

The data will not be transferred to these countries

14. Automated decision-making
No automated decisions are made.
15. Principles of personal data protection
☐ The data are confidential.
Protection of manual material:
The data processed in the data systems: user ID password registration of use access control other, please specify:
Processing of direct identifiers: Direct identifiers are eliminated during the analysis phase. The material will be analysed with direct identifiers because (justification for storing direct identifiers):
16. Processing of personal data after the end of the study
 ☐ The study data will be destroyed ☐ The study data will be archived: ☐ without identifiers ☐ With identifiers

Where will the data be filed and for how long: The tapes of the interviews, the pseudonymised interview material and the material of the background survey will be recorded on THL's network server for 10 years.



17. The rights of the data subject and their possible limitations

Under data protection legislation, research subjects have certain rights. By exercising these rights, research subjects can ensure that the protection of their privacy, which is a fundamental right, is realised. If you wish to exercise your right, follow these instructions: https://thl.fi/en/web/thlfi-en/about-us/data-protection Alternatively, contact THL's registry (kirjaamo@thl.fi) or the contact person mentioned in section 1.

If THL is unable to identify you from the data, rights such as the right of access, the right to rectification and the right to erasure will not be applied.

Withdrawing consent (Article 7 of the General Data Protection Regulation)

Where the processing of personal data is based on consent, you have the right to withdraw your consent at any time. The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal.

Right of access (Article 15 of the General Data Protection Regulation)

You have the right to obtain confirmation as to whether or not your personal data are being processed in the study and which of your personal data are processed in the study. You may also request a copy of the personal data undergoing processing.

Right to rectification (Article 16 of the General Data Protection Regulation)

If your personal data are inaccurate or incorrect, you have the right to request their rectification or supplementation.

Right to erasure (Article 17 of the General Data Protection Regulation)

You have the right to obtain from the controller the erasure of your personal data in the following cases:

- a) the personal data are no longer necessary in relation to the purposes for which they were collected or otherwise processed;
- b) you withdraw your consent on which the processing is based and there is no other legal ground for the processing;
- c) you object to the processing and there are no overriding legitimate grounds for the processing;
- d) the personal data have been unlawfully processed; or
- e) the personal data have to be erased for compliance with a legal obligation in Union or Member State law to which the controller is subject.

Derogation from the rights

Derogations from the rights described in this section 17 The rights of the data subject and their possible limitations may occur in accordance with the conditions laid down in data protection legislation in so far as the obligation is likely to render impossible or seriously impair the achievement of the objectives of scientific or historical research purposes. The need for derogation is always assessed on a case-by-case basis.

If you wish to exercise your right, follow these instructions: https://thl.fi/en/web/thlfi-en/about-us/data-protection



Contact

If you have any questions about you rights, contact THL's registry (<u>kirjaamo@thl.fi</u>) or the contact person mentioned in section 1.

Right to refer the matter to the Data Protection Ombudsman

You have the right to refer the matter to the Office of the Data Protection Ombudsman if you consider that the valid data protection legislation has been violated in the processing of your personal data.

Contact information:

Office of the Data Protection Ombudsman

Office of the Data Protection Ombudsman Visiting address: P.O. Box 4, 00530 Helsinki

Mailing address: P.O. Box 800, 00531 Helsinki, Finland

Switchboard: +358 29 56 66700 E-mail: <u>tietosuoja@om.fi</u>