

PRIVACY NOTICE OF THE STUDY

EU General Data Protection Regulation, Articles 12-14

Information for survey participants

This privacy notice explains how your and your child's personal data will be processed in the Fin-Children (FinLapset) study on the health, welfare and services of families with babies. Participation in the survey is always voluntary. You or your family will not face any negative consequences if you do not participate in the survey or if you drop out. If you drop out, the data collected before you do so can still be used in the study. Section 17 of this privacy notice explains in detail about your and your family's rights and how you may influence the processing of your and your child's data.

1. Controller of the survey

Finnish Institute for Health and Welfare

P.O. Box 30

FI-00271 Helsinki, Finland

tel. +358 29 524 6000

Contact person in matters concerning the survey:

Name: Reija Klemetti

Telephone number: +358 29 524 7265

E-mail: reija.klemetti@thl.fi

Name: Maaret Vuorenmaa

Telephone number: +358 29 524 7008

E-mail: maaret.vuorenmaa@thl.fi

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

The purpose of this FinChildren (FinLapset) study is to monitor the welfare, health and service experiences of young children and their families. The subjects of the study are babies aged around three to six months and their families in Finland. Data will be collected on a questionnaire from the child's both parents, from Kanta records and from registers. The findings of the study will be published on THL's web service, as statistical reports and in scientific publications. Individual respondents cannot be identified in the result reports. The research evidence will be used to develop services for families with children, to support regional and national decision-making, and to facilitate the evaluation and planning of national social and health policy. For more information about the survey, visit thl.fi/finlapset/vauvat.

As a research institution, THL is entitled to request health and welfare data for the purposes of this study from registers maintained by various official bodies and health care units by permission of the register controllers. Register data will only be used for the purpose of the study. The aim of using register data is to reduce the respondents' workload by eliminating the need to ask for information that can be obtained from the registers.

The personal data will be collected from the information systems of the Population Register Centre (Address source: Population Information System, Population Register Centre, P.O Box 123

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00531 HELSINKI). The telephone numbers will be picked from LeadCloud information systems. The personal data and telephone numbers will only be used to contact the research subjects and to link the register data mentioned above to the answers provided by a subject in the survey. Once the data has been combined with the information obtained from Kanta records and registers, direct identifying data will be removed from the research data.

The Finnish Institute for Health and Welfare as a public authority undertakes to store and process the survey data confidentially and in compliance with the secrecy obligation and data protection legislation. All those collecting and processing the data are subject to a duty of non-disclosure.

3. Responsible director of the survey or group in charge of the study

The responsible director of the survey is Research Manager Reija Klemetti.

Address: P.O. Box 30, 00271 Helsinki

Telephone number: +358 29 524 6000 (exchange)

E-mail address: etunimi.sukunimi@thl.fi

4. Contact details of THL's data protection officer: tietosuoja@thl.fi

5. Implementers of the study

The study is conducted by the Knowledge Management and Co-Creation unit of THL's Public Health and Welfare department.

6. Title, nature and duration of the study

Title of the study: FinChildren (FinLapset) study – a national study of families with babies in 2020

- √ Single survey
- √ Follow-up survey

The participants will only be asked to supply information for the study once, but personal data, the accumulated information and the register data linked to them will be stored and used for several years after the data collection. For example, this will enable register-based follow-up of the research data. The personal data will only be used for the purpose of linking together the data in the various registers used in the study. The register follow-up stage of the study will run for an estimated two years, and register data will be updated when necessary during the follow-up stage. After the follow-up stage, the identifying data will be converted into a format in which the data subject cannot be identified.

7. 7. Legal basis of processing personal data

In accordance with Article 6(1) of the EU General Data Protection Regulation, the legal basis for the processing of personal data is the following:

- √ Compliance with a legal obligation (General Data Protection Regulation, Article 6(1)(c))

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8. Sensitive personal data

The following sensitive personal data will be processed in the study:

- ✓ X Health data
- ✓ X Race or ethnic origin

The processing of sensitive data is based on the following special category under Article 9(2) of the General Data Protection Regulation or special condition under section 6 of the Data Protection Act:

- ✓ Processing is provided by law or it is derived directly from a duty set out for the controller by law

9. Which personal data will be included in the research data

Identifying data: the personal identity code of a child aged 3 to 6 months, the parent's name, contact details, gender.

Information collected as part of research data: welfare and health data as well as service experiences.

Data collected from registers:

Medical Birth Register (the child's gender, birth weight and height, information about the child's health after birth, diagnoses and diet up to the age of 7 days, information about the mother's health during pregnancy, diagnoses, monitoring and screenings as well as delivery and health after delivery)

Population Register Centre (the baby's personal identity code and, in multiple pregnancies, the baby's ordinal, the parent's address, year and state of birth, gender, marital status and native language)

Care Register for Health Care (information about the child's hospital and outpatient health care visits and diagnoses)

Information on care allowances, purchases of pharmaceuticals and reimbursements for medicine expenses granted to the child by Kela, and family leaves granted because of the child

Kanta information: the child's records in Kanta (diagnoses and procedures)

10. From which sources will personal data be collected

Personal data will be collected from the information systems of the Population Register Centre (Address source: Population Information System, Population Register Centre, P.O Box 123 00531 HELSINKI). The telephone numbers will be picked from LeadCloud information systems.

11. Transfer or disclosure of data outside research group

Personal data will not be regularly disclosed or transferred outside the research group. Collected research data from which personal data have been eliminated may be disclosed for research purposes against a research proposal and an approved user authorisation application.

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12. No data will be transferred or disclosed to parties outside the EU or the European Economic Area

13. No automated decision-making will take place in the study

14. The principles of protecting personal data

- √ The data are confidential.

Data processed in data systems will be protected by the following methods:

- √ User IDs
- √ User logs
- √ Passwords
- √ Access control

Processing of direct identifiers:

- √ Direct identifiers will be eliminated at the analysis phase

15. Processing of personal data after the end of the study

- √ The research register will be archived without identifiers in the National Archives of Finland permanently until further notice.

16. 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 would like to exercise your rights as a research subject, contact kirjaamo@thl.fi.**

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)

In case of inaccuracy or errors in your personal data undergoing processing, 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

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- 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 **16 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.

Right of appeal

You have the right to lodge an appeal with 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 details:

Office of the Data Protection Ombudsman

Visiting address: Ratapihantie 9, 6th floor, 00520 Helsinki

Postal address: P.O. Box 800, 00521 Helsinki

Switchboard: +358 29 56 66700

Fax: +358 29 56 66735

E-mail: tietosuoja@om.fi