

03 November 2023

Information for study participants

The Finnish Institute for Health and Welfare (THL) conducts the FinChildren / Finland100 study aimed at families with children born in 2017. The study produces data on the families' health, welfare, social inclusion, service use and service experiences, and the factors affecting all the above. This document describes how your personal data will be processed in the FinChildren / Finland100 study. 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. Section 17 of this description includes more detailed information on your rights and how you may influence 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:
Maaret Vuorenmaa, Senior Researcher
Address: THL, P.O. Box 30, 00271 HKI, Finland
Phone number: +358 29 524 6000 (exchange)
E-mail: firstname.lastname@thl.fi

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

FinChildren is a single research project carried out by THL in cooperation between the FinChildren and Finland100 research groups.

The goal of the FinChildren / Finland100 study is to produce comprehensive and up-to-date data on the health, well-being and social inclusion of children born in 2017 and their families, as well as on potential changes in these circumstances. The study also examines the families' use of family leave and of educational, social and health care services available to families with children, and possible changes in the use of these services. These are all part of THL's statutory duties. The research data will also be utilised in scientific research.

This survey is also a preliminary study contributing to the national Finland100 project prepared by THL. The project is funded by the Finnish Cultural Foundation, and it is aimed at producing data to safeguard the Finnish welfare system in the coming decades. The actual data collection efforts of the Finland100 project will be targeted at families who are expecting a baby in 2026.

The domain of the study consists of all children born in 2017 and their official parents living in Finland. The sample includes every other child born in 2017 ($N \approx 26,500$) and these children's official parents ($N \approx 53,000$).

The research data consists of two levels:

- 1) Material which consists solely of register checks and contains individual-level register data. This material contains data on all children born in 2017 and on their parents living in Finland. In addition, an effort is made to identify the siblings of the child born in 2017 from the registers in order to combine their register data with this material. The study utilises data from registers managed by the Digital and Population Data Services Agency, THL, Kela, the Finnish National Agency for Education, Statistics Finland, Tax Administration, the Legal Register Centre, and the Financial Supervisory Authority. The research data will not be combined with the survey results collected from the participants.

- 2) Material containing survey data collected from the parents and individual register-based data of children born in 2017 and their parents included in the study sample. The parents are asked to take part in the survey when the child is in pre-primary education and possibly again later when the child is 9–10 years and 11–12 years old. The main focus of the survey is on gathering experiential knowledge from the parents on the following topics: 1) the family's health and well-being, 2) the parents' coping and the flow of everyday life, 3) the parents' social inclusion and identification, and 4) the family's need for services and the adequacy of said services. No information is collected from the children themselves through the surveys. The survey data is also processed, analysed, and reported as independent material. In addition, any survey data collected from the parents can be combined with data extracted from official registers (registers managed by the Digital and Population Data Services Agency, THL, Kela, the Finnish National Agency for Education, Statistics Finland, the Finnish Tax Administration, and the Financial Supervisory Authority). By responding to the survey, each parent gives their consent to combining their own register data as well as that of their child born in 2017 with the survey data. If both parents of a child complete the survey, the data on both parents and their child will be combined. Any register data on the child's siblings will not be linked to the study material.

The results of the study will be published on the THL website, in reports and similar publications aimed at the general public, and in scientific peer-reviewed publications. The research data will be used in areas including the evaluation and planning of regional social welfare and healthcare policy.

Personal data will 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 register data has been combined, any personal identifiers are eliminated from the research data. It is not possible to directly identify individual research subjects from the data used by the researchers.

Further information on the study is available online at: thl.fi/finlapset.

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

THL is the controller as defined in the General Data Protection Regulation.

THL also cooperates with research groups from other organisations within the framework of research cooperation agreements. The partners are granted access to limited datasets without any identifiers, and they will act as joint controllers for the duration of the cooperation agreement. The partners acting as joint controllers are listed in Appendix 1 to this privacy notice.

In all cases, THL is responsible for the obligations of the controller as laid down in more detail in the GDPR.

The research subjects can submit all requests concerning the data subject's rights to THL, and THL will forward them to the partners acting as joint controllers if necessary.

4. Director or group in charge of the study

The study project is carried out by THL in cooperation between the FinChildren and Finland100 research groups.

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Phone number: +358 29 524 6000 (exchange)

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 is carried out by researchers from the FinChildren group within the Knowledge Base for the Health and Welfare Management unit operating under the THL Department of Public Health and Welfare's Knowledge Management and Co-Creation Unit, and researchers from the Finland100 group of the Biobank unit within the THL Department of Knowledge Brokers. Moreover, researchers from other THL departments and partner organisations are also involved in analysing the data and reporting on the results (see Appendix 1).

7. Name, nature and duration of the study

Title of the study: FinChildren / Finland100 study for families of children born in 2017

This is a follow-up study in which the welfare of families of children born in 2017 is examined using individual-level register data and data collected through surveys.

Both parents of children born in 2017 will receive a separate questionnaire with identical content in 2024, when their child will be of preschool age. Furthermore, the child's parents may be asked to take part in the survey again during the follow-up stage of the study.

Register data on the child born in 2017 and on their parents will be monitored starting from the pregnancy until the child turns 18 years. The register data of the child's siblings can only be monitored until the sibling turns 18 years. However, the monitoring of any sibling's register data shall begin at the earliest during the pregnancy of the child born in 2017, and it shall not exceed the monitoring period of the child born in 2017.

The register data on the child born in 2017 as well as their siblings and parents will be updated during the follow-up stage.

Once the register monitoring period of the study ends (at the latest in 2040), the research data will be stored in accordance with section 16.

8. Legal basis for the processing of 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:

- Participant's consent
- Compliance with a legal obligation
- Scientific or historical research purposes in the public interest, statistical purposes or the exercise of official authority vested in the controller (Data Protection Act, section 4, paragraph 3)

9. Sensitive personal data

- No sensitive personal data are processed in the study:

The following sensitive personal data are processed in the study:

- Race or ethnic origin
- Political opinions
- Religious or philosophic conviction
- Trade union membership
- Genetic data
- Processing of biometric data for unambiguous identification of a person
- Health data
- Sexual behaviour

Sexual orientation

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:

- Explicit consent of the research subject
- Scientific or historical research purposes or statistical purposes
- Archiving research and cultural heritage materials for the purposes of the public interest
- The sensitive data to be processed has been made public by the research subject
- Processing is necessary based on a significant public interest
- Processing is necessary based on a significant public interest related to national health
- Processing is provided by law or it is derived directly from a duty set out for the controller by law
- Data concerning a criminal conviction or offences are processed in the study.

10. Which personal data is contained in the research material

The goal of the FinChildren / Finland100 study is to map the parents' views of their own and their child's welfare, health (e.g. mood, child's temperament, interaction), social inclusion, and the use of educational, social and health care services.

Data on the child and their parents collected from official registers:

Finnish Institute for Health and Welfare (THL):

- Data in the Medical Birth Register (e.g. monitoring data on the pregnancy, delivery, and the child)
- Data in the Care Register for Health Care (HILMO) and the Register of Primary Health Care Visits (AvoHILMO) (e.g. appointment dates, diagnoses and completed procedures)
- Register of Child welfare (start and end dates for placements outside the home)
- Data in the Incomes Register

Social Insurance Institution (Kela):

- Benefit details on families with children (e.g. maternity allowance, parental allowance, child home care allowance or flexible/partial care allowance, and private day care allowance)
- Rehabilitation details (e.g. legal basis for rehabilitation, rehabilitation measures, diagnosis, main objective, and number of reimbursed visits)
- Data in the Kanta Prescription Centre and the Kela Prescription Register (e.g. Prescriptions, purchases of medicines covered by health insurance, and the ATC code of the medicinal product)
- Details on the right to reimbursement of medicine expenses (e.g. start date and diagnosis)
- Disability allowances (e.g. start date and diagnosis)
- Payment details on sickness allowances (e.g. start date of disability, professional code, and diagnosis code)
- Payment details on unemployment security (e.g. payment date, basis of payment and part of the benefit), general housing allowance (e.g. decision date, the applicant's life situation, and the number of under-age children), child maintenance allowance (e.g. payment month and code for the relevant part of the benefit), and basic social assistance (e.g. payment month, occupation, and role in the recipient household)

Statistics Finland:

- Data on education and occupation, socioeconomic status, main occupation, household income, causes of death, and longitudinal data for personal details (FOLK)

Finnish National Agency for Education:

- Varda database on early childhood education and care (e.g. start and end date and weekly hours of early childhood education and care)
- Koski registry for pre-primary and basic education (information on study rights in pre-primary education, data on extended compulsory school attendance, forms of support, and decision periods for special support)

Finnish Tax Administration:

- Incomes Register (information on salaries and benefits)

Financial Supervisory Authority:

- Earnings-related benefits

Legal Register Centre:

- Criminal record (e.g. information on fines)

Digital and Population Data Services Agency:

- Population Information System (copy available to THL): name, address, municipality of residence, gender, date and place of birth, municipality of birth, foreign country of birth, date of immigration, nationality, marital status, marital history, native language, language of service, family relations, size of household, parent's role, data on with whom the child lives, possible date of death, and the grandparents' birth state.

Identification details are needed for extracting data from official registers and for combining data from different sources. However, any direct personal identifiers will be removed from the actual research data to be analysed.

11. Sources of personal data

THL, Kela, Statistics Finland, Finnish National Agency for Education, Finnish Tax Administration, Financial Supervisory Authority, Legal Register Centre, Digital and Population Data Services Agency, and information provided by the research subjects during the survey.

12. Transfer or disclosure of data outside the research group

As a rule, personal data is not disclosed or transferred outside the research group. The collected data can be used in accordance with the Act on the National Institute for Health and Welfare (668/2008) and transferred to partners on a contractual basis (see Appendix 1). For a study that meets the THL criteria for an internal study, the decision is made by THL itself.

THL has transferred the competence for data access authorisation to the Social and Health Data Permit Authority (Findata), which is primarily responsible for the data access authorisation of applicants outside THL. However, the intended use and disclosure of data must correspond to the purpose for which the data has been provided, also in terms of any data permits granted by Findata.

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

As a rule, no data is transferred or disclosed to parties outside the EU or the European Economic Area. Data permits may be granted to THL's partners for the purpose of scientific research or statistical investigation. In such cases, all data that would enable direct identification is deleted.

14. Automated decision-making

No automated decisions are made.

15. Principles of personal data protection

All data is 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 maintaining direct identifiers):

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

The data will be destroyed
 The data will be archived:
 without identifiers with identifiers

Where will the data be filed and for how long: permanently in the National Archives

17. Rights of the data subject and possible limitations thereof

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 rights, 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 data access (Article 15 GDPR)

You have the right to be informed of whether your personal data will be processed in the study and what personal data will be 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 must 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 rights, follow these instructions: <https://thl.fi/en/web/thlfi-en/about-us/data-protection>

Contact

If you have any questions about your rights, contact THL's registry (kirjaamo@thl.fi) or the contact person indicated 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

Visiting address: Lintulahdenkuja 4, 00530 Helsinki

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

Switchboard: +358 29 56 66700

E-mail: tietosuoja@om.fi

APPENDIX 1. JOINT CONTROLLERS AND DATASETS

Organisation