

1. Data controller of the research

Finnish Institute for Health and Welfare (THL)
Postal address: P.O. Box 30, 00271 Helsinki
Street address: Mannerheimintie 166, Helsinki

University of Turku, Department of Social Research
Address: Department of Social Research, Sociology, 20014 University of Turku

Contact person for matters regarding the research:

Name: Outi Sirniö

Address: Finnish Institute for Health and Welfare, Mannerheimintie 166, Helsinki

Telephone number: +358 29 524 7964

E-mail: outi.sirnio@thl.fi

Name: Matti Lindberg

Address: Department of Social Research, Sociology, 20014 University of Turku

Telephone number: +358 50 347 0936

E-mail: mattlin@utu.fi

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

The general objective of the research is to examine the mechanisms that create social inequalities in terms of well-being and health. The research examines the extent to which socio-economic success, health (including mental health), social exclusion and family formation, and other life events in adulthood are explained by the childhood environment, genetic ancestry and different life events. In addition, the role of social security as an equalising factor for inequalities will be examined. The research describes the differences between birth cohorts and temporal changes in Finland in recent decades. The research uses molecular genetic data, which are combined with the register data of Statistics Finland, the Social Insurance Institution of Finland (Kela) and the Finnish Institute for Health and Welfare (THL).

3. Parties to the joint research project and division of responsibilities

The project includes cooperation between the Department of Social Research and the Department of Clinical Medicine at the University of Turku and the researchers of THL within the INVEST flagship programme funded by the Academy of Finland. The research team has access

to the research data via Fiona remote access environment of Statistics Finland. THL is responsible for all rights of data subjects.

In this research, the organisations listed in Section 1 act as joint controllers, i.e. they jointly determine the purposes and means of personal data processing.

To exercise the data subject's rights, the research subjects may request any information related to the research from the contact person below:

Name: Outi Sirniö

Address: Finnish Institute for Health and Welfare, Mannerheimintie 166, Helsinki

Telephone number: +358 29 524 7964

E-mail: outi.sirnio@thl.fi

If necessary, the contact person shall also forward the request to other organisations acting as joint controllers.

The research subject may exercise their rights under the Data Protection Regulation in relation to each controller. If this happens, the recipient of the request or demand may also forward it to the other joint controllers if necessary.

4. Research leader or the team responsible for the research

Pasi Moisio

Finnish Institute for Health and Welfare, P.O. Box 30, 00271 Helsinki

tel. +358 29 524 7228;

pasi.moisio@thl.fi

Jani Erola

Department of Social Research, Sociology, 20014 University of Turku

tel. +358 40 512 5286

jani.erola@utu.fi

5. Contact details of the data protection officer

Data protection officer at THL Jarkko Reittu

E-mail: tietosuoja@thl.fi

6. Parties conducting the research

Researchers at the Finnish Institute for Health and Welfare and the University of Turku

7. Name, nature and duration of the research

Name of the research: INVEST

Cross-sectional study

Follow-up study

Duration of the study (for how long personal data will be processed):

1 September 2020 – 31 December 2025. The research may be continued after 31 December 2025.

8. Legal basis for processing of personal data

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

Consent of the research subject

Compliance with a legal obligation

Performance of a scientific or historical research carried out in the public interest, compilation of statistics or the exercise of official authority vested in the controller

Legitimate interest

Other, please specify:

9. Processing of sensitive personal data

No sensitive personal data will be processed during the study.

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

Racial or ethnic origin

Political opinions

Religious or philosophical beliefs

Trade union membership

Genetic data

Processing of biometric data for the purpose of uniquely identifying a natural person

Data concerning health

Natural person's sex life or sexual orientation

Processing of sensitive personal data is based on the following special condition of the Article 9(2) of the General Data Protection Regulation:

Explicit consent of the research subject

- Scientific or historical research purposes or statistical purposes
 The sensitive data processed have been made public by the research subject
 Other, please specify:

Data relating to criminal convictions and offences are processed during the research.

10. What personal data is included in the research data

Statistics Finland's data (target group is the entire population of Finland; the data start in 1987 and end in the latest year available, unless otherwise stated below):

- FOLK basic data
- FOLK family data
- FOLK qualifications
- FOLK employment data
- FOLK income data
- FOLK cohabitation
- FOLK population census 1950
- FOLK population censuses 1970-1985
- FOLK period data: unemployment, pension, placements, job search, employment, labour market training
- FOLK household-dwelling unit data
- FOLK child-parent year
- FOLK child-parents
- EDUC_TYHR joint application for upper secondary education (all parts)
- EDUC_TREK Register of Completed Education and Degrees
- EDUC_OPISK students (all parts)
- ya246a: Structure of earnings data (inc. harmonised data), total
- YTL (The Matriculation Examination Board) module data from 1967 onwards
- Annual service set of the income distribution statistics from 2014 (selected variables)
- Results of school-leaving certificate from comprehensive school
- Postal code, country of birth, dates of migration to/from the country
- Person-spouse link table: information about spouses of a person (protected identifiers)
- Person-child link table: information about a person's children (protected identifiers)
- Relationship of the child with the parent (from the years available): biological/adopted
- Person's month of birth
- Information about cause of death (inc. ICD classification and place of death (home, hospital, etc.))

THL data:

- Register of periods of care and outpatient visits in public health care from 1969–2019
- Register of periods of care and outpatient visits in primary health care from 2010–2020
- Register of periods of care and outpatient visits in social services from 1995–2018
- Medical birth register data
- Social assistance register data
- Child welfare register data

Information about social security benefits of Kela

- Recipients and payments of housing allowance for pensioners

- Recipients and payments of general housing allowance
- Pension assistance benefits paid out by Kela
- Recipients of pension assistance of Kela
- Recipients and payments of rehabilitation assistance, supplemented with basic data
- Recipients and rehabilitation allowance benefits paid out
- Maternity grant payments
- Child benefit payments
- Child care allowance payments
- Parental allowances payments
- Child support payments
- Government guarantees of student loans
- Student financial aid payments
- Decisions for basic social assistance
- Social assistance notifications and supplementary social assistance applications sent by Kela to municipalities
- Basic social assistance payments
- Households receiving basic social assistance
- Recipients of basic social assistance (persons)
- Basic social assistance for bills (bills paid on behalf of the customer and processed vouchers)
- Information on decisions for basic social assistance by benefit periods
- Information on decisions for basic social assistance by members of a household
- Information about income regarding decisions for basic social assistance
- Information about expenses regarding decisions for basic social assistance
- Duration of periods of sickness allowance that have started
- Sickness allowance payments
- Recipients of sickness allowance
- Rights for reimbursements for medicine expenses
- Dispensed medicines reimbursed under the National Health Insurance scheme
- Doctor's fees per treatment
- Reimbursement for medical expenses
- Examination and treatment, by treatment or procedure
- Doctor's fees by speciality
- Reimbursement for medical expenses (inc. medicines) per item
- Recipients of special care allowance
- Information about payments of unemployment benefit
- Insurance periods
- Recipients of disability allowances
- Disability allowance payments

Biobank:

- Genetic risk scores from THL population surveys (FinHealth 2017, FINRISK, Health 2000/2011)

11. Sources of personal data collected

Registers of Statistics Finland, Kela and THL, and Biobank's data

12. Transfers or disclosure of data outside the research team

The data is available to the research team in the Fiona remote access environment of Statistics Finland. Data is not disclosed outside the Fiona system.

13. Transfers or disclosure of data outside of the EU or the European Economic Area

Data will not be transferred.

14. Automated decision making

Automated decisions will not be made.

15. Principles of personal data protection

Data are confidential.

Protection of manual data: Manual data are not used in the research

Data processed in information systems:

username password user registration access control
 other, please specify:

Processing of direct identifiers:

Direct identifiers will be erased during the analysis
 The data is analysed with direct identifiers because (justification for storing direct identifiers):

16. Processing of personal data after finishing the research

Research register will be destroyed
 The research register will be archived:
 without identifiers with identifiers

Where the data is archived and for how long:

17. Data subject's rights and their possible restrictions

Data protection legislation guarantees the research subject certain rights to ensure their protection of privacy under the basic rights. **If the research subject wishes to exercise their rights, please contact:**

Name: Outi Sirniö

Address: Finnish Institute for Health and Welfare, Mannerheimintie 166, Helsinki

Telephone number: +358 29 524 7964

E-mail: outi.sirnio@thl.fi

Withdrawal of consent (GDPR Article 7)

You have the right to withdraw your consent when the processing of personal data is based on consent. The withdrawal of consent shall not affect the lawfulness of processing based on consent before its withdrawal.

Right to access (GDPR Article 15)

You have the right to be informed whether your personal data are being processed in the research and which of your personal data are being processed. You can also request a copy of the personal data that is being processed.

Right to rectification (GDPR Article 16)

If there are inaccuracies or errors in your personal data that is being processed, you have the right to request that information is corrected or added.

Right to erasure (GDPR Article 17)

You have the right to request 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 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.

Exceptions to rights

On the basis of data protection legislation, there may be exceptions to the rights described in the section **17 What rights do you have and any exceptions to the rights**, insofar as the rights impede or seriously complicate the achievement of scientific or historical research or statistical purposes. The need to deviate from these rights is always assessed on a case-by-case basis.

Right of appeal

You have the right to file a complaint with the Office of the Data Protection Ombudsman if you find that the processing of your personal data has violated current data protection legislation.

Contact information:**Office of the Data Protection Ombudsman**

Street address: Lintulahdenkuja 4, 00530 Helsinki

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

Switchboard: 029 56 66700

Fax: 029 56 66735

E-mail: tietosuoja@om.fi