

1. Data Controller

Finnish Institute for Health and Welfare (THL)
P.O. Box 30, FI-00271 Helsinki, Finland

Institute for Molecular Medicine Finland (FIMM)
P.O. Box 20, FI-00014 University of Helsinki

Contact person in matters concerning the project:

Research Professor Markus Perola
Finnish Institute for Health and Welfare (THL)
P.O. Box 30, FI-00271 Helsinki
Tel.: +358 29 524 8727
E-mail: finregistry(at)thl.fi

2. Description of the study and the purposes of processing personal data

FinRegistry is a scientific, purely register-based research conducted by Finnish Institute for Health and Welfare (THL) and Institute for Molecular Medicine Finland (FIMM).

Aim of the project is to leverage nation-wide health and other supporting registry data to explore comprehensive risk trajectories of disease outcomes and use this information to derive outcome-specific prediction models. However, this research question can't be defined within a traditional epidemiological framework that pre-specifies one exposure and one outcome because this project is inherently unbiased and limiting it to only one exposure and one outcome will substantially reduce the potential for discovering novel relationships of clinical relevance. This project will use the complex relationship between health outcomes, medications, socio-demographic information and familial risk to provide new epidemiological and biological hypotheses that can then be directly followed up with more targeted studies. Research group hypothesize that many adverse health outcomes share common risk factors (e.g. mother health and socioeconomic status during pregnancy later having an effect to the child's health) and might form compound outcomes, independent from the established disease taxonomy (International Classification of Diseases, ICD). These compound outcomes possibly built over decades of follow-up and multiple conditions are expected to better describe the biological background of diseases compared to a single disease status. Hypothesis is that the combination of multiple diseases and medications can provide better predictions of the first occurrence of diseases than a traditional model based on a limited set of diseases and risk factors and reveal new epidemiological and biological insights.

3. Parties and their responsibilities in research collaboration

Finnish Institute for Health and Welfare (THL) and Institute for Molecular Medicine Finland (FIMM) will conduct the study as a scientific collaboration. During the course of the study THL is in particular responsible of data linkage and de-identification whereas FIMM is responsible of the analytical and methodological aspects of the project.

4. Principal investigator

Markus Perola, MD, PhD, Research Professor
Finnish Institute for Health and Welfare (THL)
P.O. Box 30, FI-00271 Helsinki
Tel: +358 29 524 8727
E-mail: finregistry(at)thl.fi

5. Contact details of the Data Protection Officer

E-mail address of THL's Data Protection Officer is tietosuoja(at)thl.fi.

6. Persons processing personal data in the study

Personal data will be processed by authorized researchers at Finnish Institute for Health and Welfare (THL) and Institute for Molecular Medicine Finland (FIMM). All researchers have an approval from register authorities to access the research data.

THL's research processor Markus Perola is in charge of the research group. Dr. Andrea Ganna leads FIMM's research group. Contact information:

Markus Perola, MD, PhD, Research Professor
Finnish Institute for Health and Welfare (THL)
P.O. Box 30, FI-00271 Helsinki
Tel: +358 29 524 8727
E-mail: finregistry(at)thl.fi

Dr. Andrea Ganna, Team Leader
Institute for Molecular Medicine Finland (FIMM)
P.O. Box 20, FI-00014 University of Helsinki

7. Name, nature and duration of the study

Name of the study: FinRegistry

One-time research Monitoring study/longitudinal study

Duration of the processing of personal data: The project duration is from the acquisition of registry data until December 2025.

8. Lawful basis of processing

Personal data is processed on the following basis, which is based on Article 6(1) of the General Data Protection Regulation:

- participant's consent
- compliance with a legal obligation to which the controller is subject
- performance of a task carried out in the public interest or in the exercise of official authority vested in the controller:
 - scientific or historical research purposes or statistical purposes
 - archiving of research materials or cultural heritage materials
- legitimate interests pursued by the controller or by a third party
description of the legitimate interest:

9. Personal data included in the research materials

The data from various registers will be linked using personal identity codes and then pseudonymized with a random key. Pseudonymization key will be stored separately at THL.

Research data includes all the individuals that live in Finland and are alive the 1st of January 2010 (index person) and index person's parents, spouses, children, and siblings. The relatives do not need to be alive on the 1st of January 2010.

Description of the research data is available at project's website. In addition, detailed description of the research data is available upon request from THL's contact person Markus Perola (contact information in section 1 of this notice).

The research data includes information from the following registries:

- Finnish Institute for Health and Welfare (THL)
 - Care Register for Health care
 - Register of Primary Health Care visits
 - Cancer Register
 - Care Register for Social Welfare
 - Medical Birth Register
 - Register of Social Assistance
- Digital and Population Data Services Agency (DVV)
 - Identification of research subjects, basic personal information, living history, marriage history, relatives
- Finnish Centre for Pensions
 - Earnings register
 - Pension register
- Statistics Finland (Tilastokeskus)
 - Cause of Death Register
 - Information on education, job occupation and socioeconomic status
- Social Insurance Institution of Finland (KELA)
 - Drug Reimbursement Register

- Drug Purchases Register
- Kanta Prescription Centre and Prescription Archive
- Kanta laboratory values

10. Sensitive personal data

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

- Racial or ethnic origin
- Political opinions
- Religious or philosophical beliefs
- Trade union membership
- Genetic data
- Biometric data for the purpose of uniquely identifying a natural person
- Health
- A natural person's sex life or sexual orientation

Sensitive data is processed on the following basis, which is based on Article 9(2) of the General Data Protection Regulation:

- Consent of the participant
 - Scientific or historical research purposes or statistical purposes
 - The sensitive data has been made public by the participant
 - Other: *Please clarify*
- Persona data relating to criminal convictions and offences or related security measures will be processed in the study.

11. Sources of personal data

The research data specified in section 9 of this notice are collected from registries of

- Finnish Institute for Health and Welfare (THL)
- Digital and Population Data Services Agency (DVV)
- Statistics Finland (Tilastokeskus)
- Social Insurance Institution of Finland (KELA)

12. Transfer and disclosure of the personal data to third parties

Personal data will not be transferred or disclosed to third parties. Only approved members of the research group have access to the research data.

13. Transfer or disclosure of personal data to countries outside the EU/European Economic Area

Personal data will not be transferred or disclosed outside of the EU/EEA.

14. Automated decisions

No automated decisions will be made.

15. Safeguards to protect the personal data

The data is confidential.

Protection of manual material:

Personal data processed in IT systems:

username password logging access control

other: *(please specify)*

Processing of direct identifiers:

Direct identifiers will be removed in the analysis phase

The material to be analysed includes direct identifiers. Reason: *(reason for retention of direct identifiers)*

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

The research material will be deleted

The research material will be archived:

without identifiers with identifiers

17. Your rights as a data subject and deviations from the rights

The contact person in matters concerning the rights of the participant is the person mentioned in section 1 of this notice.

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

If the processing of your personal data is based on your consent, you have the right to withdraw your consent. The withdrawal of consent does 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 personal data concerning you is processed, and, where that is the case, what data is processed. You may also request a copy of the personal data undergoing processing.

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

You have the right to obtain rectification of inaccurate personal data.

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

You have the right to obtain erasure of your personal data where one of the following grounds applies:

- a) the personal data are no longer necessary in relation to the purposes for which they were collected or otherwise processed
- b) you withdraw consent on which the processing is based
- c) you object to the processing pursuant to (please see 'Right to object' below) and there are no overriding legitimate grounds for the processing
- d) the personal data have been unlawfully processed
- e) the personal data have to be erased for compliance with a legal obligation in Union or Member State law to which the University is subject

However, you have no right of erasure if such erasure is likely to render impossible or seriously impair the achievement of the objectives of the processing.

Right to restriction of processing (Article 18 of the General Data Protection Regulation)

You have the right to obtain restriction of processing where one of the following applies:

- a) the accuracy of the personal data is contested by you, for a period enabling the controller to verify the accuracy of the personal data
- b) the processing is unlawful and you oppose the erasure of the personal data and request the restriction of their use instead
- c) the controller no longer needs the personal data for the purposes of the processing, but they are required by you for the establishment, exercise or defence of legal claims
- d) you have objected to processing pending the verification whether the legitimate grounds of the controller override those of the data subject.

Right to data portability (Article 20 of the General Data Protection Regulation)

Where the lawful basis of your personal data is your consent or performance of a contract to which you are party, and the processing of personal data is carried out by automated means, you have the right to receive the personal data concerning you, which you have provided to the University, in a structured, commonly used and machine-readable format and have the right to transmit those data to another controller.

In exercising this right, you have the right to have the personal data transmitted directly from one controller to another, where technically feasible.

Right to object (Article 21 of the General Data Protection Regulation)

You have the right to object to processing of personal data concerning you if the lawful basis of processing is the performance of a task carried out in the public interest or in the exercise of official authority or the legitimate interests pursued by the controller or by a third party. In that case, the University may no longer process the personal data unless it demonstrates compelling legitimate grounds for the processing which override the interests, rights and freedoms of the data subject or for the establishment, exercise or defence of legal claims. The University may also continue the processing of your personal data where processing is necessary for the performance of a task carried out for reasons of public interest.

Deviation from the rights

The rights described in this section may be deviated from in certain situations to the extent the rights would render impossible or seriously impair the achievement of the objectives of processing personal data for scientific or historical research purposes or statistical purposes.

The grounds for deviation are set forth in the General Data Protection Regulation and the Finnish Data Protection Act. The necessity of deviating from the rights will always be evaluated on a case by case basis.

Right to lodge a complaint

You have the right to lodge a complaint with the Data Protection Ombudsman's Office if you think your personal data has been processed in violation of applicable data protection laws.

Contact details:

Data Protection Ombudsman's Office (Tietosuojavaltuutetun toimisto)

Address: Ratapihantie 9, 6th floor, 00520 Helsinki

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

Tel. (switchboard): 029 56 66700

Fax: 029 56 66735

E-mail: tietosuoja(at)om.fi