PRIVACY POLICY/NOTICE FOR SCIENTIFIC RESEARCH

EU General Data Protection Regulation

Art. 13 and 14

Date: 06.11.2024

1. Data Controller

Tampere University Foundation sr, operating as Tampere University Faculty of Social Sciences, Kalevantie 4 33100

University of Helsinki, Institute for Molecular Medicine Finland, FIMM, Yliopistonkatu 3 (P.O. Box 4), FI-00014 University of Helsinki, Finland,

Aalto University foundation sr. School of Science, department of Computer Science, Box 11000, 00076 Aalto, Finland

Finnish Institute for Heatlh and Welfare, Mannerheimintie 166, 00300 Helsinki (P.O. Box 30),

Contact person in matters concerning the project:

Jari Koistinaho

E-mail: jari.koistinaho@helsinki.fi

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

The aim of this study is to analyse drug prescription patterns in Finland and investigate factors that associate and interact with these patterns, and with subsequent health outcomes of patients.

This is a nationwide cohort study linking data from multiple Finnish health registers. We include all individuals alive and residing in Finland on 01-01-2000 as well as individuals born after the inclusion date. Using the unique identification numbers, the source population is linked with their sosiodemographic data, healthcare episodes and drug purchases. Each drug prescription and drug purchase includes a registration number which is an identification number of the prescriber. We use the registration number to identify prescriptions on physician-level, and further, by utilizing Terhikki register, link the registration with physician's SSN. The linkage enables us investigating physician's background and the correlates of their prescription behavior in detail.

Prescription patterns and trends across specialties, sectors, practice types, and regions will be analyzed to identify suboptimal prescriptions. Physician-level factors such as socioeconomic

background, medical history, major life events, and specialty will be examined to understand the correlates of their prescription behavior. Interactions and shared relationships between physician and patient characteristics will also be studied.

The results will provide insight into the appropriateness of drug prescriptions in Finland and their impact on patient outcomes, highlighting the importance of leveraging both patient and doctor characteristics when studying prescription and disease patterns in the population.

3. Parties and their responsibilities in research collaboration

Each data controller is for its part responsible for ensuring that it processes personal data in accordance with valid Data protection legislation, the Agreement, requirements in Data Protection Terms and possible consents related to the processing of personal data. The Party processing personal data shall ensure for its part that the personal data processed are minimised, the data are accurate and kept up to date as appropriate.

Each data controller and associated researchers have access to all data. However, the researchers access, process and link only those data files that are needed to address their research questions.

4. Principal investigator

UH: Jari Koistinaho, University of Helsinki, jari.koistinaho@helsinki.fi

TAU: Anna-Leena Vuorinen, Tampere University, anna-leena.vuorinen@tuni.fi

Aalto: Sami Kaski, Aalto University, sami.kaski@aalto.fi

THL: Markus Perola, markus.perola@thl.fi

5. Contact details of the Data Protection Officer

Contact at University of Helsinki: tietosuoja@helsinki.fi.

Contact at Tampere University: dpo@tuni.f

6. Persons processing personal data in the study

Personal data will be processed by authorized researchers at the University of Helsinki, Tampere University, Aalto University and THL. All researchers have been approved by FinData and Statistics Finland.

Anna-Leena Vuorinen, Institute for Molecular Medicine Finland, University of Helsinki Tuomo Hartonen, Institute for Molecular Medicine Finland, University of Helsinki Pekka Vartiainen, Institute for Molecular Medicine Finland, University of Helsinki Zhiyu Yang, Institute for Molecular Medicine Finland, University of Helsinki Lisa Eick, Institute for Molecular Medicine Finland, University of Helsinki Essi Viippola, Institute for Molecular Medicine Finland, University of Helsinki Jakob German, Institute for Molecular Medicine Finland, University of Helsinki Kira Detrois, Institute for Molecular Medicine Finland, University of Helsinki Matteo Ferro, Institute for Molecular Medicine Finland, University of Helsinki Andrea Corbetta, Institute for Molecular Medicine Finland, University of Helsinki Kristina Zguro, University of Helsinki Bharti Ayush, Aalto University Wharrie Sophie, Aalto University Holanda De Souza Junior Amauri, Aalto University Mäkinen Lotta, Aalto University Loría Jorge, Aalto University Neill Booth, Tampere University Maria Seppänen, Tampere University Manela Karunadasa, Tampere University Tuomas Natukka, Tampere University Janina Hansas, Tampere University Peter Csonka, Tampere University Rida Batool, Tampere University Tero Aittokallio, Institute for Health and Welfare

7. Name, nature and duration of the study

Name of the study: Drug prescriprofessionals and their patients	ption and disease patterns among Finnish health care	
☑ 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 31.12.2028		

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
\square compliance with a legal obligation to which the controller is subject
\Box 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
\square 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 by FinData

Research data includes all the individuals that live in Finland and are alive the 1st of January 2000 and everyone born after this date.

The research data includes information from the following registries:

- Finnish Institute for Health and Welfare (THL)
 - Care Register for Health care (Hilmo)
 - Register of Primary Health Care visits (AvoHilmo)
- Digital and Population Data Services Agency (DVV)
 - Identification of research subjects, basic personal information, living history, marriage history, relatives
- Statistics Finland (Tilastokeskus)
 - Cause of Death Register
 - Information on education, job occupation and socioeconomic status
- Social Insurance Institution of Finland (KELA)
 - Sairausvakuutuksesta korvattavat lääketoimitukset
 - Sairauspäivärahojen maksut
 - Kelan maksetut eläke-etuudet vuoteen 2019 asti
 - Kelan eläke-etuuksien saajat vuoteen 2019 asti
 - Kelan eläke-etuuksien saajat ja maksetut eläke-etuudet vuodesta 2020 alkaen
 - Lääkemääräykset (Kanta Reseptikeskus)
- Finnish Centre for Pensions
 - Pensions register: Earning-related pensions
 - Earnings register: Unpaid periods and benefit periods under VEKL
 - Earnings register: Pension-insured earnings
- National Supervisory Authority for Welfare and Health Valvira
 - Terveydenhuollon ammattihenkilöiden keskusrekisteri (Terhikki)

10. Sensitive personal data

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)
- Finnish Centre for Pensions
- National Supervisory Authority for Welfare and Health Valvira

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

Personal data is only accessible remotely via FinData compliant secure processing environment (SPE) (SD Desktop is used in this project) and cannot be transferred outside the SPE. Only authorized researchers of the research group at TAU, HU, Aalto or THL and further approved by Findata and Statistics Finland have remote access to the research data. SPE does not have internet connection. Researchers will remotely access the data only if they are located within the EU/EEA or a country with adequate personal data protection based on the European

Commission adequacy decision (Article 45 of the GDPR). Log data of each user in the SPE is saved and available through Findata.

Personal data will and cannot be transferred or disclosed to third parties.

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

Researchers will remotely access the data only if they are located within the EU/EEA or a country with adequate personal data protection based on the European Commission adequacy decision (Article 45 of the GDPR).

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 persona 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

APPENDIX		