



Date: 12.6.2024

Information for participants of the research project “Validation of register-based quality indicators towards safe and effective pharmacotherapy in the Nordic countries: An eDelphi study”

You are taking part in a scientific study conducted at the University of Turku. This notice describes how your personal data will be processed in the study.

1. Data Controller

University of Turku

Contact person in matters concerning the project:

Name: Katri Aaltonen

Address: INVEST Research Centre, FI-20014 University of Turku, Finland

Tel.: +358-50-475 5862

E-mail: katri.m.aaltonen@utu.fi

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

This study is a sub-project of a larger mixed-methods research project “Multilevel governance and decentralization of medicine budgets - Striving for quality and sustainability (MultiMed)”, funded by the Research Council of Finland (Grant Nr. 354657), led by Principal Investigator (PI) Katri Aaltonen at the University of Turku (INVEST Research Centre).

The aim of the eDelphi study is to select, following an expert-based consensus process, a set of relevant, valid, and actionable register-based indicators and definitions that provide a credible and comprehensive comparison of prescribing quality across and within the Nordic countries.

The personal data required for the research are the email addresses of the experts who answer the surveys as eDelphi panel members. The addresses are used to administer subsequent survey questionnaires to panellists. Expert panellists will answer the surveys in their professional role and remain anonymous to each other. To examine and describe the composition of the panel, background information about panellists’ education, professional background, country, and gender will be surveyed. Individuals may be identifiable based on the combination of background variables; thus, the data without direct identifiers are considered personal data. All results will be published in a manner that individual panellists cannot be identified.

3. Principal investigator or research group

Name: Katri Aaltonen

Address: INVEST Research Centre, FI-20014 University of Turku, Finland

Tel.: +358-50-475 5862

E-mail: katri.m.aaltonen@utu.fi

4. Contact details of the Data Protection Officer

The Data Protection Officer of the University of Turku is available at contact address: dpo@utu.fi.

5. Persons processing personal data in the study

Direct identifiers (names or email addresses of participants) will be processed only by the researchers working in project MultiMed at the University of Turku.



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Data without direct identifiers may be processed within the scope of the MultiMed project research plan by researchers working at University of Turku or MultiMed collaborating researchers at Uppsala University (Sweden), University of Southern Denmark, University of Copenhagen (Denmark), the Finnish Institute for Health and Welfare, the Finnish Medicines Agency, and the Social Insurance Institution of Finland. This also includes students that process the data under the supervision of the researchers working at the University of Turku or the collaborating researchers working in the aforementioned institutions.

All researchers processing personal data will be required to sign a non-disclosure agreement. In the case of data processing by collaborating researchers outside the University of Turku, an agreement on data use, including a Non-Disclosure Agreement (NDA), is made between University of Turku and the collaborating researchers.

6. Name, nature and duration of the study

Name of the study: Multilevel governance and decentralization of medicine budgets - Striving for quality and sustainability (MultiMed)

Duration of the processing of personal data: Direct identifiers will be deleted after the eDelphi study has ended, and the study report is published, or at latest by the end of the research project: 31.8.2027.

7. 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:

- ☐ data subject's consent;
- ☐ processing is based for the performance of a contract;
- ☐ compliance with a legal obligation to which the controller is subject;
- ☐ processing is necessary in order to protect the vital interest of the data 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 interest pursued by the controller or by a third party.

8. Personal data included in the research materials

The personal data required for the research are the email addresses of the expert panel members. Email addresses are used only to administer survey questionnaires to panellists. Data will be analysed without direct identifiers.

To examine and describe the composition of the panel, background information about panellists' education, professional background, country, and gender will be surveyed. Individuals may be identifiable based on the combination of background variables; thus, the raw data without direct identifiers are considered personal data. All results will be published in a manner that individual panellists cannot be identified. The composition of the panel will be reported only in the form of aggregate descriptive statistics.

9. Sensitive personal data

No sensitive personal data will be processed in the study.



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10. Sources of personal data

Potential participants to be invited as Delphi panellists will be identified from the literature (authors of relevant publications), by contacting relevant organisations, and/or through the professional networks of the study team. Potential participants will be sent an email invitation to participate the survey. Lists of potential participants will not be kept. Snowballing techniques may be used to recruit participants (contacted experts may recruit other experts).

The experts who provide their explicit consent to participate the survey will form the eDelphi panel. Research data consists of panel members' answers to the electronic survey questionnaires. Participants will be asked for email address as part of the survey, to administer the questionnaires of subsequent eDelphi rounds to the same panellists.

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

The personal data will be transferred to following recipients outside the University of Turku/research group/researcher:

The research data without direct identifiers may be transferred to MultiMed collaborating researchers working at Uppsala University (Sweden), University of Southern Denmark, University of Copenhagen (Denmark), the Finnish Institute for Health and Welfare, the Finnish Medicines Agency, and the Social Insurance Institution of Finland, who process data within the scope of the MultiMed project research plan. In the case of data transfers, an agreement on data use, including a Non-Disclosure Agreement (NDA), is made between University of Turku and the collaborating researchers.

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

Personal data will not be transferred outside the EU/ European Economic Area.

13. Automated decisions

No automated decisions are made.

14. Safeguards to protect the personal data:

☒ The data is confidential.

☐ Protection of manual material:

No manual material will be used.

☒ Personal data processed in IT systems:

The personal data are processed within the University of Turku IT infrastructure, technically administered by the University IT Services, including backups, access control limited to project researchers, passwords, and security. Data transferred to collaborating researchers will be processed within their institutional IT infrastructures with similar safeguards. Secure transfers will be conducted according to the instructions of University of Turku IT Services.

☐ other: Not applicable.

Processing of direct identifiers:

☒ Direct identifiers will be removed in the analysis phase

☐ The material to be analysed includes direct identifiers.

Reason: Not applicable.



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

The research material will be archived:

- ☒ without identifiers
☐ with identifiers

Where will the material be archived and for how long: The anonymised survey data of respondents who explicitly consent to data archiving will be permanently archived and made openly available through the Finnish Social Science Data Archive (FSD). Direct identifiers and data from respondents that do not consent to data archiving will be destroyed at latest at the end of the research project MultiMed (31.8.2027).

16. Your rights as a data subject, and exceptions to these rights

For more details about their rights according to General Data Protection Regulation (GDPR), the participants can contact:

Name: Katri Aaltonen
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Tel.: +358-50-475 5862
E-mail: katri.m.aaltonen@utu.fi

Exceptions to data subject rights

Under the General Data Protection Regulation and the Finnish Data Protection Act, certain exceptions to the rights of data subjects can be made when personal data is processed in scientific research and fulfilling the rights would render impossible or seriously impair the achievement of the objectives of the processing (in this case, scientific research).

The need to make exceptions to the rights of data subjects will always be assessed on a case by case basis. It is likely that exceptions to the following rights will be necessary in this study:

- ☐ Right of access (GDPR Article 15)
- ☐ Right to rectification (GDPR Article 16)
- ☐ Right to erasure (GDPR Article 17)
- ☐ Right to restriction of processing (GDPR Article 18)
- ☐ Right to data portability (GDPR Article 20)
- ☐ Right to object (GDPR Article 21)

Reasons and the extend for the exceptions: Not Applicable

Right to lodge a complaint

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

Contact details of Data Protection Ombudsman:

Office of the Data Protection Ombudsman
Visiting address: Lintulahdenkuja 4, 00530 Helsinki
Postal address: P.O. Box 800, 00531 Helsinki, Finland



**UNIVERSITY
OF TURKU**

5 (5)
**PRIVACY NOTICE FOR
SCIENTIFIC RESEARCH
EU General Data Protection
Regulation Art. 13 and 14**

Date: 12.6.2024

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