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## Plan Overview

*A Data Management Plan created using DMPTuuli*

**Title:** Multilevel governance and decentralization of medicine budgets - Striving for quality and sustainability (MultiMed)

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**Template:** Academy of Finland data management plan guidelines (2021-2023)

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**Project abstract:**

This project, conducted at the University of Turku in collaboration with Uppsala university, aims to understand how governance mechanisms are connected with variation in costs for medicines, equality and quality of prescribing. The project produces novel policy-relevant evidence through comparison of Swedish regions. Sweden has decentralized medicine budgets and management, and regions have developed various strategies to promote sustainable use of medicines. The project 1) evaluates the validity of prescribing quality indicators and their applicability in the Nordic healthcare context using systematic review and Delphi method, 2) examines and compares regional variation in prescribing quality, costs and equity in medicine use across regions in Sweden and Finland using register data, 3) explores governance models across Swedish regions using interviews and considers the connection between governance models and variation in medicine use using comparative qualitative analysis (QCA).

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# Multilevel governance and decentralization of medicine budgets - Striving for quality and sustainability (MultiMed)

## 1. General description of data

### 1.1 What kinds of data is your research based on? What data will be collected, produced or reused? What file formats will the data be in? Additionally, give a rough estimate of the size of the data produced/collected.

This is version 2.0 of the DMP (Version 1.0 created outside Tuuli).

For systematic scoping review (**WP1**), data includes collected published literature with literature database records, and produced data: protocol, data extracted from the literature, and description of methods. For Delphi-survey (**WP1**), data includes survey data and informed consent forms collected from participants, administrative documents (information for participants, Privacy Notice of Processing Personal Data), and participant lists for survey administration. For register studies (**WP2**) data includes secondary individual-level register data acquired from national institutional data holders. For **Finland**, **INVEST full population data** includes Statistic Finland's population register data with population characteristics, Finnish Institute for Health and Welfare's (THL) care registers for health care (Hilmo, AvoHilmo), and Social Insurance Institution's (Kela) prescription register data. **Swedish** data, acquired in collaboration with Uppsala University (UU) includes National Board of Health and Welfare's National Patient Register, the National Prescribed Drug Register, and data on population characteristics from Statistics Sweden (SCB). For interview-study (**WP3**) collected data includes interview recordings and informed consent forms collected from participants, and produced data includes verbatim transcripts of recordings, administrative documents, and participant lists for interview administration. Further collected data includes regional-level aggregated public statistics and policy documents (**WP2&3**).

Data type	File format, size	Sensitivity	Owner	Opening	Long-term storage / archiving
Published literature	.pdf, BibTeX <10GB	No	Publishers	No	No
Literature synthesis & documentation	.doc, .xlsx <10MT	No	UTU	Metadata, protocol, methods	Publications, OSF
Secondary register data	.csv, .dta, .sas7bdat >100GB	Yes, pseudonymised, sensitive health information	Institutional data holders	Metadata, syntax	OSF, Github
Administrative documents, participants	.csv, .pdf	Identifiable non-sensitive personal information	UTU/UU	No	No
Delphi-survey	.cvs, .xlsx, .docx <10MB	Pseudonymised non-sensitive personal information	UTU	Anonymised data, metadata	Finnish Social Science Data Archive
Interview recordings	.avi, .mp4 >10GB	Identifiable non-sensitive personal information	UU	No	No
Interview transcripts	.csv, .txt, .xlsx, .pdf <10MB	No, anonymised	UU/UTU	Anonymised data, metadata	Finnish Social Science Data Archive
Policy documents, public statistics	.pdf, .csv, .xlsx, .dta, .pdf <100MB	No	Publishers	Metadata, methods	Publication, OSF

UU= Uppsala University, UTU=University of Turku, OSF=Open Science Framework

### 1.2 How will the consistency and quality of data be controlled?

Formal version control is applied for all types of data. Original/raw data are kept separately to ensure that the accuracy of data is maintained and no data are accidentally changed. All users of data will be trained to implement quality control. Scoping review (WP1) is conducted in accordance with PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) and using a reference management software. Web survey (WP1) is conducted using RedCAP available at the University of Turku, with log of all actions performed to the data. All quantitative data handling and analyses will be conducted using log files. Interview transcriptions (WP3) will be made using OpenAI's Whisper, an automatic speech recognition system available in a closed system Bianca at Uppsala University. All transcripts are checked by a project researcher.

## 2. Ethical and legal compliance

### 2.1 What legal issues are related to your data management? (For example, GDPR and other legislation affecting data processing.)

Data Protection is based on legal obligations as described in the EU General Data Protection Regulation (GDPR) and local Law, and as set forth in the Data Protection policies of participant and host institutions. The PI will fully commit to the principles of responsible conduct of research of the Finnish

Advisory Board on Research Integrity and the ALLEA's European Code of Conduct for Research Integrity. Ethical review statements will be sought for each subproject from the Ethics Committee for Human Sciences at the University of Turku and from the Swedish Ethical Review Agency in collaboration with UU. Permissions to use secondary register data (WP2) are applied for from the relevant national authorities, and used in compliance to their instructions and policies, with Data Protection Impact Assessment (DPIA) as part of the process. The data includes identifiable and sensitive personal data. The processing basis for register data is scientific research, in which case informed consent is not required according to Finnish and Swedish legislation. Data are pseudonymised by data holders or upon receipt and all data handling and analyses are conducted with pseudonymised data. The processing basis of survey (WP1) and interview (WP3) data is subject's freely given, specific, informed and unambiguous consent. Minimal data on participants is collected, and all results are reported in a manner that does not allow identification of individuals. Lists of participants for survey and interview administration include identifiable non-sensitive personal information and are kept separately from other data, and deleted after data collection and verification processes. Privacy Notice of Processing Personal Data is given to all participants. Survey data are anonymised for handling. Interview recordings will be deleted once transcripts have been produced and checked for consistency. The anonymisation and/or removing of sensitive data for data archiving are performed according to the instructions of Finnish Social Science Data Archive (FSD).

## **2.2 How will you manage the rights of the data you use, produce and share?**

Data collected and created during the project is owned by UTU. For data collected and used in collaboration with UU and UTU (WP3), a written agreement on the rights and licencing of data has been made. For each subproject, the tasks, responsibilities, rights and authorship are agreed upon in project meetings before initiating the subproject. Permission to share anonymised survey and interview data openly will be asked from participants as part of the informed consent. Open access is granted to reports, replication codes, anonymised data, metadata, scientific publications and other publications using as broad user licenses as possible, typically CC BY 4.0.

## **3. Documentation and metadata**

### **3. How will you document your data in order to make the data findable, accessible, interoperable and re-usable for you and others? What kind of metadata standards, README files or other documentation will you use to help others to understand and use your data?**

Versioning is used for all files, supported by, e.g., GitHub, and continuously updated README-files in storage root and each sub-folder, with descriptions of naming conventions, purpose and files in that storage organisation level. **WP1&WP3:** The questionnaires, codebooks, and descriptions of data collection methods (when, where, why, and how the data were collected and processed) will be documented to make them findable, accessible, interoperable, and reusable for other researchers. The metadata that contains this information will be described in accordance to the instructions by FSD, including metadata using the Data Documentation Initiative (DDI) standard. **WP2:** The institutions that manage secondary register data provide the general description of data (e.g., metadata), questionnaire, codebook, and user guides on their websites. For all analyses, the annotated syntax will be made openly available.

## **4. Storage and backup during the research project**

### **4.1 Where will your data be stored, and how will the data be backed up?**

Anonymised data and project documents are stored on project network storage spaces (e.g., Taltio network drives, Seafile cloud services) provided and technically administered by UU/UTU, including backups, access control limited to project researchers, and security. Study researchers are responsible for keeping and handling data on storage spaces with institutional backup processes. In case of sensitive data transfers within institutions, UTU/UU IT Services are consulted to ensure secure transfer. Original/raw data, participant lists, and scanned informed consent forms are stored on a separate secure storage space at UTU/UU. The Finnish register data are stored and used in the validated GDPR compliant remote system Fiona of Statistics Finland with appropriate backup procedures. The Swedish register data are stored and handled only in the institutional secured IT environment (Argos, Vesta) of UU in compliance with institutional Data Protection policies. Interview recordings will be stored and handled only in the institutional secured IT environments (Argos, Vesta, Bianca) of UU in compliance with institutional Data Protection policies.

### **4.2 Who will be responsible for controlling access to your data, and how will secured access be controlled?**

Right to access the data is controlled by responsible researcher (PI Katri Aaltonen, University of Turku), and technical access control is provided by the IT departments of UU/UTU, and in the case of Finnish register data, Statistics Finland, with the support of INVEST data infrastructure InREG at UTU. All project data on University servers have access control limited to project researchers with appropriate permissions to use data. Right to access data jointly controlled by UTU and UU is controlled by PI Katri Aaltonen and/or Professors Björn Wettermark/Sofia Kälvemark Sporrong in accordance to the Swedish Ethical Approval. Access to data will be documented and PI will be at any point able to tell who has access to what data.

## 5. Opening, publishing and archiving the data after the research project

### 5.1 What part of the data can be made openly available or published? Where and when will the data, or its metadata, be made available?

**WP1&3:** Informed consent permitting, anonymised survey data and interview transcriptions, together with appropriate metadata, will be made openly available through FSD by the end of 2027. **WP2:** Annotated syntax will be made openly available upon publication of each scientific research article.

### 5.2 Where will data with long-term value be archived, and for how long?

Anonymised survey data and interview transcriptions are permanently archived at the FSD (certified Core Trustworthy Data Repository). Manuscripts are made permanently accessible through the INVEST working paper series in the OSF pre-print repository with persistent identifier (DOI) and replication codes via Github, with persistent identifier (DOI) through Zenodo. Jointly controlled Swedish data are archived at UU in compliance to Swedish law.

## 6. Data management responsibilities and resources

### 6.1 Who (for example role, position, and institution) will be responsible for data management?

The overall data management responsibility, including DMP implementation and annual review during the project life cycle lies on the PI (Katri Aaltonen, University of Turku), who is responsible in ensuring that researchers working with project data have applied appropriate permissions, and are committed to using data as per legal obligations, ethical guidelines, and institutional data protection policies of participant and host institutions. Data management at UU is the joint responsibility of the PI and UU partners as per the agreement between UU and UTU. The PI will consult with the IT Services at UTU/UU to manage, preserve, and share the data. The PI is also responsible for the agreements on roles and responsibilities related to collaboration with UU. Data management is supported by the INVEST InREG data infrastructure at UTU.

### 6.2 What resources will be required for your data management procedures to ensure that the data can be opened and preserved according to FAIR principles (Findable, Accessible, Interoperable, Re-usable)?

The budget for data acquisition, management and remote use, as well as interview administration and transcription services are included in the research plan. Data management is part of the tasks of the PI and researchers working on the project, the salaries of whom are included in the research plan. The project benefits from the support of INVEST data infrastructure InREG at UTU, including INVEST Working Papers pre-print repository through OSF, and INVEST GitHub, with no additional costs required. Data archiving and support at FSD are offered to researchers free of charge.