

1. Title, nature and duration of research

Title of research: Gendered Chronic Disease, Embodied Differences and Biomedical Knowledge (Gen-Dis)

- Case study
 Follow-up study

Duration of research: 1 January 2021 – 31 December 2026

Duration of data processing: With the written consent of the participants, the personal details will be stored at the Faculty of Social Sciences at Tampere University for 15 years after the end of the project to enable a potential longitudinal study and follow-up studies. After this, the personal details will be destroyed. If the participants do not consent to the storage of their personal details beyond the duration of this project, their personal information will be destroyed at the end of the project. With the written consent of the participants, researchers within the project can continue to use the pseudonymised research data for the study of chronic illness after the end of the project. This facilitates comprehensive analysis of the data and the completion of research publications.

2. Data controller

- Research will be conducted in an employment contract with the Tampere University, indicating the University to be the data controller.

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3. Contact person regarding the research registry

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4. Contact information of the Data Protection Officer

Email: dpo@tuni.fi

5. Principal investigator

Name: Venla Oikkonen
Address: 33041 Tampere University
Phone number: 0504377616
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6. Researchers

Venla Oikkonen (principal investigator), Henni Alava, Ahalya Ganesh, Elina Helosvuori, Mianna Meskus, Lilli Aini Rokkonen, Maria Temmes and a researcher potentially recruited during the project.

7. Content of research records

For interviews with people living with a chronic health condition, the following personal information may be included in the research records: name, contact information, age and duration of symptoms. For interviews with people working professionally in a position relevant for the treatment of chronic diseases, the following personal information may be included in the research records: name, contact information and professional role. The personal information in the research records can be connected to the interview recordings and transcripts only through a numerical code. Only the principal investigator and the interviewing researcher have access to a participant's numerical code. The only exception is if a professional working in a public role wishes to be referred to with their real name. Personal information is saved in a secure location (password-protected external hard drive) separately from interview transcripts or audio recordings. Personal information will be collected and processed only with the consent of the participants and there is no legal or contractual requirement for providing personal data.

8. Purpose of processing personal data

The purpose of processing personal data is scientific research. The objective of the project is to understand how gendered chronic conditions such as endometriosis, fibromyalgia, hormonal migraine and chronic fatigue syndrome are treated and how people involved in their care view the challenges of gaining and providing effective treatment. In addition, the project aims to understand how ongoing societal changes such as global disruptions in the availability of pharmaceutical products and rationalisation and personalisation of medicine affect the treatment of gendered chronic conditions. In order to reach these objectives, the project conducts interviews with people living with a gendered chronic condition, patient advocates, clinicians, biomedical researchers and policy makers. The project also collects written accounts of experiences of living with a chronic condition. These texts are submitted anonymously through an online form.

For interviews with people with a chronic condition and the written accounts of illness experience, information about age and duration of symptoms is used to understand how the described illness experience relates to different life events and different stages of treatment. For interviews with people working in a professional or public position, information about professional role is used to situate the interview within the broader field of expertise on chronic diseases. In research publications, the afore-

mentioned identifiers (age, duration of illness / professional role) are replaced with more general categories: broad age groups are used instead of precise age, detailed job titles are replaced with a more general description (e.g., general practitioner, nurse). This information is used only when relevant for the analysis.

9. Lawful basis for processing personal data

The lawful basis for processing under the EU's General Data Protection Regulation, Article 6 Paragraph 1, and the Personal Data Act, Section 4:

- Public interest or the exercise of official authority
 - Scientific or historical research purposes or statistical purposes
 - Archiving of materials relating to research or cultural
- Consent
- Legal obligation of the data controller
- Legitimate interests of the Data Controller or a third party
- Other, please specify:

10. Sensitive personal data (special categories of data and criminal records)

- No sensitive personal data will be processed during the research project
- The following types of sensitive personal data may emerge in the interviews if the participant wishes to discuss them. The participants decide how much personal data they share. These types of sensitive data are not collected specifically, and personal details mentioned in the interviews are not stored in the research records that contain the participant's name.
 - Racial or ethnic origin
 - Political opinions
 - Religious or political beliefs
 - Trade union membership
 - Genetic data
 - Biometric data to uniquely identify a person
 - Health data
 - Data concerning a natural person's sex life or sexual orientation

Will personal data concerning criminal convictions and offences be processed during the research project?

- No
- Yes

Lawful basis for processing of sensitive personal data:

The lawful basis for processing under the EU's General Data Protection Regulation, Articles 9 (special categories of personal data) and 10 (personal data relating to criminal convictions and offences), and the Personal Data Act, Sections 6 and 7:

- Consent of the data subject
- The processing activities relate to personal data that has been manifestly made public by the data subject
- The processing activities are conducted for the purpose of scientific or historical research in the public interest, for statistical purposes, or in connection with the exercise of official authority
- The processing of personal data is necessary for archiving purposes in the public interest

11. Transfer or disclosure of data to external parties

- Personal data will be regularly transferred or disclosed to parties other than the members of the research group.

External transcription services will be used. Audio files without name or other identifiers will be sent to an external transcription service that has a contract with Tampere University. The audio files and the interview transcripts will be sent as encrypted files. The transcription services will sign a non-disclosure agreement and will delete all audio files and interview transcripts immediately after completing the transcription. The transcription services have no access to the project's research records with personal information.

12. Transfer or disclosure of data outside the EU/EEA

Will data stored in the research records be transferred to a country or an international organisation that is located outside the EU/EEA?

- No
- Yes, please specify:

13. Automated decision-making

Decisions will not be made by automated means.

14. Data protection principles

Protection of manual materials (e.g. paper documents):

- In a locked room
- In a locked cupboard
- Other, please specify

Protection of digital materials (e.g. information systems and equipment):

- usernames
- password
- multi-factor authentication (MFA)
- access management (IP address)

- collection of log data
- physical access control
- other, please specify

Processing of data that directly identifies an individual:

- Directly identifiable data will be removed during the analysis stage
- The materials will be pseudonymised
- The materials will be analysed without removing directly identifiable data.

Protecting data in transit:

- secure transmission, please specify: Pseudonymised research transcripts and anonymous written accounts of illness experiences will be shared within the research team via TUNI Groups, which is secured with multi-factor authentication.
- file encryption, please specify: Audio files will be sent to the transcription services as encrypted data. Interview transcripts will be sent from the transcription services to the research group as encrypted data.

15. Processing of personal data after the research project has been concluded

- The research records will be destroyed
- The research records will be anonymised and archived without personally identifiable data
- The research records will be archived without anonymisation

With the written consent of the participants, the personal details will be stored at the Faculty of Social Sciences at Tampere University for 15 years after the end of the research project in order to enable a longitudinal study and follow-up studies. After this, the personal details will be destroyed. In case of a follow-up study, the participants will be contacted personally, and separate consent will be sought. If the participants do not consent to the storage of their personal details beyond the duration of the current project, their personal information will be destroyed at the end of the project. With written consent from participants, the members of the research group can continue to use the pseudonymised research data for further research on chronic illness after the end of the project to enable in-depth analysis and the completion of research publications. Furthermore, with written consent of the participants and following a careful assessment of the sensitivity of the data by the principal investigator, parts of the pseudonymised research data may be saved in the Finnish Social Science Data Archive for use by other researchers. This follows the principle of open science according to which research data should be made available to the scientific community whenever possible. The data of those who have not consented will be destroyed.

16. Data subjects' rights and possible restriction thereof

Data subjects have the following rights under the EU's General Data Protection Regulation (GDPR):

Right of access

Data subjects are entitled to find out what information the University holds about them or to receive confirmation that their personal data is not processed by the University.

Right to rectification

Data subjects have the right to have any incorrect, inaccurate or incomplete personal details held by the University revised or supplemented without undue delay. In addition, data subjects are entitled to have any unnecessary personal data deleted from the University's systems.

Right to erasure

In exceptional circumstances, data subjects have the right to have their personal data erased from the Data Controller's records ('right to be forgotten').

Right to restrict processing:

In certain circumstances, data subjects have the right to request the University to restrict processing their personal data until the accuracy of their data, or the basis for processing their data, has been appropriately reviewed and potentially revised or supplemented.

Right to object

In certain circumstances, data subjects may at any time object to the processing of their personal data for compelling personal reasons.

Right to data portability

Data subjects have the right to obtain a copy of the personal data that they have submitted to the University in a commonly used, machine-readable format and transfer the data to another Data Controller.

Right to lodge a complaint with a supervisory authority

Data subjects have the right to lodge a complaint with a supervisory authority in their permanent place of residence or place of work, if they consider the processing of their personal data to violate the provisions of the GDPR (EU 2016/679). In addition, data subjects may follow other administrative procedures to appeal against a decision made by a supervisory authority or seek a judicial remedy.

Contact information:

Office of the Data Protection Ombudsman

Street address: Ratapihantie 9, 6th floor, 00520 Helsinki, Finland

Postal address: PO Box 800, FI-00521 Helsinki, Finland

Switchboard: tel. +358 29 56 66700

Fax: +358 29 56 66735

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The Data Controller follows a GDPR-compliant procedure for responding to subject access requests.