

Self-Management Strategies for People Living with Endometriosis

NCT: NCT ID not yet assigned

Unique Protocol ID: 2025-118-A2

Document Date: September 2025

Informed Consent Form

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Introduction

This project is part of the EUMetriosis consortium and will be conducted by researchers at Wageningen University & Research and the University of Edinburgh. To read more about the EUMetriosis project, please refer to the website at <https://eumetriosis.eu/>. This consent form aims to explain why the research is being done, what it involves, and ask for your consent to participate.

This study will examine everyday actions people take to live with endometriosis (sometimes called “self-management”). We are looking to speak with people who have a diverse range of backgrounds and social experiences to collect a variety of perspectives across Europe.

This project is funded by Horizon Europe, the European Union’s key funding program for research and innovation. This study has been approved by the WUR-Research Ethics Committee for non-medical research as meeting the *Netherlands Code of ethics for research in the social and behavioral sciences involving human participants*. You are being asked to participate to describe your experiences relating to self-managing endometriosis, through a diary study, an interview, and a focus group. You can participate in the study in English, Spanish, French, Dutch, or German. Your participation contributes to an increased understanding of realities across Europe that can be used to inform policy recommendations. We will schedule an introductory call to introduce ourselves, explain the study, learn a bit about you, and answer any questions.

Diary Study

Diaries will focus on **what everyday actions you take to live with endometriosis**. The diary study will take place over a three-month period. You can choose to complete the diary in the format that works best for you, either physically (on paper) or digitally (online). Daily entries are optional; you can decide how often you write and how detailed your entries are. We ask that participants complete at least 8 entries per month. This is roughly twice a week, though if you have more to say during a certain part of the month, you can group all the entries together. At the end of the study, photos or digital copies of your diary entries should be submitted via email to erica.selznick@wur.nl. If you prefer, hard copies can also be mailed.

Photovoice (optional component): You have the option to take part in the photovoice portion of the diary study, which involves taking photographs in addition to your diary entries of any personal themes or ideas you wish to explore relating to self-management. This part of the study is also completely voluntary. You can choose how many photos you take and how often you participate. If you choose to take part, please also submit your photographs to erica.selznick@wur.nl following the end of the study.

Photographs and written texts collected from the diary entries and photovoice will be stored in a secure online drive, accessible only to the researchers involved in this project.

Interviews

Following the diaries, there will be an interview where we will ask you questions about your experiences, opinions, and desires related to self-managing endometriosis. Examples of questions could be “What is your everyday routine to manage endometriosis?” or “Who supports you in self-managing endometriosis?” Interviews will last around 60 to 90 minutes. Interviews can take place online using Microsoft Teams or in person, depending on your and the researcher’s availability. If the interview takes place online, it will be recorded through Teams, which captures both video and audio. If in person, interviews will be recorded with a voice recorder. Recordings help ensure an accurate record of the conversation. Files will be stored in a secure drive and will be deleted after transcription.

Focus Groups

Following the interviews, focus groups will be formed based on themes from the diaries and interviews that need further attention and to develop policy recommendations. You will be contacted and invited to participate in focus groups if they take place where you live or if they focus on themes you discussed. If you are invited and do not wish to participate, your previous participation will not be affected in any way. Focus groups will last around 90 to 120 minutes. Focus groups can take place online using Microsoft Teams or in person, depending on your and the researcher’s availability. If the focus group takes place online, it will be recorded through Teams, which captures both video and audio. If in person, focus groups will be recorded with a voice recorder. Recordings help ensure an accurate record of the conversation and will be deleted after transcription. Any materials developed throughout the focus groups will have all identifiable information removed and will be photographed only with your consent. Compensation for participation in a focus group will be 50 euros per participant.

Participation in this study is voluntary. You can take breaks or stop participating at any time without having to provide any reason and without any negative consequences. You might want to stop participating if discussing sensitive material causes discomfort or if you feel tired or uncomfortable. You are not required to answer any question. If you would like to skip a question or take a break, let the researcher know at any time.

Personal Data

What information do we collect?

As part of the study, we will ask for some basic contact information such as your name, country of residence, email address, and phone number. We will also ask for demographic information such as your age, occupation, and relationship status. We collect this information to help us identify patterns and themes across different groups of participants.

How will we handle your information?

We will ask you if you would like to be named in the research, or to choose a pseudonym (a fake name to refer to you by in published materials). We can also choose a pseudonym for you. We will transcribe the interviews and, unless you request to be named, remove identifying information from your materials (photographs, texts, audio, and video recordings) so that your data cannot be directly linked to you. Audio and video recordings will be completely deleted after transcription. Publications and other study outputs may feature diary entries and interview quotes. When recording your diaries, consider whether you want

to include identifying information such as faces in photographs (diary entries that cannot be de-identified will be deleted a year after the study, unless you specifically request otherwise). Only the researchers at Wageningen University will have access to your personal data. Researchers at the University of Edinburgh will have access to your materials without the personal identifiers.

All data will be securely stored in a data management system operated by Wageningen University & Research and the University of Edinburgh up to 10 years following the end of the project in password protected, encrypted University servers, according to the policy of the Dutch Universities.

What happens with the results of the study?

The results of this study will be written up. The researchers will publish findings in a doctoral thesis and scientific journals and present them at national and international scientific meetings and conferences in various formats, including but not limited to journal articles, blog posts, policy reports, and posters. You may request to receive any publications or summaries of findings directly, or to be notified when they become available.

What if you change your mind?

You have the right to revoke your consent during your participation in the study, as well as to withdraw permission for the use of your personal data for up to 3 months after your participation. If you want to withdraw from the study, please contact Erica Selznick, erica.selznick@wur.nl. We will remove your answers and the information you have given us. Sometimes, we cannot remove all of your information, for example, information that is already in the study results or published in an article. We will explain this then. or example, information that is already in the study results or published in an article. We will explain this then.

What if you have questions?

You can also contact the researcher if you want to know more about the personal information we have about you and what we do with it. Any ethical concerns about the study may be directed to the secretariat of the WUR Research Committee at rec@wur.nl. For more information about your legal rights regarding personal data, such as the right to inspect, correct and delete your personal data, please contact privacy@wur.nl. If you have a complaint about how we handle your personal data, please also contact privacy@wur.nl. You may also file a complaint with the Dutch Data Protection Authority.

I consent in participating in this research and the use of my information as described.

- ☐ I give permission to be recorded and for the recording to be used for transcribing data.
- ☐ I give permission to use quotes from me in publications. *(Your name will not be used unless you request to be named, and identifying details will be removed so the quote cannot be traced back to you.)*
- ☐ I consent that special categories (such as race/ethnicity and sexual orientation) of personal data are collected and processed
- ☐ I want to receive updates about this project or events in the future.

Name of interviewee/participant

Date

Signature

Name of researcher(s)

Date

Signature