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Finding Endometriosis using Machine Learning:

FEMaLe

Call/Topic: Digital transformation in Health and Care

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Legislation

Legislation H2020 Framework Programme – Regulation (EU) No 1291/2013 of the European Parliament and of the Council of 11 December 2013 establishing Horizon 2020 - The Framework Programme for Research and Innovation (2014-2020) (OJ 347, 20.12.2013, p. 104).

Euratom Research and Training Programme (2014-2018) – Council Regulation (Euratom) No 1314/2013 of 16 December 2013 on the Research and Training Programme of the European Atomic Energy Community (2014-2018) complementing the Horizon 2020 – The Framework Programme for Research and Innovation (OJ L 347, 20.12.2013, p. 948).

H2020 Specific Programme – Council Decision 2013/743/EU of 3 December 2013 establishing the Specific Programme Implementing Horizon 2020 - The Framework Programme for Research and Innovation (2014-2020) (OJ L 347, 20.12.2013, p. 965).

Rules for Participation (RfP) – Regulation (EU) No 1290/2013 of the European Parliament and of the Council of 11 of December 2013 laying down the rules for the participation and dissemination in Horizon 2020 – the Framework Programme for Research and Innovation (2014-2020) (OJ L 347, 20.12.2013, p.81).

Financial Regulation (FR) – Regulation (EC, Euratom) No 966/2012 of the European Parliament and of the Council of 25 October 2012 on the financial rules applicable to the general budget of the European Union (OJ L 298, 26.10.2012, p.1).

Rules of Application (RAP) – Commission Regulation (EC, Euratom) No 1268/2012 of 29 October 2012 on the rules of application of l Regulation (EC, Euratom) No 966/2012 of the European Parliament and of the Council on the financial rules applicable to the general budget of the Union (OJ L 298, 26.10.2012, p.1).

1. DEVELOPMENT OF BASELINE QUESTIONNAIRE

The first objective in WP3 is to estimate the prevalence and geographical distribution of endometriosis-like symptoms in Denmark and the UK. In order to do so, we need to develop a set of questions on symptoms and related consequences that can be used to identify both women with diagnosed and undiagnosed endometriosis.

This report describes the development of a questionnaire on symptoms and related consequences of endometriosis. This questionnaire will initially be sent to doctors, patients, and researchers in order to reach consensus on the most relevant symptoms. Once consensus has been reached, the final set of questions on symptoms and related consequences will be included in a larger questionnaire that will be distributed to a random sample of approximately 40,000 Danish women in the reproductive age.

1.1 Development of the first questionnaire

Originally, the plan was to hold a two-day meeting with experts from within the consortium, where we should agree on which symptoms to include. Due to the COVID-10 pandemic, this has not been a possibility. Instead, we have held an initial online meeting and following this, we have developed the questionnaire based on inputs from researchers and patients. The process is described below:

- An initial online meeting was held, attended by researchers and doctors from the different work-packages of FEMaLe (WP3-WP8) as well as doctors and researchers from outside the consortium.
    - At the kick-off meeting, we agreed on how to involve patients in the development of the questionnaire and we decided on the main themes to be included in the final questionnaire.

- In a Facebook forum for members of the Danish Endometriosis Society, patients were asked to state symptoms that they found relevant to include in a questionnaire aimed at identifying women with both diagnosed and undiagnosed endometriosis.
    - This list of symptoms was sent to the doctors and researchers, who took part in the initial online meeting, and everyone were asked to add symptoms or consequences that they found missing in the list provided by the patients. At this stage, no symptoms were considered irrelevant.

1.2 International consensus study

After the development of the first questionnaire, including a gross list of symptoms and related consequences, we need to narrow this list down to the most relevant ones.

To agree on the most relevant symptoms to include in the final questionnaire, it was decided to use a **consensus study, using the Delphi method,** where both doctors, researchers and patients should be included.

The Delphi method is a structured technique depending on a panel of experts. The experts answer the same set of questions in two or more rounds. After each round, an anonymized summary of the experts' answers from the previous round is provided. Experts are therefore encouraged to revise their earlier answers based on the replies of the other experts.

During this process, it is anticipated that the experts as a group will converge. After a predefined number of rounds, the process will be stopped and the mean or median scores of the final rounds determine the results.

The flow of the planned consensus study is depicted in Figure 1. The Delphi study is planned to include two rounds. The experts will include doctors, patients, and researchers with expert knowledge on endometriosis.

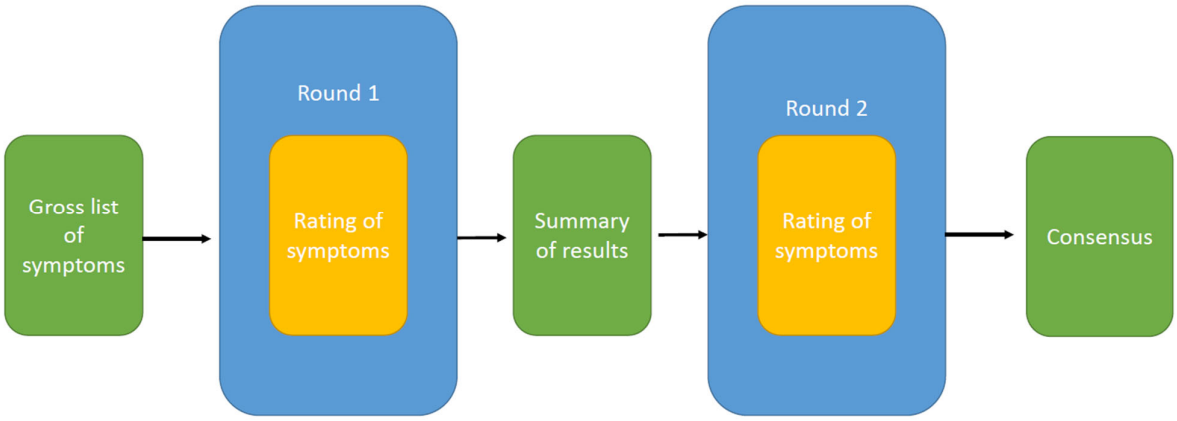


Figure 1: Survey flow

The project has been registered as a research project at Aarhus University (2016-051-000001, lb no. 2288).

To make the final list of symptoms applicable outside Denmark, it was decided to include experts also from Hungary, the UK, France, and Turkey in the consensus study.

- The initial questionnaire including the gross list of symptoms and related consequences was translated into Danish, English, Hungarian, Turkish and French with the help from FEMaLe partners in the respective countries.

- Invitation material was developed and translated into English, Hungarian, French, and Turkish. The material includes:
    - A formal invitation.
    - A participant information sheet.
    - Informed consent form.

The local FEMaLe partners in the UK, Hungary, France, and Turkey have agreed on helping with the recruitment of approximately 10 patients and a few doctors in their respective countries.

The final study population will include approximately 50 patients, 25 doctors and 25 researchers (not mutually exclusive). The recruitment has been postponed until after summer, due to the holiday season.

Once international consensus has been reached on the most relevant symptoms and related consequences of endometriosis, these will be included in the larger questionnaire aimed at 40,000 Danish women scheduled to be distributed in the late autumn of 2021.

2. Initial questionnaire on symptoms and impact of endometriosis

With this questionnaire, we would like to obtain knowledge on which symptoms, and consequences of these, **that are most relevant to ask** for when trying to **identify both diagnosed and undiagnosed** endometriosis. We ask you to assess the relevance of each of the presented symptoms/consequences using the 5-point scale: "Not necessary", "Slightly relevant", "Relevant", "Very relevant", "Necessary". If there are symptoms, which you do not feel capable of assessing, you can choose the box "Unsure/outside my area of expertise".

In the first part of the questionnaire, we ask you to assess the relevance of a number of physical symptoms. Following this, we ask you to assess the relevance of a number of psychological consequences and, finally, the relevance of a number of social consequences. At the end of the questionnaire, you have the possibility to add one or more symptoms or consequences that you feel have been overlooked in this first questionnaire.

Thank you so much for your help.

2.1 Physical symptoms

2.1.1 To what extent do you find the following symptoms relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Menstrual pain
- Pelvic pain in between menstruation
- Pain during sexual intercourse
- Pain after sexual intercourse
- Cyclic pain during defecation
- Cyclic pain during urination
- Pain at ovulation

Response categories: "Not necessary", "Slightly relevant", "Relevant", "Very relevant", "Necessary" or "Unsure/outside my area of expertise".

2.1.2 To what extent do you find the following symptoms relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Stomach ache
- Pain after having eaten
- Rectum cramps/spasms
- Blood and mucus in faeces
- Blood in urine
- Diarrhoea
- Constipation
- Feeling bloated
- A feeling of heaviness in the abdomen
- Frequent urge to use the toilet (to open bowels or pass urine)
- Acute urge to use the toilet (to open bowels or pass urine)
- Lack of appetite
- Food allergies

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.1.3 To what extent do you find the following symptoms relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Joint pain
- Muscle pain
- Headache / migraine
- Tensions in the jaw
- Lower back pain
- Cyclic pain radiating to the lower and upper back
- Cyclic pain radiating to the legs
- Cyclic pain radiating to the groin
- Cyclic chest or shoulder pain
- Cyclical pain

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.1.4 To what extent do you find the following symptoms relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Pain when standing
- Pain when sitting
- Pain when walking
- Pain when lying down
- Pain during physical activity
- Pain sensitivity to cold
- Pain sensitivity to tight clothing

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.1.5 To what extent do you find the following symptoms relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Infertility / difficulty getting pregnant
- Irregular bleeding
- Heavy menstrual bleeding
- ”Flu-like” / ”Fever-like” symptoms
- Generally feeling unwell
- Nausea
- Vomiting
- Urinary tract infection / cystitis

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.1.6 To what extent do you find the following symptoms relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Sleeping poorly / insomnia
- Fatigue / lack of energy / exhaustion
- Impaired memory
- Impaired ability to concentrate
- A general lack of perspective
- Impaired ability to plan

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.1.7 To what extent do you find the following symptoms relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Rapid heartbeat
- Dizziness
- Breathing problems
- Pain when breathing

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.2 Psychological consequences

2.2.1 To what extent do you find the following psychological consequences or impacts of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- A feeling of loneliness
- A feeling that others do not understand what you are going through
- A feeling that others think you are moaning / complaining
- A feeling of insecurity
- A feeling of helplessness
- A feeling of not being sufficient
- A feeling of being worthless
- Low self-esteem
- A changed view of yourself

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.2.2 To what extent do you find the following psychological consequences or impact of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Mood swings
- Feeling bad tempered or short tempered
- Anger
- Feeling violent or aggressive
- Feeling depressed
- Feeling weepy or tearful
- Feeling miserable
- Feeling unable to do the things you want to do because of the pain

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.2.3 To what extent do you find the following psychological consequences or impact of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Feeling that your health is outside of your control
- Feeling that the symptoms are taking away your life
- Feeling frustrated because your symptoms are not getting better
- Feeling frustrated because you are not able to control your symptoms
- Feeling unable to cope with the pain
- Feeling unable to forget the symptoms

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.2.4 To what extent do you find the following psychological consequences or impact of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Stress
- Feeling anxious / suffering from anxiety
- Worrying about pain
- Worrying about the future
- Feeling deflated about the future
- Feeling mistrusted due to symptoms
- Feeling dejected

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.3 Social consequences

2.3.1 To what extent do you find the following social consequences or impact of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- A high number of doctor / health care visits due to abdominal/pelvic pain
- A feeling that your doctor(s) / health care provider(s) are not doing anything for you
- A feeling that the doctor(s) / health care provider(s) think that it is all in your mind
- Frustration about the doctor's / health care provider's lack of knowledge about endometriosis
- A feeling like you are wasting the doctor's / health care provider's time

Response categories: "Not necessary", "Slightly relevant", "Relevant", "Very relevant", "Necessary" or "Unsure/outside my area of expertise".

2.3.2 To what extent do you find the following social consequences or impacts of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- A high level of absence from work / school
- Inability to carry out tasks at work / school
- Feeling embarrassed about symptoms at work / school
- Feeling guilty about taking time off work / school
- Worrying about not being able to carry out your job / schoolwork

Response categories: "Not necessary", "Slightly relevant", "Relevant", "Very relevant", "Necessary" or "Unsure/outside my area of expertise".

2.3.3 To what extent do you find the following social consequences or impacts of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Difficulty participating in social events
- Difficulty participating in a conversation
- Difficulty participating in large gatherings

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.3.4 To what extent do you find the following social consequences or impacts of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Difficulty managing daily chores/activities at home (including cleaning, shopping, laundry, bathing, etc.)
- Difficulty finding capacity to enjoy hobbies
- Difficulty performing physical activities/exercise

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

2.3.5 To what extent do you find the following social consequences or impacts of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Worrying about having sexual intercourse
- Avoiding sexual intercourse
- Feeling guilty about not wanting to have sexual intercourse
- Frustration because you cannot enjoy sexual intercourse

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of my expertise”.

2.3.6 To what extent do you find the following social consequences or impacts of endometriosis relevant in order to be able to **identify both diagnosed and undiagnosed** endometriosis?

- Difficulties looking after your child / children
- Inability to play with your child / children
- Inability to carry out other caring responsibilities

Response categories: “Not necessary”, “Slightly relevant”, “Relevant”, “Very relevant”, “Necessary” or “Unsure/outside my area of expertise”.

_____

2.4. Additions

If there are important symptoms or consequences that you think have been overlooked in the questionnaire, please add these here:

_____

_____

_____

_____

_____

3. Invitation Letter

Dear XX,

We would like to invite you to consider participating in an international online **consensus development process**. The aim is to reach consensus on which symptoms and consequences that are most relevant to ask for, when trying to identify and diagnose the disease endometriosis.

We are undertaking a **series of online surveys** to evaluate the views of experts on a range of suggested symptoms and consequences. The range of suggested symptoms has been developed based on literature reviews and inputs from patients and stakeholders.

At the end of this process, the consented list of symptoms and consequences will be included in a questionnaire that will be send to approx. 40,000 Danish women as part of a women's Health Survey. The aim of this survey is to estimate the prevalence and geographical distribution of endometriosis symptoms.

If you so desire, you will be listed as a named contributor in the acknowledgements of the resulting scientific publication. This is, however, not required for participation in this study and you can take part anonymously.

The study is conducted by Post Doc Karina Ejgaard Hansen and Associate Professor Dorte Rytter from the Department of Public Health as well as PhD student Henrik Damgaard Marschall from Department of Psychology, Aarhus University.

If you are interested in participating in the survey, please **return the attached consent form**. Upon providing written informed consent to participate, we will send you a unique survey link.

This is a **modified Delphi survey** which will be carried out in a series of two survey rounds, spaced about three weeks apart. It takes 10-15 minutes to complete each round and you will have about 10 days to complete each.

If you agree to participate you will receive the first survey in mid-September 2021. Results from the first round will be compiled and sent back to you in a second survey for your consideration and response. It is through a series of such surveys that the opinions of the group emerge.

There are no risks related to your participation in this research other than the contribution of your time. There is no financial compensation for participating. Your identity as a participant and your individual responses will only be known to the researchers and will be de-identified at the completion of the study, unless desired otherwise. Information that is shared back to the participant groups will be provided in summary form with no individual responses identified. You would be free to withdraw from the study at any time. If you do not respond to a survey round you will be sent up to two friendly reminders. If you do not respond to the reminders, you will be considered to have withdrawn from the study.

Please let us know if you would like to get involved in this exciting research!

Sincere thanks,

Dorte Rytter and the FEMaLe Research Team

4. Participant Information Sheet

An international online consensus development process, with the aim to reach consensus on which symptoms and consequences that are most relevant to ask for when trying to identify and diagnose the disease endometriosis

Principal investigator: Associate Professor Dorte Rytter

Co-investigators: Post Doc Karina Ejgaard Hansen and PhD student Henrik Damgaard Marschall

Introduction

You are being invited to contribute to a research study that will result in a list of symptoms and consequences that should be included in a questionnaire aimed at identifying women with endometriosis.

Before you decide, it is important for you to understand who is conducting this study, why the research is being done and what it will involve.

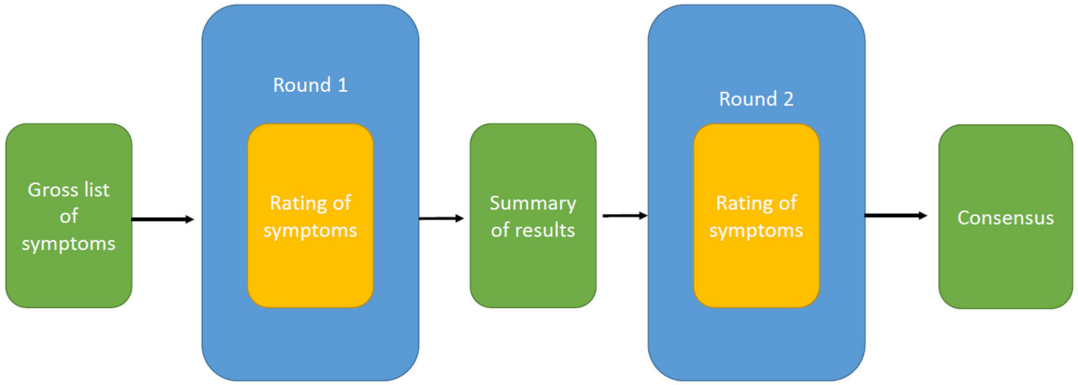
Please take the time to read the following information carefully and discuss it with others if you wish.
Part 1 tells you the purpose of this study and what your involvement entails if you take part.
Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information.
Take time to decide whether you wish to take part.

Thank you for reading this.

Procedures

Taking part involves answering a series of *two online surveys* over the course of about 1 month. Each survey will take about 10-15 minutes to answer. In between the two surveys, you will be presented with ratings from the first round.



Study process: the method used is a Delphi technique, including two rounds of surveys.

What is the purpose of the study?

Endometriosis is a severely underdiagnosed condition, and to date, there is no consensus on which symptoms are relevant to ask for in order to identify women with endometriosis.

We plan a large Danish survey among women in the reproductive age. With this survey, we wish to estimate the true prevalence of endometriosis. In order to do this, we need to include a list of questions about the most relevant symptoms and consequences of endometriosis. Therefore, we need the help of experts.

By experts, we mean individuals with endometriosis, doctors who engage with women with endometriosis, and researchers who work with endometriosis.

In this way, we hope to bring together the best knowledge. The results of this study hold the potential to reduce the diagnostic delay for women with endometriosis. This is important, as earlier diagnosis means earlier treatment of the disease and consequences hereof, which may have large benefits for future women.

Why have I been invited?

You have been invited to participate in this consensus study because you belong to at least one of the following categories:

- A patient suffering from endometriosis
- A doctor engaged with women with endometriosis
- A researcher working with endometriosis

Do I have to take part?

It is up to you to decide whether to take part.

If you decide to take part, you are still free to withdraw at any time without giving a reason.

Whilst it is no formal requirement to complete both surveys, the study quality is better when everyone who signs up also completes the whole process.

We would like to ask you to please keep this in mind when deciding whether you would like to take part.

What do I have to do and how to participate?

You will need a computer and access to the internet to take part as all aspects of this study will be online.

Before starting the round 1, you will be asked to take approximately 3 minutes to answer some personal questions (age, gender, country of residence and category of expert (patient, doctor and/or researcher)).

In round 1, you will complete an online survey where you will be asked to indicate your agreement or disagreement with the relevance of a list of symptoms and consequences of endometriosis in order to be able to **identify and diagnose** endometriosis.

You then have the opportunity to add any additional symptoms that you think have been overlooked in the given list of symptoms. This should take about 10 minutes and you will have about 10 days to complete each survey.

In round 2, you will be presented with a summary of the experts' ratings from round 1 and you will be asked to fill in a similar survey. Some items might have been added based on inputs from the 1st round.

Will my name be listed?

The answers you give will be kept confidential as per data protection policies outlined below.
No individual contributions will be identifiable.

We are planning to acknowledge anyone's contribution to the Delphi study, named or unnamed, in a list of contributors as part of the final manuscript (similar to the normal Acknowledgments section).

You can decide yourself if you would like to be listed with your name or not.

What are the possible disadvantages and risks of taking part?

No disadvantages are anticipated, and the main risk relates to data protection breaches.

However, not only will the answers you give be kept confidential as per data protection policies outlined below, but we will also mitigate this risk by encrypting and securely storing any identifiable information.

What are the possible benefits of taking part?

Taking part is of no direct personal benefit other than that you may enjoy the exchange with colleagues and contribution to the research process.

The output of this study will help researchers develop better tools to identify and diagnose women with endometriosis.

How will we use information about you?

Aarhus University is the data controller for this study. This means that we are responsible for protecting your information and using it properly.

Aarhus University will only keep your data as long as necessary for doing the relevant analyses, and as required per Danish legislation.

We will need to use information from you for this research project. This information will include your:

- Name
- Age
- Gender
- Country of residence
- Expert category (whether you are a patient, doctor and/or researcher)

Researchers will use this information to conduct the research.
We will keep all your information safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our articles in a way that no one can identify you personally unless you desire to be listed with your name.

Legal basis

As a university, we use personally identifiable information to conduct research to improve health, care, and services. As a publicly funded organisation, we must ensure that it is in the public interest when we use personally identifiable information from people who have agreed to take part in research.

This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study.

International data transfers

None. Your data will only be stored and analyzed at Aarhus University in Denmark.

What are your choices about how your information is shared?

You can stop being part of the study at any time, without giving a reason.

We need to manage your records in specific ways for the research to be reliable.
This means that we will not be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information in the attached document on duty of disclosure or by sending an email to dr@ph.au.dk

Complaint

If you wish to raise a complaint on how we have handled your personal data, please contact Aarhus University's Data Protection Officer via email: dpo@au.dk and/or via post at Nordre Ringgade 1, 8000 Aarhus C. att. 'Databeskyttelsesrådgiver'.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Danish Data Protection Agency.

You can find the contact information at www.datatilsynet.dk.

What happens to the results of the research study?

The results of this study are likely to be published in scientific journals and disseminated to the public through charities.
No personally identifiable information will be published unless desired by you.

Who is organizing and funding the research?

The Department of Public Health, Aarhus University is organizing the research.
The study is funded by the European Union.

Contact for further information

Dorte Rytter
Department of Public Health, Aarhus University
Bartholins Allé 2, 8000 Aarhus C
Email: dr@ph.au.dk

Thank you for reading this information sheet.

If you have any questions, please direct them to the researcher before signing the consent form.

5. Informed Consent Form

1. Project title

In connection with the research project 'Consensus on endometriosis symptoms' (AU ID 1284) and in accordance with the General Data Protection Regulation, we require your consent to our processing of your personal data.

2. Project description

Endometriosis is a severely underdiagnosed condition, and to date, there is no consensus on which symptoms are relevant to ask for in order to identify women with endometriosis. We plan a large Danish survey among women in the reproductive age. With this survey, we wish to estimate the true prevalence of endometriosis.

In order to do this, we need to include a list of questions about the most relevant symptoms and consequences of endometriosis. We therefore need the help of experts. With experts, we mean women with endometriosis, doctors who engage with women with endometriosis, and researchers who work with endometriosis. In this way, we hope to bring together the best knowledge.

The results of this study hold the potential to reduce the diagnostic delay for women with endometriosis. This is important, as earlier diagnosis means earlier treatment of the disease and consequences hereof, which may have large benefits for future women with endometriosis.

3. Data controller, project group and project manager

Aarhus University, CVR no. 31119103, is the data controller for the processing of your personal data. The FEMaLE group is responsible for the project (hereinafter referred to as the "project group"). The project group is headed by Dorte Rytter and can be contacted at Bartholins Allé 2, building 1260, room 241, by email (dr@ph.au.dk) or phone (+45 60 38 12 98).

4. Categories of personal data concerning you that are processed

We process ordinary personal data in the form of your name and your email address.
We also process sensitive personal data in the form of whether you have an endometriosis diagnosis.

5. Purpose and processing activities

The results of the project will be published in international journals.
It will not be possible to identify individual persons from the results.

- Purpose 1: We process your ordinary personal data for storage and to contact you in order to send you the electronic questionnaires.
- Purpose 2: We process your sensitive personal data for storage and statistical analyses.

6. Any recipients or categories of recipients of personal data

We do not share your personal data with anyone.

7. Transfer to a third country or international organisation

We do not transfer your personal data to anyone outside the EU/EEA.

8. Storage period

At present, we cannot say for how long we store your personal data. We focus on ensuring that all statistical analyses have been conducted and store your personal data for as long as it is needed for the purpose of the project and in accordance with applicable legislation.

9. The right to withdraw consent

Participation is voluntary and you may at any time withdraw your consent to the processing of personal data. This can be done by contacting Dorte Rytter. If you withdraw your consent, this will take effect as from the time of withdrawal and will not affect the legality of our processing up to this time.

Signature

I acknowledge that I have received, read, and understood the above, as the basis for my consent to the processing of my personal data for the following purposes:

The results of the project will be published in international journals. It will not be possible to identify individual persons from the results.

- Purpose 1: We process your ordinary personal data for storage, and to contact you in order to send you the electronic questionnaires.
- Purpose 2: We process your sensitive personal data for storage and statistical analyses.

(Name and date)