

## Help us to learn more about women's health, illnesses and well-being

We would like to invite you to participate in a questionnaire survey on health, illness and well-being.

“CYKLUS” is a research project that aims to contribute to knowledge about general health, symptoms, diseases and well-being. CYKLUS includes individuals of all gender identities who were born female. Our focus is on diseases and symptoms such as bleeding disorders, pain, fertility and mental health.

### All answers make a difference

If the survey is to give an accurate picture of women's health, it is important that as many people as possible take part. Your participation is also important irrespective of whether you are in good or poor health. Participation in the survey is entirely voluntary. If you are under 18, we recommend that you ask your parents if you have any doubts about the content.

### Where will we obtain your data, and how will we process it?

For the purposes of the survey, we have received information about your name and civil registration number (CPR number) from the Danish Health Data Authority, who made a random selection of women in the age group 15-50. The Danish Health Data Authority has assessed that we may receive the information in accordance with Section 10 of the Data Protection Act. The project's processing of personal data is registered in Aarhus University's register of ongoing research projects. When the results of the survey are presented, the data will be anonymous, so no one will be identifiable. You can read more about how we process your personal data here on the following pages.

### Responding to the questionnaire

It takes about 25-30 minutes to complete the questionnaire.

To take part in the survey, please return to the invitation you received in your e-box and click on the link to the questionnaire.

If the questionnaire does not open when you click on the link in your e-boks invitation, go to [www.datafabrikken.dk](http://www.datafabrikken.dk) and enter the code from your invitation letter.

If we have not heard from you within 3 weeks, we will send you a single reminder.

Your response is important and we appreciate the time you take to complete the questionnaire. We thank you in advance for your participation.

On behalf of the project group

Yours sincerely,

Associate Professor [Dorte Rytter](#) PhD  
Aarhus University, Department of Public Health

### Want to know more?

You can read more about the survey on our project website:

<http://www.ph.au.dk/cyklus2023>

# Information on how the Department of Public Health, Aarhus University (IFS) processes your personal data in connection with the “CYKLUS” survey.

## 1. We are the data controller – how do you contact us?

The Department of Public Health, Aarhus University (IFS) is the data controller for the personal data that we process about you in connection with sending invitations to participate in the survey, and the subsequent processing of the survey results. The project is registered at Aarhus University (2016-051-000001 (Women’s health and disease) and lbnr. 2501 (Determinants and consequences of endometriosis). The research project is led by Associate Professor Dorte Rytter.

Our contact details are:

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## 2. The purpose of processing your personal data

“CYKLUS” is a research project that aims to contribute to knowledge about general health, symptoms, diseases and well-being. The research project includes individuals of all gender identities who were born female. A wide range of disorders which are more frequently or exclusively reported among individuals born as women are under-studied, and their prevalence, causes and consequences for health and well-being are unknown. This applies in particular to symptoms and diseases that are underdiagnosed or which for some other reason are not identifiable in the national health registers, including conditions such as bleeding disorders, pain, endometriosis, migraine, functional symptoms and mental disorders. Even with less underdiagnosed diseases such as cardiovascular disease, there is a lack of knowledge of the symptoms, well-being and prognosis for individuals born as women. In this research project, we wish to collect information on symptoms and diseases and investigate the frequency, causes and consequences of these symptoms and disorders.

## 3. Your participation

Your answers to the questionnaire are regularly saved and are thus included in the study regardless of whether the questionnaire is fully or partially completed. However, you can change your answers until you press “Finish”.

## 4. Categories of personal data and the legal basis for processing your personal data

We process the following categories of personal data about you:

Ordinary, non-sensitive personal data:

Name

Ordinary, confidential personal data:

CPR number (Danish civil registration number)

#### Sensitive personal data:

If you respond to the questionnaire, we will process your answers to the questions. The information we process will depend on your responses. The questionnaire includes questions on menstrual bleeding, fertility, physical and mental health, symptoms, selected diseases, lifestyle and well-being.

In addition to the above information, IFS will also, via public registers, extract some further personal data about you. This includes, for example, your age, gender, socio-economic background, contact with hospital care (including diagnosis), contact with general practitioners and use of prescription drugs. IFS wishes to use this information to answer the research questions that we aim to investigate.

The information from the questionnaire will, for the duration of the data collection period, be stored on a secure server at IFS in a form that is not directly identifiable. After the data collection, the questionnaire data will be transferred to a server at Statistics Denmark and stored in a form that is not directly identifiable.

We thus process your personal data on the basis of Article 9(2)(j) and Article 6(e) of the GDPR<sup>1</sup>, as the planned research is of substantial public interest in the field of public health. We process your CPR number on the basis of Section 11(1) of the Data Protection Act<sup>2</sup>, as the processing is necessary to uniquely identify you.

#### **5. Recipients or categories of recipients**

The data may be disclosed to research projects of major importance to society, provided that the relevant permits are obtained and the applicable legislation is complied with. Such disclosure may be made pursuant to Section 10 of the Data Protection Act.

IFS, Aarhus University uses data processors, including Statistics Denmark. Aarhus University has entered into data processing agreements with the data processors and supervises the data processors' compliance with the data processing agreements in accordance with the applicable rules.

#### **6. Transfer to recipients in third countries, including international organisations**

As part of a research-based collaboration, IFS may transfer the personal data to recipients from other countries, both within and outside the EU. This applies only to the data collected via the questionnaire.

#### **7. Origin of your personal data**

We have received information about your civil registration number (CPR number) from the Danish Health Data Authority. In addition, we also receive information directly from you. We

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<sup>1</sup> Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of individuals with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) (EEA relevant text).

<sup>2</sup> Act no. 502 of 23 May 2018 supplementing the Regulation on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

may also retrieve additional information about you from public records, such as your age, gender, contact with the health service, medical information and socioeconomic background, where this is deemed necessary for the planned research project.

## **8. Storage of your personal information**

The questionnaires, your CPR number and the register data will be kept for as long as is necessary for the conduct of the survey. We cannot at the present time say how long your personal data will be processed. Your personal data will be processed by Aarhus University in personally identifiable form for as long as is necessary for the research purpose, in compliance with the rules on data storage for responsible research practice. When your personal data is no longer needed for the processing, it will be anonymised or deleted.

## **9. Information about your rights**

When your personal data is processed, you as a rule have the following rights:

- The right to deletion (or “the right to be forgotten”)
- The right to data portability – In certain cases, you have the right to receive your personal data and to request that the personal data be transferred from one controller to another.
- The right not to be subject to an automated decision based solely on automated processing, including profiling.

Please note that when Aarhus University processes your personal information as part of a research project that is in the public interest, your rights may be exempt or limited under certain conditions.

If you have any questions about our processing of your data or about your rights, you are always welcome to contact Aarhus University’s Data Protection Officer, Søren Broberg Nielsen.

You can contact our Data Protection Officer in the following ways:

By e-mail: [dpo@au.dk](mailto:dpo@au.dk)

By post: University of Aarhus, Nordre Ringgade 1, 8000 Aarhus C, att. “Data Protection Officer”

## **10. Complaints to the Danish Data Protection Agency**

You have the right to submit a complaint to the Data Protection Authority if you are dissatisfied with the way we process your personal data. The contact information of the Danish Data Protection Agency is available here: [www.datatilsynet.dk](http://www.datatilsynet.dk).