



## Take part in the national EFTER-COVID survey

Along with more than 1 million others, you are invited to help map the health of the population during and after the COVID-19 pandemic. The survey focuses on long-term effects of having COVID-19, but your answers are equally important whether you've had COVID-19 or not. It takes about 10 minutes to answer the questionnaire.

**Dear «Fornavn» «Efternavn»,**

You are invited to participate in the EFTER-COVID study, which will shed light on the extent of long-term effects of COVID-19 in Denmark. EFTER-COVID is a large, nationwide survey conducted by Statens Serum Institut in collaboration with experts from hospitals and universities.

We are writing to you now because you have been tested either negative or positive for coronavirus within the past year or so. We would like to ask you some questions about your health during the period around the test. If you have been infected, we would also like to hear how affected you were, for example, which symptoms you had. We would like to send you another questionnaire at a later date, to hear how things have gone in the months since we first asked.

We very much hope that you are able and willing to participate – even if you have not been or hardly felt ill. By participating and answering the questions, you can help create new knowledge about the burden of long-term effects and other health problems following COVID-19 in Denmark.

### How to complete the EFTER-COVID questionnaire

Return to the Danish letter in your E-boks and click on the link “Åben spørgeskema” to access the questionnaire.

Once you are on the first page of the questionnaire you can switch to the English version by clicking the “EN” button at the bottom of the page.

It takes 5–15 minutes to complete the form, depending on how many symptoms you have had.

The questionnaire can also be accessed by going to [www.survey-xact.dk/collect](http://www.survey-xact.dk/collect)

Enter your 12-digit password in the field “Nøgle”.

If you need to pause and come back to the questionnaire, you can resume answering where you left off.

You can read more about the survey on the next page.



### **May we contact you again?**

Most people infected with COVID-19 fortunately do not experience long-term health problems. However, this isn't the case for all. In the EFTER-COVID study, we will establish which long-term effects occur in those who have been infected with COVID-19, how often they occur, how serious they are, and how long they last. We are also asking people who have not been diagnosed with coronavirus in order to be able to compare with the rest of the population. We hope that this will make us wiser about how large the problem of long-term effects is, how long-term side effects present themselves in the population, and whether there are certain conditions that trigger long-term side effects, or whether they strike at random among those affected.

In order to answer such questions, we would like to contact you again with follow-up questionnaires. The follow-up forms are much shorter than the initial questionnaire, but your answers in these forms are very important for us to shed light on the duration of long-term effects. You will only be invited again if you have answered yes to the question about contacting you again in the questionnaire.

### **Participation is voluntary**

Of course, it is completely voluntary to participate, and you can leave the study at any time, but we hope that as many as possible will answer the questions.

### **Processing of personal data**

On the following pages, you can read about how we process your personal data, and about your rights under data protection regulations.

### **More information and contact information**

You can read more about EFTER-COVID on our website: [www.ssi/eftercovid](http://www.ssi/eftercovid)

The results from the study will be available on our website further along in the project.

If you have any questions, you are welcome to contact us via your e-Boks. [By clicking on this link, you can write directly to EFTER-COVID](#). You can also find the EFTER-COVID mailbox in e-Boks by clicking "Write new message" and choosing EFTER-COVID as the recipient under Statens Serum Institut. Remember to have your key app or NemID ready.

We hope that you will participate and by doing so contribute to new knowledge about the health of the population and the long-term effects of COVID-19.

Many thanks in advance for your help. Yours sincerely,

Tyra Grove Krause  
Head of Department, Infectious Disease Epidemiology & Prevention  
Statens Serum Institut



## Information about processing of your personal data

Information about how Statens Serum Institut (SSI) processes personal data about you in connection with the EFTER-COVID study.

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

SSI is the data controller for the processing of personal data that we process about you in connection with the sending of the invitation for your participation in the study, and the subsequent processing of the survey results.

Our contact details are:

Statens Serum Institut  
Artillerivej 5  
DK-2300 Copenhagen S  
CVR no.: 46837428  
Tel.: +45 3268 3268  
Email: [eftercovid@ssi.dk](mailto:eftercovid@ssi.dk)

### 2. Purpose of the processing of your personal data

In accordance with section 222 of the Danish Health Act (Sundhedloven), SSI's public authority tasks include being part of the operational preparedness against infectious diseases, including in the form of observing and monitoring infectious diseases. EFTER-COVID is a study that aims to uncover how people felt in the weeks and months following a coronavirus test (whether positive or negative) and to compare the two groups.

After having been affected by the pandemic for over a year, we now know that COVID-19 can cause rise to serious risk of hospitalisation, respirator treatment and death, especially in certain at-risk groups. New knowledge suggests that long-term effects may occur, including headaches, shortness of breath, fatigue, reduced sense of taste and reduced cognitive function (difficulties concentrating, and tendency for depression). We are asking about both severe and mild symptoms, which can be difficult pinpoint in time. It is the extent and duration of these long-term effects in particular that EFTER-COVID will study, by asking both healthy and ill people about their health before and after testing and illness.

### 3. Categories of personal data and the lawfulness of processing of your personal data

We process the following categories of personal data about you:

- Common, non-sensitive personal data, including:
  - Name
  - Address
- Common, confidential personal data, including:
  - Civil registration (CPR) number
- Sensitive personal data:
  - Health data in the form of:
    - answer to whether you have been infected with COVID-19



If you answer the questionnaire, we will also process your answers to the questions. The data we process in connection with this will depend on your answers to the questions.

In addition to the above data, SSI will – through public registries – obtain additional personal data about you, for example age, gender and socio-economic background. SSI will do this when it is necessary for SSI's work with and measures for monitoring and assessing the health of the population during and following the pandemic.

SSI's purpose is to monitor and fight the spread of disease, see section 222 of the Danish Health Act<sup>1</sup>.

We thus process your personal data in accordance with Article 6(1)(e) of the General Data Protection Regulation<sup>2</sup>, as the processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in SSI. Furthermore, we process your personal data in accordance with Article 9(2)(h) and (i), as the processing is necessary for the purpose of disease prevention and for reasons of public interest in the area of public health.

We process your civil registration (CPR) number in accordance with section 11(1) of the Danish Data Protection Act<sup>3</sup> (*Databeskyttelsesloven*), as the processing is necessary to enable us to identify you clearly.

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

The data may be disclosed to research projects of significant public importance, provided that relevant authorisations have been obtained and the applicable legislation has been complied with. Such disclosure may be made pursuant to section 10 of the Danish Data Protection Act.

SSI uses data processors, including the Danish Health Data Authority, to process personal data on our behalf. We have entered into data processing agreements with our data processors and supervise the data processors' compliance with the data processing agreements in accordance with the applicable rules.

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

As a general rule, we will not transfer your personal data to recipients outside the EU and the EEA. If the SSI should need to transfer data to countries outside the EU and the EEA, this will take place in accordance with the rules of the General Data Protection Regulation aimed at maintaining the same security level as in the EU and the EEA

#### **6. Sources of your personal data**

We have received information about your CPR number from the CPR Register. In addition, we receive information from you. We may also receive additional information about you, for example your age, gender and socio-economic background from public registers, when this is regarded as necessary for SSI's work and measures aimed at assessing the health of the population during and following the pandemic.

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

Personal data about you and any answers to the questionnaire will be retained for as long as necessary for carrying out the study. The data will then be erased or anonymised.

<sup>1</sup> Consolidation Act no. 903 of 26 August 2019 to consolidate the Danish Health Act, as amended.

<sup>2</sup> Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons 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) (Text with EEA relevance).

<sup>3</sup> Act no. 502 of 23 May 2018 on supplementary rules to the Regulation on protection of natural persons in connection with the processing of personal data and the free exchange of such data.



## 8. Your rights

Under the General Data Protection Regulation, you have a number of rights in relation to our processing of your data. If you want to assert these rights, you should contact SSI [via the EFTER-COVID project mailbox](#), which is found under the main mailbox for Statens Serum Institut in e-Boks, or by emailing [eftercovid@ssi.dk](mailto:eftercovid@ssi.dk)

### *Right to access data (right of access)*

You have a right to see the data we process about you as well as other additional information.

### *Right to rectification (correction)*

You have the right to have inaccurate data about you corrected.

### *Right to erasure*

In exceptional cases, you have the right to have data about you erased before we normally erase such data.

### *Right to restriction of processing*

In some cases, you have the right to have the processing of your personal data restricted. If you have the right to restriction of our processing, this means that, in future, we may only process the data – with the exception of storage – with your consent or for the establishment, exercise or defence of legal claims or for the protection of the rights of another natural or legal person or for reasons of important public interest.

### *Right to object*

In certain cases, you have the right to object to our otherwise lawful processing of personal data about you.

You can read more about your rights in the Danish Data Protection Agency's guide on the rights of data subjects, which you can find on [www.datatilsynet.dk](http://www.datatilsynet.dk).

## 9. The Data Protection Officer's contact details

If you have any questions about our processing of your personal data, you are always welcome to contact the Danish Ministry of Health's joint Data Protection Officer, Helle Ginnerup-Nielsen.

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

By email: [databeskyttelse@sum.dk](mailto:databeskyttelse@sum.dk)

By post: Holbergsgade 6, DK-1057 Copenhagen K, FAO: "Data Protection Officer"

## 10. Lodging a complaint with the Danish Data Protection Agency

You have the right to lodge a complaint with the Danish Data Protection Agency if you are dissatisfied with the way we process your personal data. You can find the Danish Data Protection Agency's contact details on [www.datatilsynet.dk](http://www.datatilsynet.dk).