# The Norwegian Pandemic Registry

This information describes how your personal information is processed by the Norwegian Pandemic Registry and your rights in relation to this. Please get in touch if you have questions or if anything is unclear.

You do not need to do anything, unless you want to opt out of information being collected about you, or if you want to exercise your rights.

## **About the Norwegian Pandemic Registry**

The Norwegian Pandemic Registry is an important tool for providing an overview of hospital admissions due to the coronavirus. The registry shall ensure coordinated and effective reporting of patients who are ill due to the coronavirus in Norwegian hospitals. All patients with Covid-19 admitted to hospital will be registered in the Norwegian Pandemic Registry. The results from the registry will among others be used by the Directorate of Health and the Institute of Public Health in their daily reports.

The results from will provide information about the disease Covid-19, which can be used to improve patient treatment, through analysis and research. The information collected can also be used in connection with planning, management and emergency response in the health and care services and in the health and care administration. Helse Bergen health trust is the data controller of the registry.

#### You can contact the registry if you have any questions:

Norsk pandemiregister Helse Bergen HF P.O. Boks 1400 NO-5021 Bergen

Tel.: (+47) 5597-5000

Email: norskpandemiregister@helse-bergen.no

#### What information does the Norwegian Pandemic Registry store about you?

The Norwegian Pandemic Registry contains information about your stay in hospital when you were admitted due to the disease Covid-19. An overview of the type of information that will be registered about you is provided below.

- Name
- Address
- Personal ID number
- Possible causes of infection
- Whether you are particularly exposed to infection through your work
- Length of stay at the hospital
- Previous and current state of health
- Findings on admission
- Treatment measures
- Survival

In addition to the information described here, information will be collected in accordance with the recommendations from the World Health Organization (WHO). An overview of the information concerned can be found here. After your stay at the hospital, you may also be contacted to answer some questions.

In order to ensure that the information in the registry is correct, and to collate data in the Norwegian Pandemic Registry with data in other registries, the information will be linked to personal identity. To maintain confidentiality, information such as name and date of birth is stored separate from other information in the registry.

#### Storage time

The information about you is stored and used as long as the information is necessary for the purposes described here.

# Reporting from the registry

The purpose of the Norwegian Pandemic Registry is to report to the authorities, to contribute to improving treatment for patients with Covid-19. The registry can, among other things, be used to report on:

- Admitted patients in Norway as a whole, and in different parts of the country.
- Admitted patients of different age groups, gender and risk factors.
- Analyses of the effects of different risk factors, different degrees of illness and different treatment choices on the length and severity of the illness.
- Planning and evaluation of the authorities' measures during the pandemic.

It will **not** be possible to identify you in reports from the Norwegian Pandemic Register.

### Disclosure of personal data and connection to other registries

The information in the registry can be collated with information in other regulatory and statutory registries in accordance with the Personal Health Data Filing System Act, such as the Norwegian Patient Registry and the Norwegian Surveillance System for Communicable Diseases (MSIS). The information can also be collated with the information in biobanks, as long as the biobanks are entitled to share this information. This is done to determine how the disease Covid-19 develops in different patient groups.

Information may also be disclosed from the registry in connection with scientific research on the treatment you receive and the subsequent consequences of the disease.

Your personal data can only be disclosed, or otherwise made available, pursuant to laws and regulations, such as the rules on the duty of confidentiality and the European General Data Protection Regulation.

Information may be disclosed to enterprises abroad, among other things in connection with scientific research.

#### Right to access, correction, erasure and opting out

You can request access to the information registered about you at any time, or request that the information be deleted. You can also ask for incorrect information to be corrected.

You have the right to opt out of your personal and health data being stored and used in the Norwegian Pandemic Registry. If you do not want your information to be stored, you can opt out at any time without any reason. The information about you will then be deleted. This will not have any consequences for the health care you receive. If you decide to opt out, the information about you in the registry will be erased. However, Helse Bergen health trust will continue to process information to the extent necessary to maintain the trust's duty to ensure that people who have opted out of the registry are not re-included.

You can exercise your rights by filling out a form and sending it to the Norwegian Pandemic Registry. The address is provided in the form, which can be downloaded here.

#### Access and opt-out form (PDF)

## Laws and regulations

The Norwegian Pandemic Registry is part of the Norwegian Intensive Care and Pandemic Registry and is regulated by medical quality registries, the Personal Health Data Filing System Act and the General Data Protection Regulation.

The registry shall attend to tasks in the public's best interest and has legal grounds in the General Data Protection Regulation Article 6(1) letter (e) and Article 9(2) letter (g, h, i and j). The Personal Health Data Filing System Act and medical quality registries supplement its legal basis in national law. When the registry processes your information to address Helse Bergen health trust's public law duties, the legal basis is provided by Article 6(1)letter (e).

Information about your contact with the specialist health service can be obtained and used by the registry without your consent, but you have a right of access to the information and you have a right to opt out of the registry processing your data.

You can obtain general information about your rights and freedoms with regard to data protection by contacting the data protection officer at Helse Bergen health trust by calling (+47) 55 97 50 00 or by sending an email to postmottak@helse-bergen.no

#### **Complaints**

If you believe your rights have not been upheld, you can submit a complaint to Helse Bergen health trust. You can also submit a complaint to the Norwegian Data Protection Authority.

#### **Key regulations**

- General Data Protection Regulation and the Personal Data Act
- The Patients' and Users' Rights Act:
- The Health Personnel Act
- The Personal Health Data Filing System Act
- Regulations relating to medical quality registries
- The Health Research Act