

# Consent to be included in register

Do you consent to being included in the local and central clinical quality register for rehabilitation services — "Rehabiliteringsregisteret"?

#### **Purpose**

The purpose of the registers is to raise awareness and improve the quality of rehabilitation services, both locally and nationally.

## Why are you being asked to give your consent?

Patients' perceptions of their own health represent valuable information in the efforts being made to improve the quality of rehabilitation services. We are therefore asking you as a patient to consent to be included in the registers.

## Inclusion is voluntary

Inclusion is voluntary. It will not have any negative consequences for you or your treatment if you do not wish to be included. You can withdraw your consent at any time.

## What will inclusion in the register mean for you?

You will receive two or more questionnaires in connection with your impending rehabilitation stay and any future rehabilitation stays at the same or other institution. You will be asked to complete and return these questionnaires. Once you have returned the questionnaires, the responses from the questionnaires will be entered in the local register of the institution that is treating you, and submitted to the Norwegian Directorate of Health's central register. If you decide you do not wish to receive further questionnaires, you can tell us at any time.

#### What data will be stored in the registers?

In addition to your personal data (name, national ID number and address) and the answers you give in the questionnaires, relevant data from your patient record will also need to be recorded. This includes diagnoses, background information such as home address, occupational status, etc., administrative information such as when you were admitted/discharged etc., information about treatment you have received, and the results of medical investigations and examinations.

This information will be obtained from your patient record. It will then be entered in the local register and notified to the central register.

### Who is responsible for the registers?

The health trust/rehabilitation institution where you are receiving rehabilitation is responsible for the local register (register containing data from patients of the relevant health trust/rehabilitation institution).



The Norwegian Directorate of Health is responsible for the central register (register containing data from all the rehabilitation institutions and departments in the country).

## How we store your data

The data is stored in accordance with the provisions of the General Data Protection Regulation (GDPR), the Patient Record Act, the Personal Health Data Filing System Act and the Regulation on clinical quality registers. This means for example that it will be kept securely and that no unauthorised persons will be able to gain access to it. Data about you will be stored separately from your name and national ID number.

#### How we use your data

- The data you provide in the questionnaires may be used in your treatment and included in your patient record, in addition to being entered in the registers as described above.
- The information in the local register will be used to improve the quality of rehabilitation services provided by the institution/health trust.
- The data in the central register will be used in the national work to improve the quality of rehabilitation services, including the development of national indicators that provide an indication of service quality, as well as the preparation and publication of statistics, etc. As part of this work, the information may be disclosed to and compiled with information from the National Population Register and health registers established pursuant to Sections 8 to 11 of the Personal Health Data Filing System Act, and compiled with socioeconomic information in other public registers. No identifiable information will be published.
- The information may be used for research within the field of rehabilitation in accordance with the provisions of the Health Research Act.
- The information will not be used for any purposes other than those described above.

#### How long will we store your data for?

Your data will be stored indefinitely, i.e. it will not be deleted while it is needed in order to fulfil the purpose of the registers. If there ceases to be a need for the data, or if you withdraw your consent to be included in the registers, data about you will be erased.

#### You have a right to:

- Be told what data is registered about you
- Receive information about how your data is processed
- Have inaccurate information about you corrected
- Have data that has been registered about you erased
- Receive a copy of the data that has been registered about you
- Withdraw your consent to be included in the registers

At <u>Helsenorge.no</u> you can get insight into data registered about you, and you can withdraw your consent.



## You have the right to complain about how your data is processed

If you are unhappy about the way your data is being processed, you have the right to complain to the Norwegian Data Protection Authority. To do this, send a written complaint to:

Norwegian Data Protection Authority, P.O. Box 458 Sentrum, 0105 Oslo

More information about the complaints procedure can be found here:

https://www.datatilsynet.no/om-datatilsynet/kontakt-oss/hvordan-kan-jeg-klage-til-datatilsynet/

## Contact details for your local register

If you have any questions about how your local registry processes your data or you wish to withdraw your consent, please contact your care provider at the institution.

## Contact details for the central register

If you have any questions about how the central register processes your data or you wish to withdraw your consent, please contact the Norwegian Directorate of Health by e-mail: rehabiliteringsregister@helsedir.no

Remember not to include any sensitive information in e-mail enquiries.

Enquiries can also be sent to:

Rehabiliteringsregisteret, avd. KFVR, Helsedirektoratet, Postboks 220, Skøyen, 0213 Oslo

#### Consent

I have received and understood information about the local and central rehabilitation registers and have been given the opportunity to ask questions.

I give my consent to be included in the registers, i.e. to the collection, retention and use of the data, as described above.

L	l give	my o	consent	to be	includ	ed in t	he reg	isters

Name in block letters		National ID number
Place and date	Signature	