



Date of birth

Name

## Consent form

Information and request to consent for participation in the Norwegian Spinal Cord Injury Registry – NorSCIR.

### Background

Approximately 100 persons a year suffer spinal cord injuries in Norway. Such injuries can have permanent consequences and necessitate life-long follow-up. There are three Norwegian specialist entities for rehabilitation and follow-up of patients with spinal cord injuries: Sunnaas Hospital/Oslo University Hospital Ullevål, Haukeland University Hospital in Bergen and St. Olavs Hospital in Trondheim. A national quality register for this patient group was established in 2011 in cooperation with the Norwegian Spinal Cord Injuries Association (LARS). St. Olavs Hospital has been assigned data controller responsibility for the register.

### Purpose:

The purpose of the register is to ensure expedient and safe treatment of patients with spinal injuries, and to improve our knowledge of the treatment in relation to both individual patients and the patient group as a whole.

### Where will the information be taken from?

In order to assess the quality of treatment, we need information about you from your whole care pathway. Data will be collected in accordance with national and international guidelines. The information registered is based on information obtained by doctors and other health personnel in connection with your hospital stay.

### What information will be registered?

The register will contain information about year of birth, sex, place of birth, address, date of injury, education etc. Information about the consequences of the injury and results of examinations and treatment measures will also be registered. You will also be asked to fill in a form about your quality of life at several points during your care/check-up pathway. The first registration will take place as soon as you have consented to participating in the quality register. New registrations will be made in connection with check-ups.

### Who can access the information?

Information will be transferred from the hospital where you are treated to a national register, where it will be stored in anonymous form. The register has been approved by the Norwegian Data Protection Authority. Data in the register will be stored for as long as the register has been licensed for. All data will be deleted if the licence expires. The collected data will be treated confidentially, which means that only people who work with the register will be able to read them. All persons who have access to the register are subject to a duty of confidentiality.

### Research and quality assurance

The register can be used to assess what factors have a bearing on good or bad treatment outcomes, or to establish the importance of the treatment in relation to sociomedical aspects and health economics. Such quality assurance of the health service requires the use of research methods, possibly as part of research projects. For such purposes, information from the register may be aligned with central registers, including foreign ones (the Nordic countries/EU) (see the list on page 2). The information will also be regularly aligned with information from the Norwegian Patient Register in order to calculate the register's coverage rate. You may also be invited to participate in special research studies relating to the purpose of the register. All alignment of data requires the advance approval of the public bodies required by law, for example data protection officers, the Regional Committee for Medical and Health Research Ethics, the Norwegian Data Protection Authority, the Norwegian Directorate of Health or the Norwegian Labour and Welfare Administration (NAV). All information will be processed in accordance with the principle of protection of privacy and in compliance

with applicable laws and regulations. Annual national reports from the register will be prepared. Results will also be published on a continuous basis at professional conferences and in national and international medical journals. It will not be possible to identify individuals from results based on analyses from the register.

When giving your consent to participate in the Norwegian Spinal Cord Injury Registry – NorSCIR, you accept that registered information can be used for quality assurance as well as for research purposes, and you also consent to being contacted again outside hospital check-ups.

### Rights

Registration in this register is voluntary, and written consent is required for registration to take place. If you do not wish to consent, that will not have any consequences for the treatment you receive at the hospital/in the specialist health service. You are entitled to know what information is registered about you in the register, and you can demand that information about you be deleted or corrected without having to state your reasons. You can find information about the register at [www.kvalitetsregistre.no](http://www.kvalitetsregistre.no), where you will also find information about how to proceed to if you wish to have information about you in the register deleted or corrected. The department where you receive treatment will also have information about the register.

Yours sincerely



Annette Halvorsen  
Chair of the steering committee

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Consent to participation in the Norwegian Spinal Cord Injury Registry – NorSCIR

I have read the information and consent to the above-mentioned information being registered and made available for quality assurance and research purposes.

Place: \_\_\_\_\_ Date: \_\_\_\_\_ Signature: \_\_\_\_\_

Information from the Norwegian Spinal Cord Injury Registry – NorSCIR may be aligned with the following public registers and population studies: følgende offentlige registre og befolkningsundersøkelser:

The Medical Birth Registry	FD Trygd social security database
The Cause of Death Registry	The Population Register
The Cancer Registry of Norway	Norwegian Labour and Welfare Administration (NAV)
The Norwegian Prescription Database	The Norwegian Cardiovascular Disease Registry
The Norwegian Patient Register (NPR)	The Directorate of Taxes' databases
The Norwegian National Trauma Registry	Registers in Statistics Norway
The Norwegian Registry for Spine Surgery (NORSpine)	The Nord-Trøndelag health study (HUNT)
The Tromsø Study	