

Swedish Neuro Registries, a joint national quality registry – Information for you as patient

The Swedish healthcare system constantly strives to ensure and improve quality of care, with an aim to achieving superior care results and the best possible patient satisfaction. To this end, our department submits information to the joint national quality registry – Swedish Neuro Registries. The registry contains information about patients suffering from the following chronic diseases of the nervous system: multiple sclerosis (MS), Parkinson disease, Narcolepsy, myasthenia gravis, inflammatory polyneuropathy, epilepsy, motor-neuron disease and severe neurovascular headache. In the future, additional disorders will be added to the registry.

Your participation makes better care possible

The quality registry is supported by the Swedish Association of Local Authorities and Regions (*Sveriges Kommuner och Landsting*). The registry makes possible the monitoring and improvement of your and other patients' care. Data gathered in these registries are used to evaluate which approaches, treatment strategies, medications and medical interventions produce good results, and which should no longer be used. Swedish Neuro Registries was started in the 1990s with all Swedish counties represented. MS was the first disorder included in the registry, and several other neurological disorders have been added since then. Additional disorders will be covered in the future. The aim of Swedish Neuro Registries is to promote good care for individuals with chronic neurological conditions, regardless of place of residence, gender or age. More information is available at www.kvalitetsregister.se and www.neuroreg.se.

Registered data

In order to ensure and improve the quality of neurological care, we register your personal identification number (*personnummer*), diagnosis, clinical data and treatment strategies, as well as results from laboratory and functional tests.

How your information is handled

Information about you is taken from your medical records or provided directly by you. Your information may only be used to improve the quality of care, to generate statistical reports or to aid healthcare research approved by an ethical committee. Provided information may be used for any of these three purposes after an approved confidentiality assessment. Transfer of data can be performed electronically.

You may be asked to participate in particular research studies. Your participation will, in that case, be entirely voluntary. When registry information is requested for research studies, appropriate approval by a regional ethical review board is always required.

Confidentiality

Your information is confidential and protected by the Public Access to Information and Secrecy Act (*offentlighets- och sekretesslagen*). This means that information about you may not be released from the registry in cases in which such release would entail negative consequences for you or someone close to you.

Security

Your information is protected from unauthorized access. Specific regulations ensure, among other things, that only those who are authorized can have access to data. The regulations also stipulate that no unauthorized person may have access to the data; that information must be protected by encryption; and that the login procedure to access information must be secure.

Access

Your local healthcare provider has access to the information that it submits to the registry. No other healthcare provider has access to the information. Those who manage the joint registry centrally are also authorized to access your information.

Conservation and deselection

The Patient Data Act requires that the information in the quality registry be anonymized when it is no longer needed for quality assurance purposes. However, the County Council Archives may allow the keeping of data records for historical, statistical or scientific purposes. A preservation decision for the Swedish Neuro Registries has not yet been granted.

Your rights

Your participation in the registry is voluntary and will not affect the care you receive. You may at any time request that your healthcare provider delete information from the registry. From that point on, further collection of your data will not be permitted. Further, you have the right to:

- request, once a year and free of charge, an extract of your data from Swedish Neuro Registries in accordance with § 26 of the Personal Data Act;
- request information about the access to your data that has occurred;
- have incorrect information corrected and have third parties informed of this amendment;
- receive compensation if, according to the Patient Data Act, your data has been violated.

Responsibility for personal data (Central Personuppgiftsansvarig)

The board of directors of Karolinska University Hospital has ultimate responsibility for the quality registry.

Contact details for the joint national quality registry - Swedish Neuro Registries

Jan Hillert, registry holder, e-mail: jan.hillert@ki.se

Lillemor Bergström, coordinator, e-mail: info@neuroreg.se

Address: Department of Neurology, Karolinska University Hospital, 171 76 Stockholm

You can also contact the Data Protection Officer at your local healthcare provider or centrally at Karolinska University Hospital, 171 76 Stockholm. Telephone: 08-517 700 00

Local contact at the department