

Information for patients and relatives

The National Stroke Register (Riksstroke) is a national register with its seat in the Västerbotten County Council. The aim of the register is to support high-quality care for all stroke patients irrespective of their place of residence, gender and age. Since 1998, all hospitals in Sweden report to the register. The register is funded by the National Board of Health and Welfare and the Swedish Association of Local Authorities and Regions <http://www.kvalitetsregister.se/>

Approximately 25,000 admissions due to stroke are recorded each year in Sweden. Patients with TIA are also recorded in the register due to the fact that TIA is a risk factor for developing a stroke. A summary of the recorded data takes place at Norrland's University Hospital in Umeå. The results are presented in an annual report which can be found at www.riksstroke.org under the tab annual reports.

In order to obtain reliable data, it is important that most of those who suffer from a stroke or TIA are included in the register. Reliable data increases the possibility to improve the conditions and treatment for those who suffer from a stroke or TIA and their relatives.

Recorded data

Stroke

The data that is recorded during the acute stage of the stroke includes the patient's personal identity number, gender, living arrangements and functional ability before the onset of stroke. Medical treatment, risk factors, complications linked to the illness, team assessments and medical examinations are also recorded.

A follow-up is carried out either by a letter or a phone call three months after the onset of stroke. Earlier questions are followed up with a questionnaire. Patients are also given an opportunity to comment on the treatment that they have received. Questions about general health and the support received after leaving the hospital are also included in the questionnaire.

A similar survey is also carried out one year after the onset of stroke. This gives the patients an opportunity to comment on the support that the municipality has provided. The results are presented in a report entitled "One year after the stroke", which can be found at www.riksstroke.org under the tab other reports.

TIA (Transient Ischemic Attack)

TIA is an ephemeral lack of oxygen in one of the arteries in the brain. Each year, approximately 10-12.000 patients have TIA. The patient's personal identity number and gender are registered during the acute stage of TIA. Medical treatment, risk factors, complications linked to the illness, team assessments and medical examinations are also recorded.

Processing patient data

Data is collected from the patient journal and the patients themselves. The data in the quality register may only be used for developing and ensuring the quality of stroke treatment, for compiling statistics and for health care research purposes. Data may also, after confidentiality assessment, be disclosed to those who are going to use it for any one of these three purposes. Data that may be disclosed from the register may be sent electronically. Data used in research requires the approval of an ethics board.

Confidentiality

The data in the National Stroke Register is treated according to the Public Access to Information and Secrecy Act in the same way as medical records. This means that data from the register may only be disclosed when it is certain that the disclosure does not cause any damage or distress to the patient and his/her relatives.

Security

The data in the register is protected from unauthorised people. There are specific security regulations in place, which means e.g. that only those who need your data may get access to it, that it must be ensured that data has not been disclosed to any unauthorised persons, that the data is protected by encryption and that secure log-in is used in accessing the data.

Access

The caregiver reporting to the register has direct access only to the data that they are reporting. No other caregiver has access to this data. Those who manage the register can and may have access to the data.

Erasure of data

The data is erased from the register when it is no longer needed for developing and ensuring the quality of stroke treatment.

Your rights as a patient

- Participation in the National Stroke Register is voluntary and does not affect the treatment that you receive. Should you wish to decline to have your data registered, please inform the contact person mentioned below.
- You have the right to demand, at any time, all data stored about you to be erased from the register
- You have the right to obtain a log file with information about the caregivers that have had access to your data and the times when someone has accessed your data.
- You have a right to damages if your data is processed contrary to the Personal Data Act or the Patient Data Act.
- You have a right to demand rectification if your personal data has not been processed in accordance with the Personal Data Act.
- You have the right, once per year, to access the data stored about you free of charge (extract from the register). Requests for an extract from the register must be made in writing, signed and sent to the contact person mentioned below.

Contact information:

Contact us if you wish to

- Receive information about the caregivers that have had access to your data and the times when someone has accessed your data.
- Obtain more information about the register.
- Decline to have your data reported to the register.
- Have your data erased from the register.

.....
(Contact person at Riksstroke)

Should you wish to obtain an extract from the register, please send your request, in writing, to:

.....

(Personal data representative/local authority)

Personal data representative

Local authority (political board or council) for the data gathered and reported to the register is:

.....

Central organisers of the register are the Västerbotten County Council, Norrland's University Hospital in Umeå.