

## **Information regarding participation in the National Quality Registry for Stroke (Riksstroke)**

At this care unit, we register information regarding patients who have suffered a stroke or TIA in the National Quality Registry for Stroke (Riksstroke). The purpose of the registry is to promote good care for all stroke patients, regardless of where they live, their gender or their age. To obtain reliable data, it is vital that the majority of those who suffer a stroke or TIA are included in the registry. Reliable data increases the possibilities of improving the conditions both for those who have suffered a stroke or TIA and for their loved ones.

### **What information is registered**

Data is collected by the nursing staff and from the patients. In addition, some data is retrieved from patient records, the national population register and other registers.

**Stroke** When you come in for emergency care, your personal identity number, gender, type of accommodation and functional ability prior to onset of stroke are registered. Other information registered includes medical treatment, risk factors, disease complications, team assessments and examinations. Three months after the onset of stroke, a follow-up is conducted where you are contacted via letter or phone call. Prior issues are then followed-up using a questionnaire. You are then given the opportunity to provide opinions on the care you have received. A similar survey is conducted one year after the onset. Here you have the opportunity to submit opinions on the support measures provided by the municipality.

**TIA** When you come in for emergency care, your personal identity number and gender are registered. Other information registered includes medical treatment, risk factors, disease complications, team assessments and examinations.

The County Council of Västerbotten has the overall legal responsibility for the personal data in Riksstroke. The body with overall responsibility is centrally referred to as the controller. The care unit assumes a local legal responsibility for the collection of data.

### **Contact information**

When your information is included in a quality registry, you have certain rights. Read more about these below. If you would like to contact Riksstroke regarding your rights, use this contact information:

Riksstroke, Target point PA room 1013, Norrland's University Hospital, 901 85 Umeå

Tel. +46 (0)907858783, E-mail address [info@riksstroke.org](mailto:info@riksstroke.org), Website <http://www.riksstroke.org/>

Contact information for care unit

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(contact person, name of care unit, hospital, county council/region)

You can also contact a Data Protection Officer with questions that concern your personal data kept in a quality registry. The Data Protection Officer monitors compliance with laws that relate to the processing of personal data. If you would like to know who is the Data Protection Officer at this care unit, contact the staff above.

The Data Protection Officer at the central controller agency is: The Västerbotten County Council Executive Committee, Norrland's University Hospital, 90185 Umeå, E-mail address [dataskyddsbud@vll.se](mailto:dataskyddsbud@vll.se)

### **You are contributing to better care**

By participating in a national quality registry, you are helping to improve care. Participation is voluntary and it does not affect the care you receive. The data is used to compare the care received across different care units and care providers around the country. The results can be used for improvement initiatives and research. The quality registry contributes to new knowledge on what constitutes best treatment, and the more patients included, the more accurate the results.

### **Support in legislation**

All parties processing personal data must have legal grounds to do so. Processing of personal data in quality registries is regulated by the General Data Protection Regulation (GDPR) and chapter seven of the Swedish Patient Data Act (PDL). It is permitted to register data in a quality registry as the data is of public interest to society and vital within the field of medical care. The staff processing personal data in a quality registry are subject to statutory professional secrecy.

### **How your data is used**

Data concerning you in a quality registry may only be used to develop and assure the quality of health care, to produce statistics, and for research within health and medical care. The data may also, following a confidentiality assessment, be provided to a party that will use this data for one of these three purposes. If data may be disclosed, this can be done electronically.

### **Confidentiality**

Data concerning you in a quality registry is protected by the professional secrecy within health and medical care as stipulated in the Public Access to Information and Secrecy Act. As a rule, this means that data concerning you in a quality registry may only be disclosed if it is clear that it will not be detrimental to you or someone close to you if the data is disclosed.

### **Security**

The data concerning you in a quality registry is protected against unauthorised access. Only those requiring the data to carry out their work may have access to it. Checks are performed to ensure that no unauthorised persons have gained access to the data, so-called log

management. The data is protected with encryption. Logging in to the registry to access data is done in a secure manner.

### **Access**

Authorised staff at the care unit who have entered the data in the quality registry have access to this specific data. No other care provider can access the data. Authorised staff working at the quality registry have access to all data in the registry.

### **Storage time and data erasure**

Data concerning you is deleted when it is no longer needed to develop and assure the quality of health care.

### **Your rights**

- You have the right not to have data concerning you being registered in the quality registry.
- You have the right, at any time, to have data concerning you erased from the quality registry.
- You have the right to know if data concerning you is being kept in the quality registry and, if so, to obtain a copy of this at no charge, a so-called registry extract. You have the right to receive the data in electronic form.
- You have the right to have incorrect data concerning you rectified. You have the right to have incomplete data supplemented.
- Under certain conditions, you have the right to request that the processing of data concerning you be restricted. This applies during the period when other objections are being assessed. The restriction means that the quality registry may not do anything with the data concerning you aside from continuing to store it.
- You have the right to obtain information regarding which care units have had access to data concerning you and when this occurred, a so-called log extract.
- You are entitled to damages if data concerning you is processed in contravention of the General Data Protection Act or the Swedish Patient Data Act.
- You are entitled to submit complaints to the Swedish Data Protection Authority, which is the supervisory authority in this area.