

INFORMATION FROM YOUR CARE-PROVIDER

Information to patients and their relatives regarding the processing of personal data by the Swedish national quality registries

Within the Swedish health service there are more than 100 different National Quality Registers, and they are used in all hospitals.

Vision

The National Quality Registers shall:

- contribute to saving lives and to the achievement of equality of health
- be used actively for follow-up, education, quality development, improvement, research and management

Purpose

The purpose of the National Quality Registers is to make health and sickness care equivalent and of high quality nation-wide and to ensure that treatment guidelines are adhered to.

You can contribute to better care

By being included in the National Quality Registers you contribute to the improvement of health care throughout Sweden. Your participation in the quality register is voluntary and does not affect the care you receive. Your data are used by the care provider for comparison with other care-providers in the country. This information makes it possible to decide which work procedure, which methods of treatment and which medicines give the best results. The information is subsequently used by the care-providers to improve their work.

As care-providers, we compile information about patients in accordance with the Patient Data Act (2008:355). Our ambition is to compile data relating to as many patients as possible. The greater the number of patients involved, the more reliable are the conclusions and the greater is the possibility of developing the care provided.

These data are recorded

The data recorded by the National Quality Registries are the Civic Registration Number (date of birth), health-care contacts, diagnoses, treatment etc. Sometimes information which you yourself provide on questionnaire forms which you receive are also recorded.

Who is responsible for the National Quality Registers?

As care-providers, we are responsible for entering your data in the National Quality Register and for ensuring that they are transferred to the register in a secure manner. We are also responsible for your data when we use them in our internal quality work. We are not however responsible for the quality register. The region is normally responsible. On www.kvalitetsregister.se you can see which region and which register-keeper is responsible for the register in which your data are recorded.

This is how we use your data

Information is recorded in the quality register in order to enable the quality of the care provided to be continually improved and to provide statistical information. The data may also be used in research but only with the approval of the Ethical Review Authority. Data may furthermore be subject to data discovery for clinical research.

In order to compile and find information, we use not only your civic registration number but also various search functions. Sometimes data from the quality register are coordinated with data from other registers which contain information relating to health care and the population.

When statistical information from the registers is published it is impossible to identify information relating to any particular individual.

These persons have access to information about you.

Only certain members of our staff register information about you and have electronic access to the information. In addition, only specially appointed persons working with the quality registers in the regions have access to the data relating to individual patients. The information in the National Quality Register may only be given to someone outside the health care service if it is clearly shown that neither the patients nor their relatives will suffer in any way as a result. In practice, only researchers can extract personal data about individual patients from the quality register.

This is how your data are protected

The information about you as a patient is protected by several laws: EU's General Data Protection Regulation, the Public Access to Information and Secrecy Act and the Patient Data Act. This means that there are strict regulations concerning who can have access to the information about you. The information has the same strong protection as your medical case notes. There are also controls to ensure that no unauthorized person can gain access to the information, that your data are protected by encryption and that access to the data can only be achieved by logging in according to a secure procedure.

Legal support for the Swedish National Quality Registries

All persons processing personal data must be legally authorised in accordance with EU's General Data Protection Regulation, and also in certain cases also by Swedish or other legislation. The Swedish National Quality Registers are considered to carry out a task in the public interest in accordance with Article 6 e of EU's General Data Protection Regulation and are therefore permitted.

The Quality Registers are also regulated by Chapter 7 of the Patient Data Act.

There is thus legal support for us and for the region responsible for the National Quality Register processing your data. Information about a person's health is classified as sensitive personal information and the processing of such information requires a legal basis, but such data may according to the EU's General Data Protection Regulation be recorded in the register because it is necessary for reasons related to the medical profession and the provision of health and sickness care (Article 9.2h) and it is also supported by the Patient Data Act.

Storage time and removal of data

Information relating to you will be removed when it is no longer needed for developing and ensuring the quality of health care. The archive authority in the region responsible for the National Quality Register may however decide to save your information until further notice for use for historical, statistical or scientific purposes.

Your rights

At this health centre, we register information in the National Quality Register. If you as a patient do not wish us to register information about you, you have the right to choose not to participate. If so, please inform the staff or contact the keeper of the register afterwards. See the information above.

You also have other rights:

- You have at any time the right to ask that the information about you be removed from the register.
- You have the right to receive confirmation that personal data relating to you are being processed in the region responsible for the quality register and if so to receive a copy of your personal data free of charge.
- You have the right to know to what categories of recipient your information may be given, e.g. for research purposes. You also have the right to know whether information about you is taken from any other source than your medical case notes or you personally.
- You have the right to receive your personal data in an electronic format.
- You have the right to have incorrect personal data corrected and to complement incomplete personal data.
- Under certain conditions, you have the right to request that the processing of your data be restricted. This applies during the time when other rights claimed by you are being assessed. The restriction means that the National Quality Registries can do nothing with your data other than to continue storing them.
- You have the right to information regarding which care unit and at what time someone has had access to your data. You have the right to damages if your personal data are handled in conflict with EU's General Data Protection Regulation or the Data Protection Act.
- You have the right to submit a complaint to the Swedish Data Protection Authority.

Contacts

If you require more information about the National Quality Registries, to gain access to your information, to request a correction to or limitation of the information about you or to request that the information be removed, you can contact us or the region which is responsible for the register concerned.

You can read more about all the National Quality Registries at www.kvalitetsregister.se