# Information to patients about registration in The Swedish Intensive Care Registry

[Namn på Vårdenheten] records data on patients in The Swedish Intensive Care Registry. Data are collected by healthcare professionals and from patients.

The register monitors the volume, quality and outcome of intensive care in Swedish intensive care units. The work also includes registration of requests for admission to intensive care units and follow-up after intensive care. The main purpose of the register is to develop the quality of care. This means that before your ICU care, you may have been contacted by staff from the Intensive Care Unit (MIG-Mobile Intensive Care Groups) of a general care ward because of abnormal values in respiration, pulse, blood pressure, kidney function, level of consciousness or other incipient failure of any organ. This information on vital signs failure has been recorded and registered by the intensive care unit. Even after the ICU stay, you may be called to a follow-up appointment where information describing the situation before the illness and conditions during the stay may be of interest (e.g. level of ADL function, work capacity, BMI). This information is also recorded and reported to the Swedish Intensive Care Register.

The person who has overall responsibility is called the Central Personal Data Authority (CPUA). Region Värmland has overall legal responsibility for the personal data in The Swedish Intensive Care Registry.

[Namn på Vårdenheten] has a local legal responsibility for the collection of data.

## Contact

More information is available at www.icuregswe.org or at www.kvalitetsregister.se

When your data is included in a quality register, you have certain rights. Read more about them below. If you want to get in touch with The Swedish Intensive Care Registry regarding your rights, please use these contact details:
Göran Karlström
Phone: 010 – 839 14 90
goran.karlstrom@icuregswe.org

You can also contact a Data Protection Officer (DPO) with questions related to data about you in quality registers. Data protection officers monitor compliance with laws relating to the processing of personal data.
The data protection officer of [Namn på Vårdenheten] is [kontaktuppgifter].

The Data Protection Officer of the Board of Region Värmland is:
Erika Malmberg, erika.malmberg@intechrity.se

**You contribute to better care**By joining a National Quality Register, you contribute to better care. Participation in the register is voluntary and does not affect the care you receive. The data is used to compare care between different hospitals and healthcare providers around the country. The results can be used for improvement work and research. The quality registers contribute to new knowledge about what is the best treatment and the more patients are included, the more reliable the results will be.

**Support in the law**

Anyone processing personal data needs to rely on a legal basis. The processing of personal data in quality registers is regulated by the General Data Protection Regulation (GDPR) and chapter seven of the Patient Data Act (PDL).

It is permitted to register data in quality registers because the data is of general interest to society and important in healthcare. Staff handling personal data in quality registers are subject to a statutory duty of confidentiality.

All information on legal issues and quality registers can be found here: <http://kvalitetsregister.se/drivaregister/juridikochregelverk.1946.html>

## How your data is used The data about you in quality registers may only be used to develop and ensure the quality of care, to produce statistics, to conduct research in healthcare and to quantify data for clinical research. The data may also, after confidentiality assessment, be disclosed to someone who will use it for the purposes of quality assurance, statistics and research. If data can be disclosed, it can be done electronically.

**Confidentiality**

The information about you in quality registers is protected by health care secrecy in the Public Access to Information and Secrecy Act. As a general rule, this means that information about you may only be disclosed from quality registers if it is clear that neither you nor anyone close to you will suffer harm if the information is disclosed.

**Security and safety**Your data in quality registers is protected against unauthorized access. Only those who need the data to carry out their work are allowed to access them. It is checked that no unauthorized person has accessed the data, known as log tracking. The data are protected by encryption. Logging into the register to access data is done in a secure way.

## Access to the data Authorized staff of the healthcare unit that has entered the data into the quality register have access to that data. No other healthcare provider can access the data. Authorized staff or the responsible CPUA authority working on the quality register have access to all data in the register.

## Retention period and deletion Your data is deleted when it is no longer needed to develop and ensure the quality of care.

## Your rights

* You have the right not to have your personal data recorded in the quality register.
* You have the right to have your data deleted from the register at any time.
* You have the right to know whether information about you is in the quality register and, if so, to receive a copy of it free of charge, known as a 'register extract'. You have the right to receive the data in electronic form. Contact the quality register directly to obtain such an extract.
* You have the right to have incorrect data about you corrected. You have the right to have incomplete data completed.
* You have the right to demand that the processing of your data be restricted if
* You consider that the personal data is not accurate and during the time that the responsible CPUA authority checks this.
* You consider the processing to be unlawful and oppose the erasure of the personal data and instead request a restriction of its use.
* In a situation where the national quality register no longer needs the personal data for the purposes of the processing, but you consider that you need them for the establishment, exercise or defense of legal claims.
* Restriction means that the quality register is not allowed to do anything with your data other than continue to store it.
* You have the right to receive information about which healthcare unit and at what time someone had access to your data, known as a log extract.
* You are entitled to compensation if your personal data is processed in violation of the GDPR or the Patient Data Act.
* You have the right to lodge a complaint with the Data Protection Authority, which is the supervisory authority in this area.