[Name of healthcare unit] registers patient data in The Swedish Intensive Care Registry. Data is collected by healthcare staff and from patients.

The registry monitors the volume, quality, and outcomes of intensive care in Swedish intensive care units. The work also includes registering requests for admission to intensive care units and follow-up after intensive care. The main purpose of the registry is to improve 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) in a regular care unit due to abnormal values in breathing, pulse, blood pressure, kidney function, level of consciousness, or other incipient failure of an organ. This information about vital function failure has been recorded and registered by the intensive care unit. Even after intensive care, you may be called to a follow-up appointment where information describing the situation before the illness and conditions during the care period may be of interest (e.g., ADL functional level, work capacity, BMI). This information is also recorded and reported to The Swedish Intensive Care Registry.

The Regional Council of Uppsala Region is the central data controller (CPUA) and has overall legal responsibility for the personal data in the register. [Name of healthcare unit] has local legal responsibility for the collection of information about you.

## **It is voluntary** Participation in the registry is voluntary and does not affect the care you receive. Notify staff at your local healthcare facility if you do not want to be included in the quality registry.

## **Legal support**Anyone who processes personal data must have legal support for doing so. The handling of personal data in quality registers is regulated by the General Data Protection Regulation (GDPR) and Chapter 7 of the Patient Data Act (PDL).

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

## **How your data is used**The data about you in quality registers may only be used to develop and ensure the quality of care, produce statistics, and for research in healthcare. The data may also, after a confidentiality review, be disclosed to someone else who will use it for one of these three purposes. If data may be disclosed, this can be done electronically. All use for research purposes requires the approval of an ethics review board.

**Confidentiality**Your information in quality registers is protected by healthcare confidentiality under the Public Access to Information and Secrecy Act. This means that, as a general rule, your information 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**The information about you in quality registers is protected against unauthorized access. Only those who need the information to perform their work are allowed access to it. Checks are carried out to ensure that no unauthorized persons have accessed the information, known as log monitoring. The information must be protected by encryption when it is sent.

**Access**Authorized personnel at the healthcare unit that entered the information into the quality register have access to that specific information. No other healthcare providers can access the information. As the entity responsible for the register, authorized personnel at the CPUA authority may also access information about you.

**Storage period and deletion**Following a decision by the archiving authority in Region Uppsala, your data will be stored for the time being for use for historical, statistical, or scientific purposes.

## **Your rights** When information about you is included in a quality register, you have certain rights:

* Participation in the quality register is voluntary; you have the right to refuse to allow information about you to be registered.
* You have the right to have information about yourself deleted from the quality register at any time.
* You have the right to know if information about you is included 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 information in electronic form.
* You have the right to have incorrect information about you corrected. You have the right to have incomplete information supplemented.
* Under certain conditions, you have the right to request that the processing of your information be restricted. This applies during the period that a check is being carried out. Restriction means that the quality register may not do anything with your information other than continue to store it.
* You have the right to receive information about which healthcare units have had access to information about you and when, known as a log extract.
* You may be entitled to compensation if the information about you is handled in violation of the Data Protection Regulation or the Patient Data Act.
* You have the right to lodge a complaint with the Data Inspection Board, which is the supervisory authority in this area.

## **ContactQuality Register**More information is available at: [www.icuregswe.org](https://www.icuregswe.org/en/)If you would like to contact The Swedish Intensive Care Registry, contact details can be found on the website under “About SIR”

**Data Protection Officer**The Data Protection Officer monitors that the controller complies with the laws governing the processing of personal data. Contact details for the Data Protection Officer at the Regional Council of Uppsala: Box 602, 751 25 Uppsala, telephone: 018-611 00 00,
e-mail: dataskyddsombud@regionuppsala.se

You can also contact your local Data Protection Officer at your hospital.