**INFORMATION FOR PATIENTS ABOUT THE SWEDISH INTENSIVE CARE REGISTRY (sir)**

The National Quality Register, The Swedish Intensive Care Registry (SIR), monitors the volume, quality and results of intensive care at Swedish intensive care units (ICU). The work also includes registration of requests for entry into the intensive care department and follow-up after intensive care. This means that before you were admitted to the intensive care unit, you may have been contacted by staff from the Intensive Care Unit (RRT - Rapid Response team) at the regular ward due to deviating values in breathing, pulse, blood pressure, renal function, awareness or other onset of any organ. These data on failure in vital functions have been reported and registered by the Intensive Care Unit.
Even after intensive care, you may be called to the after-care clinic for some time after discharge from the ICU. At this follow-up reception measurements of your health-related quality of life through a health survey will take place. The survey focuses on how your health status, such as illness or disability, affects your quality of life. These data are also recorded and reported to SIR

To develop and secure the quality of intensive care, [enter healthcare provider] wants to report information about you to SIR. Central Data Responsible Authority for this registry is Värmland County Council. [enter healthcare provider] is personally responsible for the handling in connection with the collection of information about you and sent to SIR.

**You contribute to a better healthcare!**

By participating in the National Quality Register, you will help to improve the care provided. Participation in the register is voluntary and does not affect the care you receive. The data are used to compare intensive care between different hospitals and healthcare providers around the country. The data on treatment and outcomes for patients are then used in our work for improvement of care. The Quality Register contributes to new knowledge about how to treat intensive care conditions and the more people who participate, the more statistically reliable the results will be.

**Data recorded**

To develop and secure the quality of intensive care, we want to register your social security number, your healthcare contacts (including source of admission to ICU and discharge to ward), your diagnosis, your treatment, some test results and, if possible later follow up your care with new contact with you.

**Search term**

SIR and Värmland County Council use different search terms to find and compile data in addition to your social security number. The following search terms are used: region, hospital, unit, municipality, diagnosis, gender, age, time of care, details about admission and discharge, treatments, and possible treatment strategy for life-sustaining treatment.

**Legal basis**

Everyone who deals with personal data must rely on a legal basis. [enter healthcare provider] and Värmland County Council may collect and record data in SIR because it is considered as a necessary task of public interest in society (Article 6.1 e). We may also deal with health records in the registry because it is necessary for reasons related to the provision of healthcare (Article 9.2h). Our staff, as well officials in Värmland County Council and SIR, are also subject to statutory duty of confidentiality (Article 9.3). There should also be legal support in Swedish legislation in accordance with Data Protection Ordinance regulations when processing personal data in quality records. Such provisions can be found in Chapter 7. Patient Data Law (2008: 355).

**How your data is handled**

Information about you is collected from your patient record and from yourself. Your data in the quality register may only be used to develop and secure the quality of intensive care, produce statistics and research in the healthcare. An estimate of the number of people who meet certain predefined criteria and can therefore be included in the research is made at the request of the researcher prior to the planned clinical research. The data may also be disclosed to anyone who will use the data for any of these three purposes, after confidentiality testing. If data may be provided by SIR, it may be done electronically.

**Secrecy**

Your data in the quality register is protected by the health and safety secrecy in the law about Public and Privacy Act (2009: 400). As a rule, it means that information about you may only be submitted from [enter the name of the quality register] if neither you nor any related person suffers but if the data is disclosed.

**Security**

Your data in SIR is protected against unauthorized persons. There are special requirements for security measures such as: means that only those in need of your data have access to them, that it is verified that no unauthorized data are taken, that your data is protected by encryption, and that login to access data can only be done safely way.

**Access**

As an in-reporting healthcare provider, competent personnel at [enter reporting healthcare provider] have direct access to the data we reported to SIR. No other healthcare provider has direct access to this information. As responsible for the register, competent personnel at SIR within Värmland County Council can also share information about you.

**Legislation about storage and sort out the data**

Your information is deleted in accordance with Chapter 7. Section 10 of the Patient Data Law when they are no longer needed to develop and secure the quality of intensive care. At present, SIR has decided that data is saved for at least 15 years.

**Your rights as a patient**

* You are entitled to not receive your data registered in SIR
* You also have the right to retrieve data about yourself in the registry at any time.
	+ You have the right to confirm whether your personal data are being processed by the County Administrative Board at Värmland County Council and, if so, get a copy free of charge on your personal data. You also have the right to receive personal data in electronic format that is generally acknowledged, unless you request anything else. More information about requesting access to your information and how they are disclosed can be found here: <http://www.icuregswe.org/patient-och-narstaende/patientinformation-om-sir/>.
* You are entitled to receive personal information about you who are incorrectly corrected and to supplement incomplete personal data.
* You are entitled to require that the processing of your information be limited if:
	+ You consider that your personal information is incorrect and for a time that allows the County Administrative Board at Värmland County Council to check if the personal data are correct.
	+ You consider that the processing is illegal and opposes you to delete your personal information and instead request a restriction of their use.
	+ A situation arises when the County Administrative Board at Värmland County Council no longer needs the personal data for the purposes of the treatment (see above) but you consider that you need them to determine, enforce or defend legal claims.
* You are entitled to receive information about which care unit and at what time someone has accessed your information.
* You are entitled to damages if personal data is handled in violation of the General Data Protection Regulation or Patient Data Law.
* You are entitled to file a complaint with the supervisory authority

**Contact details**

For more information about SIR, access your data, request correction or limitation:

sir@icuregswe.org, Svenska Intensivvårdsregistret, Region Värmland, Landstingshuset,
Att: Göran Karlström, 651 82 Karlstad, 010-839 14 90 (SIR-växel).

If you want to delete your data from SIR or if you want information about the access that has occurred to your data, the same contact paths as above apply.

If you would like to contact the Data Protection Officer at [enter the name of the care provider] or at Värmland County Council:

* Data Protection Officer at [enter healthcare provider]: [enter email address, email to the Data Protection Officer's email or other responsible administrator and phone number to switchboard].
* Data Protection Officer at the County Council Board at Värmland County Council:
Erika Malmberg; 072-549 64 34; erika.malmberg@intechrity.se

General information concerning the quality register can be found at: [www.kvalitetsregister.se](http://www.kvalitetsregister.se)