

Information letter about the Norwegian Intensive Care Registry

This letter contains information about how information about you is collected and processed by the Norwegian Intensive Care Registry (NICR). Please take the time to read through this letter, and contact your treatment provider or the NICR if you have any questions.

Why have you received this information letter?

You have received this information letter because you or one of your next of kin is receiving or has received intensive care treatment in a Norwegian hospital. Information about stays in intensive care units are reported to the NICR. In this letter, you will find information about how the NICR processes data about you, what your rights are and how you can exercise your rights.

What do you have to do?

You do not have to do anything, unless you want to opt out of the NICR collecting information about you or wish to access data or have data corrected or erased. See details below.

What is the Norwegian Intensive Care Registry?

The Norwegian Intensive Care Registry (NICR) is a national medical quality register that collects information about stays in intensive care units in Norwegian hospitals. The purpose of the registry is to report on the activities of Norwegian intensive care units, help to assure the quality of the activities, and contribute to research on intensive care treatment. The data controller is Helse Bergen health trust, which ensures that the personal and health data registered are processed securely and in accordance with the applicable data protection and confidentiality requirements. The Regulations relating to medical quality registers regulate how the NICR operates.

What data are registered about you in the Norwegian Intensive Care Registry?

The NICR contains information about your stay in the intensive care unit. Examples of such information include the length of the intensive care stay, previous and current state of health, reason for admission to the intensive care unit, relevant diagnosis codes, intensive care interventions and survival. You may also be contacted after your intensive care stay to answer some questions. In order to ensure that the information in the registry is correct, and to enable data in the NICR to be aligned with data in other registers, the information is linked to personal identity. Data about you will be stored and used for as long as necessary to achieve the purpose of the registration in accordance with the applicable laws and regulations and respecting data protection considerations. Further information about the Norwegian Intensive Care Registry is available on our website: <https://helse-bergen.no/norsk-intensivregister-nir>

What happens to information about you?

It will not be possible to identify you in reports from the NICR. Your personal data can only be disclosed subject to valid approval in accordance with the applicable regulations, or they can be aligned with information from other registers. In some cases, your personal data can be disclosed across national borders, including to countries with weaker data protection regulations than Norway. In such cases, a guarantee that your data will be protected in accordance with the European regulations will be required.

Your rights to opt out of being registered and to access to, correction and erasure of data

If you do not want information about you to be stored in the NICR, you can opt out at any time without giving a reason. You can also request access to the information registered about you and request that registered information be corrected and/or erased. This will not have any consequences for your treatment. If you wish to exercise these rights, you or your next of kin can contact the intensive care unit where you were admitted on the phone number provided. If you would like more information, contact your local intensive care unit or the Norwegian Intensive Care Registry. Information about your rights and freedoms with regard to data protection can be obtained from the data protection officer at Helse Bergen health trust by calling (+47) 55 97 50 00 or by sending an email to postmottak@helse-bergen.no. If you believe your rights have been violated, you can submit a

Local intensive care unit's contact details:



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complaint to Helse Bergen health trust. You can also submit a complaint to the Norwegian Data Protection Authority.

Yours sincerely, the head of the Norwegian Intensive Care Registry