

Invitation to participate in a survey

You have received this invitation because you were admitted to an intensive care unit and have therefore been registered in the Norwegian Intensive Care and Pandemic Registry. All registered persons are entitled to access the information registered about them, have registered information corrected or erased, and opt out of being registered in the registry. You can find more information on our website: <https://helse-bergen.no/norsk-intensivregister-nir/informasjon-til-pasientar-og-parorande>. You can also find a short version of this invitation on the website.

The next pages contain a questionnaire about health and quality of life. Participation in this survey is voluntary, so if you do not wish to take part, you can ignore the invitation. Patients' experience after receiving intensive care treatment is important in enabling us to better understand the consequences of serious illness. We therefore ask you to answer these questions and return the completed form to us. When you submit the completed form to us, you consent to your answers being registered in the Norwegian Intensive Care and Pandemic Registry and used in the same way as other register data.

In order to contribute to the development of new knowledge, the Norwegian Intensive Care and Pandemic Registry will disclose your answers to research projects that request them. Data will only be disclosed in accordance with laws and regulations, including rules relating to the duty of confidentiality and the European General Data Protection Regulation (GDPR).

The Norwegian Intensive Care and Pandemic Registry is a national medical quality register. 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. Results from the registry will yield knowledge about intensive care treatment through analyses and research.

Information from the registry can be aligned with information from other health registers established pursuant to laws or regulations under the Personal Health Data Filing System Act. The information can also be aligned with information held by biobanks, as long as the biobanks are entitled to share the information. Information from the registry can be disclosed to research and quality improvement projects. Your personal data can only be disclosed, or otherwise made available, in accordance with laws and regulations, including rules relating to the duty of confidentiality and the European General Data Protection Regulation (GDPR). Data may be disclosed to enterprises abroad, for example in connection with scientific research. The data controller is Helse Bergen health trust. The legal basis for the processing of data is the General Data Protection Regulation Article 6(1) letter (e) and the Regulations relating to medical quality registries, cf. the Regulations relating to medical quality registries Section 1-4.

If you have questions, or if anything is unclear, feel free to contact the registry directly using the contact information below.