

Information memo on the National Quality Register for Electroconvulsive Therapy (National ECT Register)

This memo contains information about how the data we collect about you is processed in the National ECT Register (NER). We ask that you take the time to read this memo thoroughly and contact your therapist or NER if there is anything you wonder about.

Why am I getting this letter? You are receiving this information because you or a loved one is receiving or has received electroconvulsive therapy (ECT) at a hospital in Norway. Information about ECT processing is reported to NER. The memo contains information about how NER processes data about you, what rights you have and how you can exercise those rights.

What do I need to do? You do not need to take any action unless you wish to reserve yourself against NER collecting information about you, if you want access to the information, or to correct/delete the data. See below for more information about this.

What is the National ECT Register? The National ECT Registry (NER) is a national medical quality registry that collects information on ECT treatments given in hospitals in Norway. The purpose of NER is to obtain an overview of ECT treatments performed in Norway, contribute to ensuring quality in the field, obtain knowledge about how patients experienced treatment and contribute to research on ECT. The Bergen Health Trust is the data controller and ensures that personal and health data in the registry is processed in a secure manner and in accordance with requirements for personal data protection and confidentiality. The Medical Quality Registries Regulations regulate how NER is run.

What information is available about me in the National ECT Register? NER contains information about your ECT treatment. The information will be collected from medical records and from own examinations in connection with the treatment and planned check-ups six months after completion of treatment. Information included in the register: name, personal identity number, diagnoses and treatment provided, health information including symptom level, relevant medical history, side effects and the patient's views on treatment. Technical and clinical data from treatment may also be recorded. Before and after your ECT treatment and half a year after, you may be contacted to answer questions about your health and your experience of the treatment and any side effects. To ensure that the information in NER is correct and to make it possible to compare data in NER with data in other registers, the information is linked to your personal identity. You can find more information about the National ECT Register online:

helse-bergen.no/nasjonalt-kvalitetsregister-for-elektrokonvulsiv-terapi-ect

What happens to the information collected about you? It will not be possible to identify you in reports from NER. The register's annual report is based on anonymous aggregate data and is officially available online: www.kvalitetsregistre.no. The website explains which data has been registered.

One of the purposes of the quality register is to obtain new knowledge about the treatment, and this may require, among other things, the disclosure of data for research projects or linking of data with other registers. Your personal data may only be disclosed to a research project if this is done according to the purpose of the register, and if there is valid approval from the Regional Committee for Medical and Health Research Ethics or other relevant public bodies as required by law. For research projects, it may be relevant to link your data in the register with information from patient records, as well as with other public registers such as the Norwegian Patient Register, the National

Population Register, the National Pharmaceuticals Register, registers at Statistics Norway and the National Quality Register for Treatment in Mental Health Care for Adults. Your personal data may in some cases be disclosed across national borders, also to countries where the data protection regulations are weaker than in Norway. In this case, a guarantee is required that your data is safeguarded in accordance with the European GDPR regulation.

The data is stored for as long as necessary to fulfil the purpose of the register, in accordance with applicable laws and regulations and with respect for privacy. All collected data is treated confidentially, and everyone who works with information from the register has a duty of confidentiality regarding matters they become aware of.

Your right to be forgotten (reservation), to access the information, rectify incorrect information, or have it deleted. If you do not want data about you to be registered and stored in NER, you can opt out at any time without having to explain why. You may also request access to the data stored about you and correct and/or delete the data. This will not affect your treatment. If you wish to opt out, you can do this yourself under the privacy settings on helsenorge.no, or by contacting the hospital/department where the ECT offer is organized. If you would like more information, you can contact the National ECT Register directly.

The Bergen Health Trust has appointed a data protection officer to help ensure that personal data is processed lawfully and that your rights to personal data protection are safeguarded. You can contact the Data Protection Officer if you have general questions about your rights (by phone 55 97 55 58) or by e-mail: personvernombudet@helse-bergen.no. If you believe that your rights to personal data protection have been violated, you have the right to contact the Norwegian Data Protection Authority or the Norwegian Board of Health Supervision.

Greetings from the National ECT Register, by Director Hallvard Lund-Heimark

Contact details for the National ECT Register:

nasjonaltecregister@helse-bergen.no

Contact details for your local ECT unit: