

Bergen, 24.02.2021

Information on personal data in the Norwegian Hip Fracture Register

You have received this letter from the Norwegian Hip Fracture Register because you have had surgery for a hip fracture. Every time a person has hip fracture surgery in Norway, the details are recorded in the Hip Fracture Register. You are not obliged to have this information in the Hip Fracture Register and you can object at any time to the processing of your data. It will have no effect on the treatment you receive if you choose not to have your data in the Register. You will find information on how you can object at the end of this letter.

The purpose of the Register

The Norwegian Hip Fracture Register is a national quality register. The purpose of the Register is to develop new knowledge that can help to prevent illnesses and injuries that lead to hip fractures, as well as improving and quality assuring treatment methods and patient care. The main aim is thus to improve the quality of treatment of people with various types of hip fractures. The register also forms an important basis for research. Emphasis is placed on patients' quality of life and satisfaction. A further goal is to provide information and advice to surgeons and public agencies on the best treatment for the various types of hip fractures.

Haukeland University Hospital, under Helse Bergen, is responsible for processing data for the Register. Day-to-day operations are performed by the Register itself, which is part of the Orthopaedic Clinic of Haukeland University Hospital. Helse Bergen is responsible for ensuring that your data are processed according to Norwegian law, the European General Data Protection Regulation and the Norwegian Health Register Act.

The Register will contain the following data about you:

- General information: name, date of birth and ID number, address and gender. The National Population Register will be consulted to ensure that your personal data are correct.
- Health information: type of hip fracture, year of surgery, date of fracture, information on the implant and surgical method, etc.
- Patient-reported information on quality of life following a hip fracture (PROM).

The data are collected from an electronic form completed by the surgeon immediately after your operation; the surgeon then sends the form to the Hip Fracture Register. When you are discharged from hospital, another form is filled in with information about your medical treatment, any complications that occurred during the hospital stay, and where you are going after discharge. In addition, at 4, 12 and 36 months after your operation you will be asked to complete a questionnaire about your quality of life, pain and satisfaction with the result of your operation. This is entirely voluntary. For some health issues, we may wish to contact you to ask you further questions.

Comparison with information from other sources

In connection with research projects or to ensure that the data in the Hip Fracture Register are complete and correct, it may be appropriate to obtain data related to hip fractures from other public registers. Each time another register is consulted, this will be announced on our website

(<https://helse-bergen.no/nrl>). Relevant registers for accessing such data are the Norwegian Prescription Database, the Norwegian Cardiovascular Disease Registry, the Medical Birth Registry of Norway, the Norwegian Cancer Registry, the Cause of Death Registry, the Norwegian Information System for the Nursing and Care Sector (IPLOS) and the Norwegian Patient Registry (this contains data on all patients admitted to hospital or treated at outpatient clinics or by specialist doctors).

Personal data will not be used for research, unless the study has been approved by the Regional Committees for Medical and Health Research Ethics, the privacy officer of the institution responsible for the research or the Norwegian Data Protection Authority.

Disclosure of data from the Hip Fracture Register will only be permitted when this is in accordance with the aim of the Register. Names, dates of birth and ID numbers are replaced by a code when data are disclosed. In this way, the data are de-identified and cannot be traced back to you. The data are stored indefinitely. All information collected is treated confidentially, and all those whose work involves data in the Register are bound by confidentiality obligations regarding any information that may be available to them. Helse Bergen, the data controller, will ensure that your privacy rights are protected at all times.

Right of access, modification and deletion of data

You have the right of access to information held about you. If you believe that the information about you is incorrect, you can ask for it to be corrected. You also have the right to request deletion of your personal data from the Register.

You can exercise your rights by contacting the Norwegian Hip Fracture Register on 55976450, at nrl@helse-bergen.no, or at <https://helse-bergen.no/nrl>.

Contact details

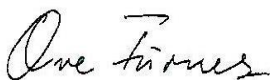
Further information about the Hip Fracture Register may be obtained by contacting:

The Norwegian Hip Fracture Register, Helse Bergen, Orthopaedic Clinic, Haukeland University Hospital, Møllendalsbakken 7, 5021 BERGEN. Phone: 55973742/55976450. You can also find information about the Register at <https://helse-bergen.no/nrl>.

Helse Bergen HF has appointed a privacy officer to ensure that personal data is processed in accordance with the law and that your rights to privacy are protected. You can contact the privacy officer if you have any general questions about protection of your rights to privacy. Phone: 55975558, email: personvernombudet@helse-bergen.no.

If you believe that your rights to privacy have been violated, you are entitled to contact the Norwegian Data Protection Authority or the Norwegian Board of Health Supervision.

Kind regards

A handwritten signature in black ink, appearing to read 'Ove Furnes'.

Ove Furnes
Chief Physician/Professor
Head of the Norwegian Arthroplasty Register

A handwritten signature in black ink, appearing to read 'Jan-Erik Gjertsen'.

Jan-Erik Gjertsen
Chief Physician/Professor
Head of the Norwegian Hip Fracture Register