

Request for registration in the Norwegian Arthritis Registry (NorArthritis)

Background and goals

By this we ask your permission to enroll you in the Norwegian Arthritis Registry. To ensure high quality treatment to all patients we need to improve our knowledge of the inflammatory joint diseases (diseases characterized by inflammation of the joints or spine, such as rheumatoid arthritis). A major goal of the registry is to use the registry data for quality improvement and research on inflammatory joint diseases, for instance concerning genetic factors, causes of disease, effect of treatment and outcome.

Being enrolled in the registry is voluntary and requires informed consent. This means that we may only include you in the registry after you have signed a consent form. By signing, you agree to let the information be used in future quality- and research projects on inflammatory joint diseases.

The registry will contain the following information on you:

Name, gender, date of birth, personal registration number, and data concerning diagnoses and treatment. In addition data such as residence, education, comorbidity (other diseases than your rheumatic disease), medication, time of diagnosis and disease duration as well as smoking habits will be registered.

Collection of information

The data will be collected using the medical journal or its equivalent and some of the data will be registered by the patient at each follow-up, guided by qualified staff. Helse Bergen HF is in charge of the data handling of the registry. All registration is done using data technology and data may not be accessed by unauthorized persons.

Data handling

The data are stored electronically permanently or as long as necessary to ensure the goal of the registry, as above mentioned. All collected information will be handled confidentially and persons handling the data must sign a confidentiality agreement concerning knowledge gained through the registry. Helse Bergen HF is in charge of the data handling and as such, will secure your privacy rights.

Access to personal information, and the right to correct or delete information

You may at any time be granted access to the information in the registry concerning yourself. Furthermore, you have the right to have corrected possible errors in your data and you may demand that all collected information on you is deleted from the registry without your providing a cause for your wish. Anonymous data files which have already been used in research projects may however not be deleted. Whether you chose not to be included or if you decide to withdraw your consent, will not influence your treatment program. Should you wish to enforce your rights you may contact Helse Bergen HF by the registry leader.

Delivery of data from the registry will only be allowed when in agreement with the goal of the registry. Data will be delivered in the form of de-identified files. This means that information will be handled without identifiable data such as name, date of birth or other

directly recognizable information. A code-number connects you to your data through a list of names. Only authorized personnel at the registry may access this name list and thus re-identify you. In some cases, data may be delivered back to the department at which you are treated, in relation to quality improvement projects.

Merging data with other sources

In research- or quality projects it may be necessary to compile information from the registry to information from medical records, health surveys, or other registries (see attachment). Furthermore, data from the registry may be used as part of large international research projects for instance evaluating treatment in different countries.

All research projects must be approved by the Regional Committees for medical and health research Ethics and other official authorities as claimed by the law.

Data may be compared to data in the Norwegian Patient Registry in order to evaluate data completeness and degree of coverage.

Information concerning on-going research projects from NorArthritis may be found at the web-site: www.norartritt.no

Contact information

You may find additional information about the registry at <http://www.norartritt.no/>

If you have questions regarding your participation in the registry, you may contact registry leader; Consultant doctor, PhD Bjørg-Tilde Svanes Fevang, Department of Rheumatology, Haukeland University Hospital Phone number: 55975400/55976467, or the local contact person.

Helse Bergen HF has a data protection officer who may give general advice concerning your privacy rights: personvernombudetelse-bergen.no, tlf 55975558

You may complain to the Norwegian Data Protection Authority if your rights concerning your personal data protection has been violated.

Consent form	
- Adults 16 years or older	
Register The Norwegian Arthritis Registry	
Register leader Bjørge-Tilde Svanes Fevang	Department Department of Rheumatology, Haukeland University Hospital
<p>I have read the information form "Request for registration in the Norwegian Arthritis Registry» and I am aware of the aim of the registry, what data are registered, how data are collected and handled, and my rights concerning access to data, and the right to correct or delete data from the registry.</p> <p>I am aware that information is collected from my medical record or equivalent system, which is part of the registry. Collected data will be used in quality of treatment projects as well as in research concerning chronic inflammatory joint diseases.</p> <p>I hereby consent to having data on me included in the Norwegian Arthritis Registry and that this information may be used in quality of treatment projects as well as in research concerning chronic inflammatory joint diseases.</p>	
Name in block letters	Personal identification number (11 digits)
Date	Signature
To be filled in by person representing the registry	
I confirm to have given information about the Norwegian Arthritis Registry	
Date	Signature
Eventuelle kommentarer:	