Information regarding the Norwegian Arthritis Registry (NorArthritis) and the right to opt out

Background and Purpose:
The Norwegian Arthritis Registry collects data on patients with chronic inflammatory joint diseases, including rheumatoid arthritis, psoriatic arthritis, peripheral spondyloarthritis (primarily peripheral joints), axial spondyloarthritis (primarily spine), and juvenile idiopathic arthritis. The main objective of the register is to ensure quality, as well as consistent treatment and follow-up for patients with these conditions. In order to provide the best possible care, we need more knowledge. Another key purpose of the register is therefore to use the collected data for quality assurance and research on inflammatory joint diseases.

The Norwegian Arthritis Registry has been operational since 2014. In 2025, the register changed from being consent-based to opt-out based. This means that all patients with the aforementioned rheumatic diseases are now automatically included in the register upon receiving their diagnosis. Patients with a known inflammatory rheumatic disease who were not previously included in the register will be enrolled at their first rheumatology consultation after the register became opt-out based. Patients who previously consented to participation in the register will remain included, and no changes have been made to the type of information collected. Patients who previously declined participation will remain excluded.

Information Registered About You:
NorArthritis collects your name, national ID number, and information about your rheumatic diagnosis, date of diagnosis, disease activity, and the treatment provided. Additional information includes gender, place of residence, education, comorbidities, smoking habits, as well as your own assessment of disease activity, function, and quality of life.

Opting Out of the Register:
You may opt out of the register at any time without providing a reason, and doing so will not affect your treatment. You can opt out via HelseNorge or by contacting your local healthcare provider directly. If you opt out, no further information about you will be transferred to the register, and previously collected data will be deleted. Deletion of data does not apply to anonymized research files that have already been used in research.

Data Collection:
Most information is collected from your medical record. In addition, during each outpatient visit, you will be asked to complete questionnaires regarding your health, disease, and quality of life. Helse Bergen HF is the data controller for the register. Data are recorded using various digital systems (GTI, Helseplattformen, and MRS), depending on where in the country you live. In all cases, your data is protected from unauthorized access.

Data Processing:
The data is stored electronically for as long as necessary to fulfil the purposes of the register. All collected information is handled confidentially, and anyone working with data from the

register is bound by a duty of confidentiality. Helse Bergen HF, as the data controller, ensures that your data protection rights are upheld at all times.

Deletion, Access, and Correction of Information:
You have the right to access the information recorded about you, and you can request correction or deletion of any incorrect data. An access report can be requested via HelseNorge. You may also contact your local healthcare provider for corrections or deletion.

Disclosure of Information:
Disclosure of information from the register will only occur in accordance with the register's objectives. If data is to be used for research, prior approval from the Regional Committee for Medical and Health Research Ethics (REK) is required. Information is usually provided as de-identified summaries. In some cases, it may be necessary to use your national ID number to link data from other sources. In such cases, identifying information is delivered separately from files containing health information. Research files will be handled without names, national ID numbers, or other directly identifiable information. A code links you to your data via a name list. Only authorized personnel associated with the register have access to this list and can trace the data back to you.

Linking with Data from Other Sources:
For research or quality assurance purposes, and to enrich the data in the register, information from NorArthritis may be linked with data from medical records, health surveys, or other registers (see separate attachment). Data from the register may also be used in larger international research projects, with the aim of comparing treatments across countries. Personal data will not be used for research unless the study has been approved by the Regional Committee for Medical and Health Research Ethics and any other relevant authorities as required by law. Data may be regularly linked with other sources, such as the Norwegian Patient Registry, Cancer Registry, or other databases, where appropriate.

Information about ongoing research projects for NorArthritis can be found on our website: www.norartritt.no

Legal Basis for Processing Personal Data:
The legal basis for data processing is the General Data Protection Regulation (GDPR) Article 6(1)(e), Article 9(2)(j), and the Norwegian Regulation on Medical Quality Registers §1-4. The information shall be processed without the consent of the registered individuals, cf. the Regulation on Medical Quality Registers §3-2.

Contact Information:
More information about the register is available at: http://www.norartritt.no
If you have questions about your participation in the register, please contact the Head of the Registry:
Senior Consultant, Professor Bjørg-Tilde Svanes Fevang, Department of Rheumatology, Haukeland University Hospital
Phone: +47 55 97 54 00 / +47 55 97 64 67

Helse Bergen HF has a Data Protection Officer who can provide general advice on your data protection rights:
Email: personvernombudet@helse-bergen.no
Phone: +47 55 97 55 58

You also have the right to contact the Norwegian Data Protection Authority (Datatilsynet) or the Norwegian Board of Health Supervision (Statens Helsetilsyn) if you believe that your health information is being processed in a way that violates your data protection rights.