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Nationwide quality register for inflammatory rheumatic diseases in pregnancy

FROM THE SPECIALTIES

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Pregnant women with inflammatory rheumatic diseases are included in a nationwide register that serves as a basis for research and collaboration across Europe.

Knowledge on inflammatory rheumatic diseases in pregnancy has traditionally been limited. In 2006, Norway established *RevNatus*, a nationwide quality register for pregnant women with rheumatic diseases, to track maternal disease during pregnancy

and throughout the first postpartum year. The register has improved our understanding of disease activity, pharmacological treatment, pregnancy risks and health-related quality of life in this patient population in Norway.

Who is included in the register?

The register is one of very few of its kind in Europe. It was paper-based until ten years ago, when it was digitised and designated a nationwide quality register. A biobank was also established at that time. The register is administered by the Norwegian National Network for Pregnancy and Rheumatic Diseases at the Department of Rheumatology, St Olav's University Hospital in Trondheim, and managed by Central Norway Regional Health Authority. Patients from 19 rheumatology centres throughout Norway are included in the register. Nearly 4000 women and more than 3000 pregnancy outcomes have been recorded. The register includes women with inflammatory arthritis, connective tissue diseases and vasculitis who are under specialist care.

The register has undergone several revisions. Since 2021, variables have been recorded in accordance with recommendations from the European Alliance of Associations for Rheumatology (1). These include validated disease activity measurements, disease modifying anti-rheumatic drugs and patient-reported data on health-related quality of life. Selected pregnancy outcomes are also recorded, including pre-eclampsia, mode of delivery, gestational age and birth weight. Postpartum data on breastfeeding and contraceptive use are also recorded.

Patients should ideally be included in the register in the preconception period. Data are collected at structured outpatient check-ups at the rheumatology centres, according to national and international recommendations (2).

European research collaboration

The register is used for research purposes and to monitor whether patients receive comparable follow-up and treatment in the different regional health authorities. Twenty original articles have been published using register data, most of which formed part of doctoral and postdoctoral research. A European collaborative project, involving joint analysis of data from four registers, has also been completed.

Data from the register can be linked to several national health registers, and in three research projects, register data have been linked with the Medical Birth Registry of Norway. A primary aim of the doctoral and postdoctoral research has been to investigate the impact of inflammation on pregnancy outcomes. The studies show that minimising disease activity is crucial to reducing the risk of adverse pregnancy outcomes, particularly hypertensive disorders such as pre-eclampsia (3, 4). Register data also show that disease-modifying anti-rheumatic drugs, such as tumour necrosis factor inhibitors, are increasingly used during pregnancy in patients with arthritis, which is in line with the latest European recommendations (5, 6).

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