

EULAR
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Kilchberg,
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NEW: CORE DATA SET FOR PREGNANCY REGISTRIES

The European League Against Rheumatism (EULAR) has published new recommendations on the need for a core data set for prospective pregnancy registries

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EULAR established the first consensus-based core data set for prospective pregnancy registries in rheumatology. This will increase the knowledge about women with inflammatory rheumatic diseases (IRD) during pregnancy.

Several registries have been set up to collect information on pregnancy in women with various types of IRD. Although there are overlapping goals, not all groups collect the same information from their patients, which makes it difficult to compare outcomes – and for different registries to work together on shared data projects.

A EULAR multidisciplinary task force worked together to define a core data set for registries and observational studies that collect information about women with IRD throughout their pregnancy, and for 4 weeks after birth. The group reached agreement on 51 key items that should be collected in all pregnancy registries in rheumatology. The items are split across three core areas: maternal information, pregnancy, and treatment.

Maternal information includes data about women's demographics such as age and weight, details of their IRD diagnosis and severity, and any other underlying diseases. The pregnancy area covers history of previous pregnancies, including pregnancy loss and stillbirths, as well as information on the outcome with the current pregnancy – such as complications, and information about the baby at birth. Medical treatment information should be recorded for 12 months before conception, during pregnancy and for 4 weeks after birth.

This is the first consensus-based core data set for prospective pregnancy registries in rheumatology. EULAR hopes it will encourage multinational collaborations and help to increase knowledge about pregnancy outcomes in women with IRDs, and the safety of IRD treatment during pregnancy.

Source

[Meissner Y, et al. Ann Rheum Dis 2020 Published Online First: 14 October 2020. doi: 10.1136/annrheumdis-2020-218356](https://doi.org/10.1136/annrheumdis-2020-218356)

About EULAR

The European League against Rheumatism (EULAR) is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with rheumatic and musculoskeletal diseases (RMDs). EULAR aims to reduce the burden of RMDs on individuals and society and to improve the treatment, prevention and rehabilitation of RMDs. To this end, EULAR fosters excellence in education and research in the field of

rheumatology. It promotes the translation of research advances into daily care and fights for the recognition of the needs of people with RMDs by the EU institutions through advocacy action.

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