

## Biennial report

### Study Groups

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#### Epidemiology and Registry & Observational Drug Studies

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Date of annual report submission: 26.03.2019

#### Summary of last year's activities

Previous leaders of this study group were Prof. Johan Askling & Will Dixon, who have stepped down in 2017. Prof. Finckh took over the study group in 2018. The study group was started in 2008 around a task force (Dixon WG, Carmona L, Finckh A, et al. *EULAR points to consider when establishing, analysing and reporting safety data of biologics registers in rheumatology*. Annals of the Rheumatic Diseases 2010;69:1596-1602.)

The study group had an official meeting at the 2018 EULAR conference, where it was decided that we would meet annually at the congress and discuss methodological aspects and new research ideas, with interested investigators.

Over the last two years, following initiatives have been started, progressed or published:

- The 'EULAR recommendations for a core data set to support observational research and clinical care in rheumatoid arthritis' have been published (Annals of the Rheumatic Diseases. 2018, vol. 77, no. 4, p. 476-479, EULAR project EPI012), which aims at harmonizing characteristics for new registers in rheumatology, and optimise opportunity for collaboration across European registers."
- A similar initiative has been performed in Giantocellular Arteritis (GCA) and accepted for publication. The task force (EPI017 – EULAR project) has developed a core set of variables to be collected in national and/or supra-national registries for patients with GCA. (Ehlers L, et al. "2018 EULAR recommendations for a core data set to support observational research and clinical care in giant cell arteritis". In press in Ann Rheum Dis 2019)
- Another task force has proposed a new instrument to assess symptoms in persons at risk of RA questionnaire and validated the tool. (Beers-Tas MV. Et al. "Initial validation and results of the Symptoms in Persons At Risk of Rheumatoid Arthritis (SPARRA) questionnaire, a EULAR project." RMD Open. 2018 May 21;4(1):e000641)
- The maintenance of the Eular Outcome Measures Library (OML) has continued and new instruments have been added (PI: Loreto Carmona, <http://oml.eular.org/>). OML is a repository of validated outcome measures in many languages.
- A new task force has been approved in 2018 and had its first of two meetings in Zurich, namely the 'EULAR Points to Consider when analysing and reporting comparative effectiveness research with observational data in rheumatology', with as convenor Dr Courvoisier.

The study group is supporting the standing committee (ESCEHSR) in the organisation of epidemiology related educational activities. This includes in particular:

- The “EULAR course RODS: “Rheumatology Outcomes In the Digital Space”, which will be held for the 3rd time this fall in Amsterdam. The previous two courses took place in 2013 and 2015 in Prague and were focused on registries (the acronym RODS then stood for Registers and Observational Drug Studies). These meetings have been highly successful, bringing together close to 200 rheumatologists and researchers from many countries, as well as epidemiologists and pharma representatives. An attempt to have this course in fall 2018 failed, in a large part because of late and insufficient promotion, which should be corrected for the 2019 edition.
- The EULAR Epidemiology Course, which took place for the 7<sup>th</sup> time from the 28-30th June 2018 in Berlin. The main goal of the course is to increase the interest, knowledge and skills of young researchers in epidemiology and stimulate critical thinking in the design and interpretation of clinical research studies.